



Hydranencephaly Newsletter March 2008

This is the fifth edition of the Hydranencephaly Newsletter. It's 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.

Topics of the month:
School for children with Hydranencephaly, An Unfinished Mother, Child of the Month

School Options for Children With Hydranencephaly

The families of children with Hydranencephaly have chosen a wide variety of situations for their children. In this edition of the newsletter, I'll offer their stories as well as a explanation of some of the different terms and options.

Main Options

1. Inclusion
2. Mainstream program
3. Segregated class
4. Home schooling

These are the main options available to families. In some cases a family chooses 1 option and in others a combination of options are chosen.

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Special Education Terms

Community Setting: This is a setting outside of school property where I.E.P. goals and objectives are the focus of instruction.

Early Intervention - special education and related services pursuant to the IDEA provided to children under the age of 5.

FAPE: FAPE is the acronym for a Free and Appropriate Public Education. It is one of the most misunderstood concepts of the Individuals with Disabilities in Education Act (IDEA). And it often causes the greatest conflict between parents and schools. A required component of IDEA, FAPE mandates that school districts provide access to general education and specialized educational services. It also requires that children with disabilities receive support free of charge as is provided to non-disabled students.

In 1990, the law was reauthorized and renamed the Individuals with Disabilities Education Act (IDEA). It provided access to general education services for children with disabilities by encouraging that support and related services be provided to children in their general education settings as much as possible.

Over the years, the courts have helped define what FAPE is and is not. In short, it is vital for

parents to understand that IDEA is not an entitlement program that provides disabled children with a better education than is provided to non-disabled students. (for more information on this see page 4)

Full Inclusion: Full inclusion means that all students, regardless of handicapping condition or severity, will be in a regular classroom/program full time. All services must be taken to the child in that setting.

Homeschooling: The parent provides all instruction and in most cases other services come into the home.

IDEA: Individuals with Disabilities Education Act

IEP: Individualized Education Program Individualized Education Program (IEP) is a written agreement between the parents and the school about what the child needs and what will be done to address those needs. In accordance with the Individuals with Disabilities Education Act (IDEA, formerly PL 94-142), IEPs must be drawn up by the educational team for the exceptional child and must include the following:

1. The student's present levels of academic performance.
2. Annual goals for the student.
3. Short-term instructional objectives related to the annual goals.
4. The special education and related services that will be provided and the extent to which the child will participate in regular education programs.
5. Plans for starting the services and the anticipated duration of services.
6. Appropriate plans for evaluating, at least annually, whether the goals and objectives are being achieved.
7. Transition planning for older students.

Inclusion: Inclusion is a term, which expresses commitment to educate each child, to the maximum extent appropriate, in the school and classroom he or she would otherwise attend. It involves bringing the support services to the child (rather than moving the child to the services) and requires only that the child will benefit from being in the class (rather than having to keep up with the other students). Proponents of inclusion generally favor newer forms of education service delivery.

Least Restrictive Environment: (A) IN GENERAL - "To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily." {IDEA}

Mainstreaming: Generally, mainstreaming has been used to refer to the selective placement of special education students in one or more "regular" education classes. Proponents of mainstreaming generally assume that a student must "earn" his or her opportunity to be placed in regular classes by demonstrating an ability to "keep up" with the work assigned by the regular classroom teacher. This concept is closely linked to traditional forms of special education service delivery.

Reasonable Accommodation - an adoption of a facility or program for a child with a disability that can be accomplished without undue administrative or financial burden.

Related Services: Related Services means transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education. These services include speech-language therapy, occupational therapy, physical therapy, vision services, hearing services, assistive technology services, vocational assessments/training, recreation, and transition planning to prepare students for adult life.

Resource Room - a special education placement that is provided in conjunction with or as a supplement to a child's regular education program.

