



Information and support for families of children with Hydranencephaly

Hydranencephaly Newsletter May 2008

This is our monthly newsletter about Hydranencephaly and the issues a child with Hydranencephaly might face. . Its purpose is to share information on the various aspects of Hydranencephaly as well as to show case our beautiful children. Much of the information presented in the newsletter will originate from the Hydranencephaly Mailing list or group, which is hosted by Yahoo groups.

Topic of the month:

Spasticity management part 2: Therapy, Positioning and Equipment

Spasticity Management

In this edition of the newsletter I'm giving information on what therapy might look like for a child with Hydranencephaly. I'll also talk about some of the different types of therapy, positioning with splints/orthotics, and some of the equipment children with Hydranencephaly use. The information given here is just to help families be aware of what types of therapy and equipment might help your child with Hydranencephaly.

- to prevent deformities and to maximize comfort. This is done using a wide variety of pieces of equipment.
- 4. Using different methods such as hydrotherapy, Hippo Therapy (Horse back riding), massage to relax tight muscles and improve function
- 5. Using medications to reduce spasticity
- 6. Surgery to prevent or repair damage from the spasticity.

To do that, many different strategies can be used, including both treatment and positioning. In this section are some suggestions based on the experiences of families including treatments and equipment used.

Physical Therapy

For children with Hydranencephaly, the main purposes of Physical Therapy are:

1. to maintain or improve function of all limbs
2. to prevent deformities and contractures
3. and to help your child be as comfortable as possible.
4. to help them learn to play and have fun

What Physical Therapy Looks like in a child with Hydranencephaly:

Physical Therapy (PT, or Physio) in a child with Hydranencephaly will have a number of components.

1. preventing deformities by doing range of motion exercises (called stretches or ROM).
2. using splints, braces, etc to maintain a good position in each of the limbs.
3. teaching you how to position your child

Table of Contents	
Physical Therapy	1
Neurodevelopmental Therapy	2
How to get therapy for your child	2
Passive range of motion exercises	3
Other types of therapy	4
Hippotherapy (Horseback riding)	4
MOVE	5
Orthotics/Braces	6
Positioning	6
Equipment overview	7
Equipment Pictures	8
Equipment Links	9
May Birthdays	9
May "Sadaversaries"	9
Therapy for Brandon	10
Awareness ribbon link	10

Neuro-developmental Treatment is the form of therapy most often used for our children.

www.ndta.org

Physical therapy: NDT-trained (neuro-developmental treatment), for gross motor skills. Considered one of the mainstay therapies for cp, it is used to decrease spasticity, strengthen underlying muscles, and teach proper or functional motor patterns. A good PT will also teach the family/care-givers how to help the person with cp to help themselves.

What is Neuro-Developmental Treatment?

Neuro-Developmental Treatment (NDT) is a therapeutic approach used in working with people who have central nervous system insult that create difficulties in controlling movement. Berta and Karel Bobath of London, England, a therapist/physician team, developed the NDT approach in the 1940's. Originally working with children with cerebral palsy and adults with stroke, they believed in treating the many complex problems with control of movement caused by central nervous system insult. Persons having minimal to severe motor difficulties can benefit from the Neuro-Developmental Treatment approach.

Theory of Neuro-Developmental Treatment

While the practice of the NDT approach is supported by research in the movement sciences and psychology, the understanding of how and why Neuro-Developmental Treatment works is constantly updated and refined. As the understanding in the sciences changes, NDT theory is modified and enhanced. There are currently four broad statements of belief in NDT theory:

- A person's ability to function is a result of their many body systems working together smoothly and efficiently. Additionally, parts of those systems such as a muscle, sensory process or respiratory pattern assist with the movements in the person's unique daily environment.
- Those who use the NDT approach base efficient movement on the study of motor control, motor development and motor learning. There are consistent ways that people learn and lose motor skills throughout their lives. This can be studied and compared to people who have movement problems that interfere with learning motor skills.

- People with central nervous system insult exhibit some predictable difficulties with their movement that results in loss of function.
- Treatment begins with an assessment of the person's functional performance. It then focuses on building the person's abilities while addressing the movement problems. The goal of NDT is to help the person achieve functional skills by addressing movement difficulties.

