



Hello from the Special Friends Foundation! Thank you so much for contacting us! The Special Friends Foundation was founded to assist individuals with RTS and their families. We hope that you will find the information and binder provided helpful. It is important to us that you know that you are not alone and that there are resources for you and your family, for every child is a blessing that brings joy into the world. Please do not hesitate to contact us with any questions.

Please feel free to read through the RTS information and share it with your medical providers, educators, family and friends. We have also included a binder, which can be used to keep your child's medical and educational history. To organize the Master File, we suggest that you follow the recommendations in the book, *From Emotions to Advocacy: The Special Education Survival Guide* By Pam Wright and Pete Wright. The outline of the Wrights' suggestions is included in the binder. If you would like further details and other information, please refer to the Wrights' website.

It is very important that you keep a copy of all your child's reports, as you hold the central core of information about your child. We recommend that you ask for your child's reports at the time of the visit or procedure. You have a right to any written material about your child. We find it is easiest to get the report at the time of the event. Otherwise, when you call years later, it usually will be impossible to find. Typically, when you ask for a copy, they will add your name to the list of people that the report will be sent to, and often this takes some time. It is best to ask them when you can expect the report and then follow up on it.

It can be overwhelming to think about organizing your child's information. Our goal is to keep it simple, to have a complete picture of information, and to allow you plenty of time to just love your child. Please feel free to contact us with any questions. We look forward to keeping in touch with you.

Sincerely,

Michelle Farrell
Director of Family Services



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Heaven's Very Special Child

A meeting was held quite far from earth
"It's time again for another birth"
said the Angels to the Lord above,
"This special child will need much love."

His progress may seem very slow.
Accomplishments he may not show
And he'll require extra care
From the folks he meets way down there.

He may not run or laugh or play
His thoughts may seem quite far away
In many ways he won't adapt
And he'll be known as handicapped.

So lets be careful where he's sent
We want his life to be content
Please, Lord, find the parents who
Will do a special job for you.

They will realize right away
The leading role they're asked to play
But with this child sent from above
Comes strong faith and rich love.

And soon they'll know the privilege given
In caring for this gift from heaven.
Their precious child so meek and mild.
Is Heavens Very Special Child!

-Edna Massimilla



Welcome To Holland by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

Where Do I Start?

Done	Service/Action	Date Called. Spoke with.	Scheduled/Comments
	Establish emotional support/Join a parent Group.		
	Join the RTS E-Mail List. Contact Janet Estes at janet.cook@shaw.ca		
	Set-up a binder, folder or file drawer with your child's medical history: dates, reports, app't summaries, etc.		
	Establish a Primary Care Physician.		
	Schedule a thorough medical exam (share with the physician the pamphlet on RTS).		
	Schedule an interdisciplinary team evaluation (physician, therapists, psychologist, social worker).		
	Copy and distribute packet of information about RTS to give to health care providers.		
	Schedule a dentist app't for children over 3 yrs.		

Where Do I Start? (continued)

Done	Service/Action	Date Called. Spoke with.	Scheduled/Comments
	Schedule a speech therapy evaluation.*		
	Schedule a physical therapy evaluation.*		
	Schedule an occupational therapy evaluation.*		
	Schedule an Early Intervention Evaluation (0-3 years).		
	Schedule an evaluation by the School System (3-21 years).		
	Obtain a copy of your health insurance policy and become familiar with it.		
	Investigate Medicaid eligibility.		
	Investigate Social Security eligibility.		

*Your child can receive all of his/her evaluations in an interdisciplinary team assessment, instead of scheduling separate appointments. Just make sure that each discipline mentioned is involved.

Medical issues to be aware of:

Submitted by Lorrie Baxter, parent
President United States Parents Group

At the 1998 conference, recommendations were made of what needed to be done after a diagnosis of RTS is given in covering the medical issues that some of the children have. The following areas were covered:

(Remember not every child will have every issue, these are just issues to be aware of, and I repeat your child will NOT have all of these issues.)

1. Undescended testicles in the males - orchipexy should be done as soon as possible.
2. Kidney & bladder tests should be done to check for reflux or any defects.
3. An MRI for Tethered Spinal Cord is now recommended. An Ultrasound may be done before one year of age. New advances with the MRI allow them to see the spinal cord move during the MRI, creating a better picture. If any parent should notice complaints from their older child on leg aches, regression in bowel/bladder control, more walking difficulties, they should consult with pediatric orthopedics to have an MRI if one has not been done in the past to check for the Tethered Spinal Cord.
4. Onset of puberty and growth also can make the orthopedic problems of walking, scoliosis, knee problems, and hip problems worse.
5. A complete cardiac exam needs to be done as well as pulmonary tests.
6. Anytime surgery or anesthetics will need to be used, an Anesthesia Consult is recommended because of possible tracheal collapse, cardiac arrhythmias, or refluxing.
7. An eye exam is recommended at birth and regularly from there on by a pediatric ophthalmologist because of the high frequency of eye problems in RTS.
8. Pediatric Dental visits need to be started as early as possible.
9. If GE reflux is present or suspected, tests should be done to determine the extent of problem. It is recommended to have a PH test done, an endoscopy, & testing for the reflux and associated esophagitis.
10. Corrections should be done to alleviate the problems with the thumbs and toes, depending on the extent of the defect and how the child can use them without surgery.