Special Education Setting: This setting is primarily composed of students with disabilities with primary instruction presented by a teacher who is licensed with a special education Endorsement

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IEP More Details

There are very specific requirements as to what must be included in a child's IEP. Briefly (there is really no way to state these briefly), these are as follows:

- 1) A statement of the child's present levels of educational performance including: how the child's disability affects his/her involvement and progress in the general curriculum; or for preschoolers, how the disability affects the child's participation in appropriate activities;
- 2) A statement of measurable annual goals, including benchmarks or short term objectives related to:
meeting the child's disability related needs to enable the child to be involved in and progress in the general curriculum; and
meeting all of the child's other educational needs that result from his/her disability;
- 3) A statement of the special education and related services, and supplementary aids and services to be provided to the child and a statement of the program modifications or supports for school personnel that will enable the child: to advance appropriately toward attaining annual goals;
to be involved in the general curriculum as well as extracurricular and nonacademic activities; and
to be educated and participate with non-disabled children in these activities;
- 4) An explanation of the extent, if any, to which the child will not participate with non-disabled children in the regular class and other activities, including:
a statement and supporting evidence that indicates why the student's disability prevents him/her from being educated in a less restrictive environment with the use of supplementary aids and services;
- 5) A statement of any modifications necessary in order for the child to participate in student achievement tests and if such tests are not appropriate for the child, a statement of why not and how the child will be assessed;
- 6) The date that services and modifications will begin and the frequency, location and duration of these services and modifications;

7) For students 14 years old or younger, a statement of the transition service needs of the child according to the child's IEP and courses of study (i.e. vocational education);

8) For students 16 years old, or younger if appropriate, a statement of the needed transition services;

9) One year before a student turns 18, a statement that the student has been informed of his/her rights that will transfer to the student at age 18;

10) A statement of how the child's progress toward the annual goals will be measured and how the child's parents will be regularly informed of their child's progress at least as often as parents are informed of their non-disabled children's progress.

When appropriate, the IEP team should also consider the following:

- The strengths of the child and the concerns of the parents for enhancing the education of their child;
- The results of the most recent evaluations of the child;
- Behavioral interventions, strategies and support when appropriate;
- Braille instruction for blind or visually impaired students or other types of instruction as is appropriate for the child;
- Language and communication needs for deaf or hearing impaired students;
- Assistive technology needs and services;
- Linguistically appropriate goals, objectives, programs and services for students whose primary language is not English;
- Participation of the regular education teacher where appropriate.

For more information about the laws and other information about what your child is entitled to in school please see:

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

A lot of this information doesn't apply to children with Hydranencephaly but it gives a good picture of what is considered to be a Free and Appropriate Public Education

FAPE Myths

Children with disabilities cannot be charged for:

- Materials
- Student fees
- Any other costs that are requested of general education students

Children with disabilities are not required to:

- Complete basic requirements for graduation.
- Pass state-approved assessments that demonstrate State standards.

The district must provide:

- A specific specialized program or school setting that is chosen by the parent;
- A program that provides the child greater access to educational materials than their non-disabled peers.

*FAPE also does not require that a school provide educational services that are superior to those provided to non-disabled peers

The student with a disability:

- Must be provided preferential treatment or guaranteed placement in extracurricular activities;
- Does not have to meet the basic requirements of participation that are required of non-disabled peers.

FAPE Facts

Special education and related services are provided:

- At public expense
- Under public supervision and direction Without charge to the parent or guardian.

Children with disabilities are provided:

- Modifications
- Accommodations
- Support services under their Individual Education Plans (IEPs).

These allow them to have access to and benefit from instruction so they can meet the standards of the State Education Authority.

The district must provide a program that:

- Complies with the procedural requirements of IDEA;
- Addresses the child's unique needs as identified by evaluations, observation, and the child's educational team and,
- Is coordinated to ensure the child is able to make adequate progress in the educational setting.

FAPE requires that the quality of educational services provided to students with disabilities be equal to those provided to non-disabled students.

The student with a disability:

- Must have access to non academic and extracurricular activities equal to those provided to non-disabled peers.

Education: Family's experiences

Josh (1/22/99-3/2/05)



School was the best thing for Josh, he got all his therapies & loved the interaction with all the other kids. We did not feel School would be beneficial at all to Josh, but we were so wrong.