The Practice of Neuro-Developmental Treatment

Therapists who use the NDT approach believe that early treatment can be instrumental to success. However, the approach also works with individuals who have long-term disabilities, but have the potential to gain new functional skills. To assist people in learning functional skills, the therapist first observes the movements the person can do. They then analyze the areas in which there are movement difficulties. The therapist observes the movement, often putting his/her hands on the person to feel how the person moves, i.e., what muscles are working and how they work. By guiding the correct movement with his/her hands on the person, the therapist often finds that more functional movements can begin. Guidance is removed as the person is able to perform the skill more independently and efficiently. Carefully planned verbal instructions or other forms of guidance may be used by the therapist to help people learn new skills. In addition to this direct treatment, therapists who use the NDT approach believe that the person being treated is best served by a team. This could include their family, physicians, other therapists, teachers, nurses, orthotists or others

How to get therapy for your child

All children in all countries (as far as we know) are entitled to various types of therapy, and equipment. Your child's doctor should be able to tell you who to talk to about it. If he/she can't, we have a comprehensive list of resources for each state as well as a number for other countries. This page has an overview of the various programs:

<http://www.hydranencephaly.com/Care/Resources.htm>

Passive Range Of Motion Exercises

http://www.medformation.com/ac/mm_qdis.nsf/qd/n d2524g.htm

Range of Motion exercises are one of the most important types of physio therapy for children with Hydranencephaly. They help to prevent deformities and contractures. They also keep the child looser and more comfortable. A physio therapist will teach you how to do the most appropriate exercises for your child. The information presented here is just to give you an idea of the why and how they're done.

General Information:

What are passive range of motion exercises?

Range of motion exercises are also called "ROM" exercises. These exercises are done to keep muscles, joints, tendons, and ligaments from tightening up. ROM exercises are called active or passive. Passive ROM is done when a person cannot do the exercises alone and needs someone to help him. It is called active ROM when a person can do the exercises by himself. Do not do passive range of motion exercises for your family member without first talking to caregivers. Together you will decide what exercise plan is best for the person.

Why is it important to exercise?

- Exercising is good for the body and helps keep the body well. Not exercising may cause weak muscles, poor blood flow, and locked joints, such as ankles or knees. Poor blood flow can lead to blood clots which may cause a stroke. It is very important for a person to continue to exercise if they are ill or injured. Needing to stay in bed or a in wheelchair also makes it very important to keep exercising.
- Regular exercise helps the heart pump stronger and easier. A person breathes quicker and more often while exercising. This helps prevent infections that may happen if a person does not breathe or cough deeply enough. When the heart and lungs work stronger, more blood gets to the muscles, bones, and skin. Increasing blood flow brings more oxygen and other good things to body tissues and organs. Walking and other exercises help make BMs and urine more regular. Exercising can also make a person feel better, more relaxed, and happier.

Getting started:

- A caregiver will teach you how to do the

passive ROM exercises for your family member. At first you should practice the exercises with the caregiver present to help. The caregiver can make sure you are doing the exercises right. Caregivers can also show you the easiest way to do the exercises so you don't get hurt or tired.

- Raise the bed to a height that is comfortable for you. This will help to keep you from straining your muscles. Make sure the wheels of the bed or wheelchair are locked before you start.
- All of these exercises should be done slowly and gently. Never force or overstretch a muscle. This can hurt the muscle instead of helping. The exercises should never cause pain or go beyond the normal movement of that joint.
- Stop the exercise right away if the person has pain. Call the person's caregiver if the pain does not go away.
- Move the joint slowly if the person has muscle spasms (tightening). Then move the joint only to the point of resistance, which is where you cannot bend the joint any more. Put slow steady pressure on the joint until the muscle relaxes.
- Set aside time to do these exercises every day. You may want to break the exercise program into 2 or 3 sessions. You can then do the sessions at different times of the day instead of doing them all at once. Include the exercises in the person's normal activities, such as watching TV or when bathing. This will make the time go faster and help the person relax more.
- Repeat each exercise 3 times or as often as the person's caregiver suggests. You may be told to increase the number of times each exercise is done as the person gets stronger.