This child did **NOT** have RTS. However, this is an **example** of a fact sheet that can be helpful to hand to professionals and for you to keep track of all the information

Name

Address

Phone number

Cell number

Email address

Parent's names

Mom's Pregnancy

- Supraventricular Tachycardia
- Full bed rest
- Rh Negative (both Mom & Bo)
- Group B Strep +
- Amniocentesis at 36 ½ weeks (for lung maturity)

Birth

- Born August 8, 2002 in Atlanta, Georgia
- Premature – 36 ½ weeks, 6lbs. 8oz., 21" length
- Induced labor, arrest of dilation
- Cord around neck, heart rate dropped
- Emergency c-section, jaundice, apgars 8,9

Diagnoses/Concerns from Doctor & Therapists

- Abnormal Head Shape (diagnosis)
- Anxiety/PTSD (diagnosis) (from the dr.'s appts, surgeries, tests)
- Cerebral Palsy
- Developmental Delay (diagnosis)
- Sensory Integration Dysfunction (diagnosis)

Surgeries

- Strabismus Surgery 04/17/2003
- Ear Tubes 09/16/2003
- Cranial Vault Reconstruction (front) 10/31/2003
- Cranial Vault Reconstruction (back) 04/16/2004

Completed Tests

- ✓ * CT scan 3-D reconstruction 01/06/2003
- ✓ *CT scan w/ & w/out contrast 01/16/2003
- ✓ Chromosomal (extended banding) 02/06/2003
- ✓ EEG 03/01/2003
- ✓ FISH test for Williams Syndrome 11/02/2003
- ✓ Hearing test 01/01/2004
- ✓ MRI 01/21/2004
- ✓ Plasma Amino Acids 01/26/2004
- ✓ *Swallow study 01/30/2004
- ✓ Urine Organic Acids 02/21/2004
- ✓ *Skeletal Survey 02/26/2004

Physical

- Chronic ear infections
- Down turned palpebral fissures
- Eczema
- Epicanthal folds, ptosis
- Frequent drooling
- Left hand preference
- Low set ears, left ear – top is folded over
- Muscle tone fluctuates, weak trunk, tight limbs
- Narrow palate with high arch
- Non-verbal
- Reflux (treated with Prevacid at bedtime)
- Short nose with wide nasal bridge
- Skull is brachycephalic with left plagiocephaly
- Some mottled iris coloration
- Stork bites on eyelids, forehead & nape of neck
- Strabismus
- Toe walking (reaction when he gets excited)
- Toes (clinodactyly & hypoplastic 5th toes, hypoplastic great toes)
- Upper lip shows cupid's bow
- Wide-based, unsteady gait

Behavior

- Anxiety
- Craves movement (wants to be held & walked constantly)
- Difficulty sleeping, chokes & coughs
- Extremely social with adults, but not his peers
- Hand flapping and screeching
- High tolerance for pain
- Loves music
- Mouthing objects
- Short attention span

Sensory Integration Dysfunction

- Auditory hypersensitivity
- Easily over stimulated
- Sensitivity to light
- Tactile Defensiveness

Therapy at Easter Seals

- Early Childhood Education (2x week)
- Occupational Therapy (1x week)
- Physical Therapy (2x month)
- Speech Therapy (2x week)

Master File

The steps to organize your Master File, according to the Wrights, are dating all documents, file all documents in a Three-Ring Notebook and read the Master File for the “Big Picture.”

Assemble your Three-Ring binder and make a Master Document List for the first page. The headings for the Master Document List are Date, Author, Type, and Significance. Now, whenever, you receive a document lightly date it with an erasable pencil, in case you need to make copies. Keep the original clean, if you need to write on the document, make a copy or use sticky notes that you attach to the document. The next step is to record the document on the Master Document List and place the document at the end of the binder. This allows you to read the binder in chronological order to get the “big picture”.

Once you assemble your child’s binder, you will be able to clearly read your child’s educational and medical history. It is so important that you are your child’s advocate. Once the information is well organized and easily accessible; you can better understand the “big picture,” assist your child toward their goals, and establish a more cohesive approach towards education and medicine.