We took him at first as he only went 2 half days then we worked up to 2 full days then he went full time when he was well. He got his own transport with a trained escort who also worked with him in class.

He really enjoyed his days at School & did really well in all his classes, he won 3rd prize in 2 art competitions & got to meet the Lord Mayor of Leeds & received 2 Certificates & his art work was framed & hangs on my wall. He also won Star of the week many times for his effort in class. His music Teacher adored him, when he first went to School & she knew his problems she thought he was a china doll & was very careful with him, she soon realised he liked noise & banging the drum she named him Her Billy Bongo.

Noah age 6 1/2



Noah attends mainstream school for 4 days per week and special school one day a week so that he can 'access programs' (i.e. hydrotherapy). The mainstream school has been fantastic at including Noah and setting up an individual program to suit

him. The school has purchased different equipment for him (a massage mat, MP3 player, tent to set us as a 'little room') and have set up an area for him to be able to work on his vision. The students are fantastic with him everyone says hello to him and they know to come up and touch him when they say hi so that he knows they are there. At the beginning of the school year we took Noah to each class room and explained why he was in a wheelchair, why he is tube fed (and also showed them how it is done) and they asked questions. This really helped them to not be scared of him and to accept him. The school even pays for a maxi taxi to take Noah for an extra swim each week and then back to school. We have been very lucky as this school is the best in the district for inclusion. Other parents haven't been so lucky.

Paul (7/26/93-5/14/03)



I choose to have my angel attended a center base school as our local school district was not equipped to handle a child with his needs. He rode the bus 5 days a week and attended the school age program at our Center for the Disabled. He received OT, PT, Special Ed, Group OT & PT and hydro therapy. Our Center for the disabled is so well equipped to handle kids like ours. There was a heated pool for hydrotherapy, a Hand clinic, Seating specialists, a dentist who work with differently able kids & adults, therapeutic horse back riding, the classrooms took field trips and outings just like "normal " school kids did. They had lots of switches and pieces of equipment to put the kids in to keep them moving through out the day! There were so many different Dr's and clinics in which we utilized the the center. The school age program utilized the M.O.V.E program, one of my main reason for wanting him there.

Mobility Opportunities Via Education (M.O.V.E.) uses physical positioning to foster learning.

<http://www.cfdsny.org/educationServices.html>
 Pauli was very, very lucky in that his teachers & therapists really looked out for him. They challenged him but also knew when he reached his limit. We had a daily communication note books each of his therapist's, teacher and school nurse wrote to me in. He loved riding the bus, socializing and getting his one on one therapies! The were skilled nurses and a nurse's office on site. Pauli went down twice a day for tube feeds and breathing treatments or meds. Right before he past away it was approved in his IEP for one on one aide. He was starting to not tolerate a 5 day school week. We were going to drop down to three days a week with a one on one aide. Our school district worked with me and not against me. He had an amazing bus driver and aide who took care of each kiddo like they were their own. We had a wonderful experience with school, I wouldn't of had it any other way! Parent(s) and school worked very well together in our situation and my son reaped the benefits of it!

Brennan, age 6



Brennan goes to a Special Ed Center close to where we live because I don't believe the surrounding mainstream schools around our area has neither the staff nor knowledge of how to treat and care for someone totally dependent like him. He's had 2 years of pre-school and is now in kindergarten. As with any school there is always room for improvement, but here they do their best to meet the needs of the child/parent and has already accommodated a couple of my requests. Brennan and maybe one other child is wheelchair dependent, the rest of his classmates are ambulatory with different disAbilities. I am told his favorite part of the day is "circle time" where they sing, etc. There's about 7 kids in his class, the teacher and two aides; and the school nurse is wonderful. At this time, I have to say we are mostly pleased with how Brennan is getting along at school.