For more of an explanation of Passive Range of Motion exercises and pictures of it being done, please go to:

Caring For Your Child With Hydranencephaly, Part 5A, Section 3, p 38

or to:

<http://www.hydranencephaly.com/PhysicalDevelopment/therapyrangeofmotion.htm>

Other types of Physical Therapy For Our Children

Therapy for our children isn't just stretches. Here are some pictures of several of the children doing therapy.

Here are some pictures where balls and a roll are being used for therapy. The children in the pictures are Brandon, Noah, Ethan and Heather.



Hydrotherapy/Swimming, preferably in a warmer-than-average pool. Any exercise or movement done in the water will be easier and more effective at exercising muscles. Recreational therapists may be used to teach your child how to swim. For some people with cp, swimming is their only independent mobility.

Below is a picture of Brandon getting Hydrotherapy.



Horseback riding: Hippotherapy

<http://www.americanequestrian.com/hippotherapy.htm>

Benefits abound in the horse's movement, bonding with an animal, and it's just flat-out fun. Kids who can't walk get a sense of what it feels like, and kids with arm movement learn how to take care of these beautiful beasts as well as learn to ride. It is also a very effective means of stretching legs, arms, and the back. This one comes highly recommended by just about everyone who's lucky enough to have access to it. A number of the children with Hydranencephaly participate in riding programs for the disabled.

American Hippotherapy Association *A Special Interest Section of NARHA*

What is Hippotherapy?

Hippotherapy is a treatment that uses the multidimensional movement of the horse; from the Greek word "hippos" which means horse. Specially trained physical, occupational and speech therapists use this medical treatment for clients who have movement dysfunction. Historically, the therapeutic benefits of the horse were recognized as early as 460 BC. The use of the horse as therapy evolved throughout Europe, the United States and Canada.

Hippotherapy uses activities on the horse that are meaningful to the client. Treatment takes place in a controlled environment where graded sensory input can elicit appropriate adaptive responses from the client. Specific riding skills are not taught (as in therapeutic riding), but rather a foundation is established to improve neurological function and sensory processing. This foundation can then be generalized to a wide range of daily activities.

Why the Horse?

The horse's walk provides sensory input through movement, which is variable, rhythmic and repetitive. The resultant movement responses in the client are similar to human movement patterns of the pelvis while walking. The variability of the horse's gait enables the therapist to grade the degree of sensory input to the client, and then use this movement in combination with other clinical treatments to achieve desired results. Clients respond enthusiastically to this enjoyable learning experience in a natural setting.

Physically, hippotherapy can improve balance, posture, mobility and function. Hippotherapy may also affect psychological, cognitive, behavioral and communication functions for clients of all ages. Clients who may benefit from hippotherapy can have a variety of diagnoses: examples include Cerebral Palsy, Multiple Sclerosis, Developmental Delay, Traumatic Brain Injury, Stroke, Autism and Learning or Language Disabilities. However, hippotherapy is not for every client. Each potential client must be evaluated on an individual basis by specially trained health professionals.

Here's a picture of Nikki riding a horse.



MOVE

<http://www.move-international.org/about>

This is a treatment used for some of the children in their school programs.

What is MOVE?

MOVE (Mobility Opportunities Via Education)® helps children and adults with disabilities acquire increased independence in sitting, standing and walking to experience, learn and gain more mobility, better health and enhanced personal dignity. The mission statement of MOVE is founded in the belief that the ability to move is the first foundation stone in building personal dignity.

With increased abilities to sit, stand and walk, this decreases the burden of care for families and other care providers and brings new opportunities for fuller participation and involvement in family life and for integration and inclusion in the wider community.

MOVE produces results through hard work, repetition and dedication by trained professionals and families throughout the world. The commitment by these professionals and families means people once relegated to spending life in a bean bag or wheelchair have gained or

regained mobility that permits them to interact in life and their community.

