

KIDZ



www.texaskidz.com

ADVOCATES FOR KIDZ AND FAMILIES WITH SPECIAL NEEDS

Volume 2, Issue 4

July/August 2005

Monthly Meeting Info

May 2005 Summary:

Attorney Mark Boon spoke on living wills and special needs trusts.

June 2005 Summary:

No speaker this month. The adults visited with each other while the children tackled two craft projects! A great time was had by all.

Upcoming Meetings:

Speakers in the following months will be: Janet White (siblings point of view), and Margo Dewkett (personalities). You don't want to miss out on these!



JULY 2005 Meeting:

Dorothy Hull will be speaking on self-advocacy on July 12th at 6:30. All are encouraged to attend.

KIDZ MONTHLY MEETINGS

PLACE: NEW BEGINNINGS BAPTIST CHURCH
600 GEORGE RICHEY RD.
LONGVIEW, TX
(SEE MAP)

TIME: 2ND TUESDAY OF EACH MONTH
FROM 6:30 PM TO 8:00 PM

Childcare is available at no charge.

About Us...

KIDZ is a group of parents with special needs children who have joined together to provide support and information for other parents with special needs children regardless of how minor or severe the disability.

- Monthly Meetings
- Bi-monthly Newsletters
- First Contact Brochures
- Support Line (Connecting Parents to Parents)
- Special Events

Visit us on the web at www.texaskidz.com or call or write for more information about KIDZ and our programs. KIDZ mailing address and phone number can be found on the last page of this newsletter. ■

Family Focus

This column highlights stories from different families.

By Mike & Brandy Bailey

Michael was born 2 months early due to the fact that I had high blood pressure. For the first month of his life, we thought we had ourselves a small, but healthy baby.

The doctors told us that Michael had a few problems with his heart but that they were common in premies and it should heal on its own. A month went by and they were sending us to a children's hospital that had pediatric cardiologists on staff. First the doctor told us our baby had a heart defect called aortic stenosis and would need open heart surgery to survive. What a shock! Then we had



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Respite (n.) a brief rest
from a difficult task

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First Contact Brochure

Distribution of our First Contact Brochures around town continues. Be on the lookout for them and be sure to spread the word about them. The response has been great so far with well over 500 being placed and requests for more!

One of the goals of this brochure is to inform new parents and existing parents that there are other families in our community with special needs children who are going through, have been through, or will go through the same challenges and uncertainties that they are facing.

Family Focus continued from page 1

geneticists come into the picture telling us that with the heart defect our son has it is usually something genetic. They ran tests. Tests that took months to get results back. It was torture waiting. The tests came back and it was positive for trisomy 13. This means

"For the first month of his life, we thought we had ourselves a small, but healthy baby."

that he has an extra 13th chromosome. The geneticist told me not to bother doing the heart surgery - to just let my child die - because of the quality of life he would have. I told him that I would not play God. God gave me this baby and if He wants to take him that He would. I refused to just "let my child die." Praise God we found a surgeon who would perform the surgery. So, at 4 months old he had open heart surgery. That same day he was breathing on his own (which we were told he would never do). He is now 3 years old and still beating all the odds. He is truly our miracle. People and doctors alike are amazed at how well he is

"...Michael - a little boy who the docs said if he even lived, that his quality of life would not be worth anything...a little boy so full of life, always wanting to help others..."

doing. He has had several minor surgeries along the way and every time it is scary, but just like He was there through that first 4 months of Michael's life, God has been right there by our sides protecting our precious baby. We thank God every day for Michael - a little boy who the docs said if he even lived, that his quality of life would not be worth anything...a little boy so full of life, always wanting to help others -our miracle Michael. ■

Encouraging Words

"I have learned two lessons in my life: first, there are no sufficient literary, psychological or historical answers to human tragedy, only moral ones. Second, just as despair can come to one another only from human beings, hope, too, can be given to one only by other human beings."

- Eli Wiesel



- **KIDZ** has a website! You can view our newsletters, current and past issues, along with many other interesting things at www.texaskidz.com.
- We need your help! One of our goals is to have a “library” of information pertaining to different diseases, afflictions, or disabilities that you have dealt with. We would like to make this information available to others who are faced with the same situation for the first time. Please ensure that all the information you submit is 100% accurate. Send articles or references to info@texaskidz.com or mail copies to KIDZ, PO Box 10015, Longview, TX 75608-0015.
- If you are interested in purchasing advertising space in our newsletters, please e-mail us at info@texaskidz.com. Ads will be restricted to a limited number per issue and will be accepted/denied and placed at our discretion.
- **KIDZ** is working on getting universally accessible playground equipment placed in the Longview area. If you are interested in helping with this effort, which will benefit your children and the entire community by allowing all children to play together in one place, please contact us!