Kayda (12/2/88-6/23/00)



Kayda had a varied school experience. Her first 2 years were a nightmare as the school didn't want her. They thought she was a waste of time. They kept her in a room by herself most of every day because she was noisy. Her next school was wonderful. Inclusion is the only option in our district and the principal bent over backwards to find ways to include Kayda. Things like having her arrive before everyone else and then being in the hall greeting children with her Big Mack (talking switch) as they arrived. This worked well until she was 10 and started months of screaming. So, then they put her in a gr 1-2 class where she and her noise fit in well. About 6 months before she died, she started getting sick every time she went out so I made the decision to keep her at home. She wasn't healthy enough at the time to really need a school program.

Factors to Consider in choosing a school setting for your child:

1. Your child's health. Will the risk of increased germs be worth the benefits of being with other children?
2. Does the school want your child? If the school doesn't want or is afraid of your child, I've found that it's a losing battle trying to get them to work with you.
3. Who will your child spend the day with? Will he/she be with other children with challenges, by themselves, with typical children, etc. Which setting do you think will be best for your child?
4. How will your child get too and from school? How long will he/she have to ride on a bus or in your car? Will this work for your child?
5. Will your child get therapy at school or will you still have to take him/her to therapies outside of school.
6. Where will your child get the most attention?
7. How many children per teacher? Will your child have a 1-1 aide or share one among many children?

For Grieving Families

An Unfinished Mother

Written by Clara Hinton

When child loss occurs, a mother goes through a difficult time of emotional turmoil and questioning. “Am I still a mother?” “Does my child still have a birthday each year, or does time stand still?” “Can the mother/child relationship continue to grow, or am I now an ‘unfinished mother’?”

Losing a child places a mother on a road that begins a lonelier journey than ever expected—one that can never really be explained. There was a beginning, but with the death of the child, there is no middle and no end. Everything seems so unfinished. Hopes and dreams were stopped far too soon. Joy was snatched away so suddenly. A mother is left with empty arms and an empty heart. Nothing can ever be complete when a child’s life ends.

When the death of a child occurs, a mother is stopped in her tracks, and she suddenly feels inadequate and incomplete. She wears a new name. She is an “unfinished mother”, never being able to see the rest of the picture. She will never be able to watch her child mature into a young adult. She will never be able to see all the pieces fit together. The picture will always have part of the scenery missing. It is so painful to be an unfinished mother! Child loss makes everything seem so empty and incomplete.

The reality of child loss is devastating to a mother. There are overwhelming feelings of guilt, inadequacy, and most often feelings of failure. These feelings can overwhelm a mother for several months following the death of a child, and it can be quite difficult to build a support system to carry a mother through this roller coaster of emotions. Very few people will understand a mother’s explanation of feeling like she is an unfinished mother.

There will come a critical point in this journey of grief when a mother must reach deep inside her inner resources and make a conscious decision to accept herself just as she is—a mother whose heart has been touched by the pain and grief of child loss. Only then can she start to put together some of the broken pieces and begin to feel like there will be a day when she will feel more like a complete mother than an unfinished mother.

When a child dies, life is suddenly thrown completely off balance. A mother is left feeling like her identity has been taken away. It is often a long difficult journey to find that place of identity as a mother again. It’s hard to understand that there is unfinished living that will never be completed. Peace can finally come to a mother’s heart when she realizes that there is a big difference between having unfinished business and being left feeling like an unfinished mother.

A mother is never “unfinished.” No matter how brief her time was with her child, the bond of love between mother and child was complete. A mother’s love for her child is unending. Dreams may shatter and circumstances may change, but a mother’s love remains strong. As a mother travels the path to healing, it is important for her to remind herself often that she is a mother forever. Her motherhood did not stop when her child died. This understanding of motherhood releases the feelings of guilt and failure and allows a mother to begin to see herself as a whole person again—a complete mother.

A mother is never an “unfinished mother.” A mother’s love runs far too deep to ever be called unfinished!