What MOVE is and isn't

[http://www.moveinternational.org/stories/storyReader/\\$58](http://www.moveinternational.org/stories/storyReader/$58)

MOVE IS:

- a philosophy
- functional, useful, measurable progress for setting life goals
- a collaborative effort between families and professionals- "It takes a team to move"
- a program that offers assistance for people with a singular disability to complex disabilities
- a program that changes ways of thinking, changes attitudes and promotes inclusive living
- a structured program based in assessment and accountability
- a top down approach that helps develop skills beyond the highest skills an individual already possesses
- a way of life used throughout the day, used anywhere in an activity
- embedded into existing curricula and activities
- cost-efficient and effective

MOVE IS NOT:

- a cure
- a developmental, bottom-up model
- limited to people with multiple disabilities
- appropriate for individuals who can already sit, stand and walk
- a pull-out, stand alone program
- seeking to replace other services
- a therapy
- an equipment-based program
- a meaningless "exercise" program

MOVE International
1300 17th Street
CITY CENTRE
Bakersfield, CA 93301-4533
USA
800-397-MOVE(6683)
e-mail: move-international@kern.org

There are many other types of therapy available. For more information please check out:

<http://www.hydranencephaly.com/Physical%20Development/therapy.htm>

Orthotics/Braces

Another way of maintaining good positioning and to keep your child from getting contractures is orthotics or braces. The first one your child may get is called a Ankle Foot Orthotic (or AFO). Here are a couple of pictures of children wearing AFOs.



These help to keep the feet in a good position.

Another frequently used orthotic is a Thoracic Lumbar, Sacral Orthotic (TLSO). Basically it's a back brace. There are quite a few types available. The most common one uses a hard plastic that is molded for your child. Here are some pictures of Chrissy and Kayda wearing theirs. Chrissy's is designed to be worn under her clothes. Kayda's is worn over her clothes and acts as straps for her wheelchair.

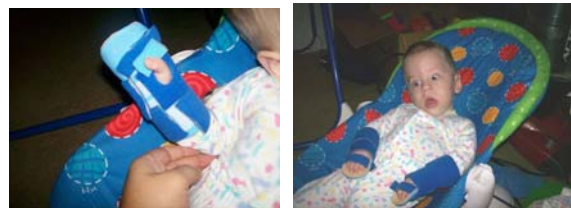


There are also soft back braces that provide some support. This type of brace would be used to give some extra trunk support but wouldn't work for a child who already has scoliosis or kyphosis. Here is a picture of Heather wearing a Benik brace



Some children also wear arm splints usually just at night to keep their hands from curling in too much.

Here are some pictures of Brandon wearing his hand splints.



As I'm sure you can imagine, children don't always like to wear their splints/orthotics. You have to balance comfort vs benefit and perhaps tolerate less time than what a professional recommends in them. Do what works best for your child. This may mean taking them on and off more often. If your child cries the whole time they're in a particular device talk to your therapist to see if changes can be made or if time in them has to be decreased.

These are the most often used splints or braces for our children.

About Positioning

<http://www.novita.org.au/Content.aspx?p=73>

Positioning is a word used by therapists to describe the posture or position of the body that best enables a child to achieve every day activities, such as eating and sleeping. Just imagine the number of positions and postures you use in your daily life. Imagine if you had to do everything in your whole day sitting in one position. We all need to change our position during the day, depending on the activity we are doing, and our comfort. Some children with a disability may be unable to change their own position, and so positioning equipment and extra help is often needed.

For more information on positioning and how to help your child through positioning please see the above website. I have just included a few sections that I feel are related to children with Hydranencephaly.

Why is positioning important?

If a child is using all their energy to maintain a position, or are using their hands for support, play and movement can be hindered. To get some idea of what this is like, imagine trying to learn to write while lying on your back or swallowing with your head back! Good positioning can:

- challenge children to learn new skills
- limit fatigue (tiredness) by providing extra support
- provide pressure relief and comfort
- prevent muscles becoming tight over time
- allow children to mix with others and play
- improve concentration and learning
- improve hand skills such as handwriting
- improve breathing posture, and improve digestion, eating and drinking
- prevent pain and discomfort.

Positioning equipment

There are lots of different types of positioning equipment. Some common ones include:

Standing frames - These can be a good way to get some weight bearing for healthy bones, while also stretching many leg muscles. Children can use standing frames for activities when other children are standing, providing them the chance to be at the same level as their friends.

Corner chairs - These are useful for stretching the muscles behind the knee (hamstrings). They allow children to be well supported when they are sitting on the floor.