Handicap Accessible Children's Park
Lubbock, TX

If you would like to be on the mailing list to receive our KIDZ newsletter, please call Amber at (903) 663-5936 or e-mail us at info@texaskidz.com

FAST FACTS

“Trisomy 13 syndrome is a disorder of human chromosomes which occurs in approximately 1 in 10,000 live born infants. Trisomy 13 is due to the presence of an extra #13 chromosome.”

“The major implications of Trisomy 13 involve a predisposition to congenital malformations (birth defects)...an increased mortality in infancy, and a developmental disability in older children. In addition, older infants can have visual difficulties...and a hearing loss. The increased mortality is related to difficulties with breathing due to either interrupted breathing (apnea), or problems of lung development. In addition, gastroesophageal reflux and feeding problems can occur and predispose to aspiration adding to this risk. Usually the heart defects are not serious enough to be a major health threat in the newborn period.”

Support Organization For Trisomy 18, 13, and Related Disorders.
Retrieved Jun. 16, 2005, from

http://www.trisomy.org/html/trisomy_13_facts.htm

Trisomy 13 Related Web Sites:

<http://www.livingwithtrisomy13.org>

<http://www.trisomy13survivors.org>

<http://www.noahsneverendingrainbow.org>

Additional Resources:

<http://www.benotafraid.net>

<http://www.marchofdimes.com>

<http://www.rarediseases.org>



KIDZ would like to say a special “thanks” to ...

Atty. Mark Boon for speaking on living wills and special needs trusts.

All of those **volunteering** to watch the kids during our meetings!

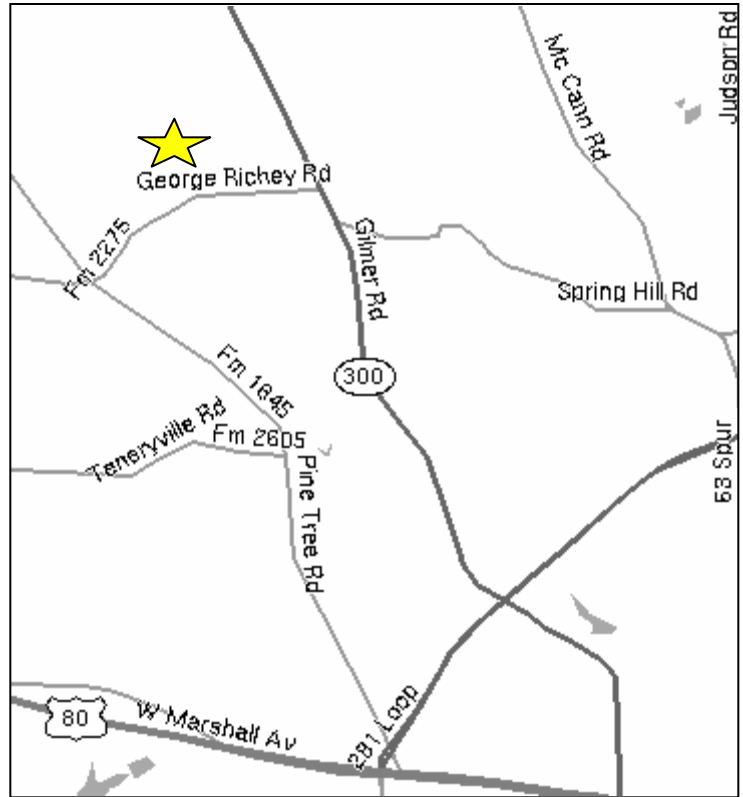
Early Childhood Intervention (ECI) for providing copying and mailing services for our newsletters!

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If you would like to make a donation to KIDZ, please make checks payable to:

NBBC c/o KIDZ

Donations are tax deductible.

KIDZ is a bimonthly publication. As the KIDZ fiscal sponsor, New Beginnings Baptist Church oversees donations and disbursements on behalf of KIDZ in order for KIDZ to direct its efforts to the families in need.

KIDZ
P.O. Box 10015
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