March

“Sadaversaries”

(birthdays & anniversary dates for those who have died)

Joshua: Jan. 22, 1999-**March 2, 2005**
Jacob: **March 2, 1989**-Oct. 28, 1992
Heather: Jan. 18, 2001-**March 2, 2007**
Blake: Sept. 21, 1998-**March 3, 2000**
Eaven: **March 3, 1998**-Sept. 23, 2002
Tanner: **March 8, 2000**-Dec. 1, 2001
Stasia: May 17, 1987-**March 11, 1990**
JD: Dec. 1, 1999-**March 13, 2003**
Kirsten: **March 13, 1991**-Dec. 2, 2005
Katie: Dec. 20, 1985-**March 20, 2004**
Joshua R.: **March 25, 2000**-Nov. 14, 2003
Megan: Feb. 24, 2000-**March 25, 2002**
Tyson: Aug. 2, 2002-**March 27, 2003**
Jacob N.: **March 28, 2000**-July 9, 2000

Child of the Month

Natan Shai



Well it sure has been a hectic time since we were privileged to receive Natan Shai. It happened one day back in November 2007 when I received a call from the Social Services Dept. letting us know of a 3 month old baby who had been left in the hospital with some kind of brain damage, and asking if we would like to come and get him... (we'd applied to foster a special needs baby about a year previously).....

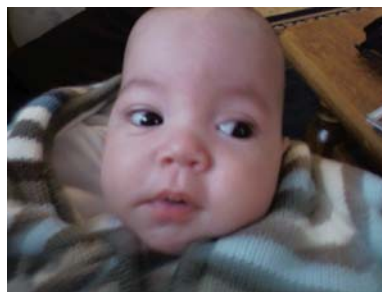
We traveled to the hospital the next day, and visited our little angel. We knew at the first instant that this was the right thing to do and that Natan Shai was 'our' baby - a gift from God. Our biological children were delighted, and it was a very special time for all of us.

Natan Shai was born prematurely, 25 weeks into the pregnancy, and was consequently left in the hospital thereafter. He had a brain hemorrhage right after he was born and none of the hospital staff thought that he'd make it, so they didn't even look for a foster care family for him in the beginning. But our Natan Shai is a fighter and with God's help he pulled through. A week later 'Erev Hanukah' we were privileged to make him a Brit and give him his name. It was beautiful and lots of people came who had heard about the story. We chose the name Natan Shai (which means in English 'Given Gift' because he was actually born on the same day as Avigail my oldest daughter and I arrived in Uman (Ukraine) in August to visit Rabbi Nachman's gravesite. Rabbi Natan was Rabbi Nachman's main student and he had the privilege of writing all of Rabbi Nachman's teachings. We had just been to Rabbi Natan's gravesite in Breslov before arriving in Uman. His biological mother had requested the name 'Shai', although she didn't want any contact thereafter. We felt it was the least we could do for her. So the two names fitted perfectly together. Natan Shai was diagnosed as having

Hydranencephaly and Hydrocephalus. Due to the latter he was scheduled for an urgent shunt operation to help relieve the water around his brain. With God's help he had the shunt put in at the Rambam hospital in Haifa and after four days we were released.

Unfortunately little did we know that during the operation Natan Shai caught a bacterial Streptococcus germ in his blood, so about a week after the operation he was feeling terrible with a very high temperature and throwing up. We were re-admitted to hospital where he had very strong antibiotics through an I.V. It was a long stay (three weeks), but thank God we were transferred to the Safed hospital, which meant that me and Naor could take it in turns to be there with him, which gave us both a break and the opportunity to be with our children at home.

Thanks to everybody's prayers we are now at home with Natan Shai and he is doing well. He still needs another months worth of antibiotics which does drain him and give him a nasty stomach ache, but with God's help he'll be O.K. Besides that he needs regular physiotherapy to help him develop properly. In another month or so he'll have another C.T. done to check out what's going on with his brain, after the shunt operation.



Natan Shai and his family live in Israel.

March Birthdays

Gemma: March 1, 2002
Dillion: March 4, 2002
Leah: March 7, 2004
Edrik: March 14, 1997
Gracie: March 20, 2004
Shane: March 24, 2005
Christine: March 26, 1996
Alicia: March 29, 2000