Floor wedge - Tummy lying (prone) over a floor wedge is a good way to stretch the muscles at the front of the groin, (hip flexors) and the spine. This position works the muscles that help to maintain head and trunk posture.

Positioning to prevent deformity

Children with some disabilities develop muscle tightness or deformity as they grow due to:

- spending longer periods of time in certain positions
- spasticity—The increased stiffness or ‘muscle tone’ experience by children with

cerebral palsy. Muscle spasm can often be felt when such a child’s limbs are moved. The limbs are hard to bend or straighten because of the spasticity of the muscles. The doctor usually finds increased tendon jerks in a child with spasticity, or increased muscle tone which is the level of tension in the muscle.

- growth – bones growing more quickly than muscles
- limited active movement
- children being unable to move themselves or ‘stretch out’ on their own.

Positioning can help to manage muscle tightness and deformities. A physiotherapist will be able to advise on the best positions to use.

For information on positioning in a wheelchair, please see this article:

http://www.novita.org.au/library/Factsheet-Positioning_Tips_for%20WC_users.pdf

There is a lot more information about positioning on this site: <http://www.novita.org.au/Content.aspx?p=73>

Equipment your child may use

Wheelchairs: There are many different types of wheelchairs available. They range from your standard type chair to chairs that are more like strollers. In addition to the standard chair most children will have custom seating built into their chair.

Standers: Standers are a very important piece of equipment for your child. They allow the child to stand which is very important in helping the hip socket to form which helps to prevent hip dislocation. They also give the child a different perspective on the world. They can either be “prone” where the child is more on his/her stomach leaning forward, or “supine” where the child lies more on his back.

Car seats: Again, there is a wide variety of car seats available for children with special needs.

Alternate seating: There are many types of seats that your child can use for a break from their wheelchairs. The most popular is the Tumble Form feeder seats. There are also “corner” chairs that help your child sit upright for short periods of time.

Bath chair: These hold your child in a safe position while being bathed. They can either sit in your bathtub or go on a stand so that they can be used in a shower. Hint: they’re great to take to the beach too.

Here are some pictures of children with Hydranencephaly in the various types of equipment they may use at some time in their lives.

			
Bella in a Panda Wheelchair	Ethan in his Kimba stroller	Here is the floor base for Ethan's chair	Noah is in an Invacare Action Orbit
			
Sean is also in a ottobok Kimba	Kayda is in a Quickie Zippy	Nikki is in a Tumble Forms Tri Stander	Bella in a Buffalo stander
			
Ethan in a Gazelle Stander	Jeremy is in what is called a Dynamic Stander; it moves	Kayda is in a Rifton Stander	Sean is in an Otter bathing system bath chair
			
Ethan in a Rifton Blue wave bath chair with stand	Ethan in a tumbleforms side lyer with wedge	Ethan in a tumbleform feeder seat	Sean is in a corner chair.

These pictures show just a few of the different types of equipment your child might use. On the following page are links to further information on the specific brands of equipment.

Here are some links to information on the various pieces of equipment, some of which are pictured on the previous page:

Wheelchairs/Strollers:

OTTO BOCK KIMBA wheelchair...

http://www.ottobockus.com/products/pediatric_mobility/kimba_tiltinspace.asp

Quickie Tilt in Space wheelchair:

<http://www.phc-online.com/URLrewrite.asp?404>;http://phc-online.com:80/Tilt_in_Space_Wheelchair_p/quickie-zippie-ts.htm&Redirected=Y

Kid Kart: (this is a popular chair but not pictured on previous page)

<http://www.usatechguide.org/itemreview.php?itemid=842>

Panther chair:

<http://www.adaptivemall.com/panpedwheel.html>

More Stroller type chairs:

<http://www.adaptivemall.com/allstrolpus.html>

Bath Seats:

Otter Bathing System:

<http://www.adaptivemall.com:80/otbasy.html>

Rifton Blue Wave Bath seat:

<http://www.adaptivemall.com/riblwabasy.html>

More Bath seats and shower chairs:

<http://www.adaptivemall.com/asbat.html>

Car Seats:

This isn't a special needs car seat but works well for children once they're out of the rear facing seats:

<http://www.toysrus.com/product/index.jsp?productId=2908500>

The following car seats weren't pictured but are ones used by some of our families:

Special Tomato MPS car seat:

<http://www.adaptivemall.com/sptompscarse.html>

Britax Traveler Plus:

<http://www.adaptivemall.com/btrtrpl.html>

Columbia Car seat (another popular one)

<http://www.adaptivemall.com/colorseat.html>

For more car seats:

<http://www.adaptivemall.com/safetycarseats1.html>

Standers:

Rifton Supine Standers:

<http://www.adaptivemall.com/risubo.html>

Tumbleform Tri Standers:

<http://www.adaptivemall.com/sitenavigation.html>

Prime Engineering Super Stand (not pictured above but several families have it and love it):

<http://www.primeengineering.com/index.php?n=38&id=40>

Gazelle stander:

<http://www.adaptivemall.com/gazelleps.html>

More standers:

<http://www.adaptivemall.com/standers.html>

Alternate positioning devices:

Feeder Seats: (this is a favourite seat)

<http://www.adaptivemall.com/tumforfeedse.html>

Special Tomato Multi Positioning seat:

<http://www.adaptivemall.com/spectommulse1.html>

More seats:

<http://www.adaptivemall.com/adchairandse.html>

General equipment link:

<http://www.adaptivemall.com/asteccat.html>

May Birthdays

Kaleigh: 5/4/99
Savannah: 5/8/06
Christian: 5/9/05
Samuel: 5/12/98
Nikki: 5/21/98
Talia: 5/25/05
Olivia: 5/26/03

May "Sadaversaries"

(birthdays and anniversary dates for children who have died)

Raistlin: 9/697-**5/3/01**
Luke: **5/8/94**-11/6/07
Jenessa: **5/9/05**-8/5/05
Blaine: **5/16/01**-2/25/05
Christian: 11/15/98-**5/16/07**
Stasia: **5/17/87**-3/1//90
Belen: **5/22/99**-11/11/05
Matthew Pace: **5/24/00**-12/30/02
Jason Fogg: 8/13/90-**5/31/01**

Therapy For Brandon, age 20 months

What therapy is like for Brandon is hard to describe at times. He has been having therapy since he was 3 months old. He receives 45 min OT (Occupational Therapy), 45 min Speech, 30 min PT (Physical Therapy), 1 hour Vision therapy, 20 minutes Massage, and whatever I can add into it at home.



Brandon is like any child he will work well some days and than others he will not do well at all. He goes for Physical Therapy 2 times a week and I have not been to a lot of them because he has them at his DDS early intervention program. The times I have been there they do the walking motion with him while they are holding him. They have a stander they stand him for 15 min or less depending on how he reacts.



He gets his range of motions during this time and other things as well. During his OT therapy we do range of motion with him first and then ball time, then we move onto other things, some of them are just playing with him some or incline plane, rolling over etc. During his Speech Therapy we do read time, oral motor skills, sign language, sometimes we eat during speech to see how he does.



In vision therapy we do tracking, stimulate the pupils and also we do a lot with sensory toys. We use play dough, different texture balls and books.



During Massage we just relax and have a blast lol. What else could you do with massage. I think that the therapy he is receiving has benefited him in so many ways. He has learned not to be so tactile with other people touching him. His vision has improved, his mobility has improved, he can sign more and yes and sometimes combines the two. I can't imagine what he would be like with out his therapy. I have heard of families who do not have any done because they don't think it will help. But the way I look at it is why not try you will never know what it might do for them in the long run.

I have big plans for Brandon in the future we are going to go to the REACH program <http://www.reachinstitute.org/> in June and this is a program that will enhance Brandon's therapies. Which it will design a program just for him and he will have to go by it and learn it. I am hoping that it will help him learn to walk, see better, or even sit up. I know he might not do these things but like I said before why not try what will it hurt. We live in a small town so I am trying to get to the news out to the local places of all of the other therapies that we could do for him. I do know we are hoping to start aquatic therapy soon. I just cant wait to see what he can prove to the world that he can do with a little hard work and love.

Amber Pollard
Brandon Pollards mom



Help raise awareness of Hydranencephaly by purchasing a magnetic car ribbon.

Please go to: <http://www.hydranencephaly.com/awarenessribbons.htm> for information on how to order yours.