



# Families Together, Inc.

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Wichita Center 1-888-815-6364 • Topeka Center 1-800-264-6343 • Garden City Center 1-888-820-6364 • Kansas City Center 1-877-499-5369  
Statewide Spanish parent line 1-800-499-9443 (All toll free numbers for Kansas parents + education advocates)

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## Building Relationships with the School

Submitted by Lori Burnshire, Wichita Center

### Communication is Key

Parents of children with special needs will interact with many professionals throughout their child's educational career. Each year going "back to school" may mean seeing many new faces. Your child may have a new bus driver, paraprofessional, related services professional or classroom teacher. Finding the time to meet and greet each new person may be a challenge. However, establishing and maintaining good working relationships with these many professionals is important to your child's educational success.

The foundation to any successful relationship is open and frequent communication. If your child is transitioning to a new school and a new team, make your first interaction of the school year a positive one. Introduce yourself to the teacher and other professionals who will be working with your child early in the school year. Make a great first impression by sharing something positive about your child. If your child is returning to a school where the team has had difficulty communicating in the past, don't let past experiences dictate how this school year will be. Instead, identify the barriers that have interfered with effective communication and work on resolving them.

Once successful communication has been established, parents and teachers should work together to develop a system to keep dialog flowing. This might include notebooks that travel with the child, frequent notes from teachers or even phone calls. Use this system to share any concerns or ideas right away. By communicating early you can avoid becoming frustrated and keep situations from becoming a major problem.

Everyone benefits from effective communication. The more the team knows, the better understanding they will have of the child and the more successful the school year will be.



### Inside this Issue...



- Information on Families Together Events ..... p. 2
- Q & A ..... p. 3
- Early Communication Break-down and Repair Project .... p. 3
- Downey Side ..... p. 3
- Family Story ..... p. 4-5
- Early Intervention
- Leave No Child Behind Conference Registration.... p. 6
- From the Director's Desk ... p.7
- Kansas Resources..... p. 8
- Internet Resources..... p. 8
- Sound Beginnings ..... p. 9
- Get to Know Your Legislator ..... p. 9
- Self Determination and Transition Conference..... p.10
- Family Voices ..... p. 10
- Education Advocate Update ..... p. 10
- Calendar of Events.....p. 11
- Regional Cruise ..... p. 11
- Families Together PNC/FEW Registration ..... insert
- Planning for the Future flier .....insert

# Usted Esta Invitado...A Uno De Nuestros Secretos Bien Guardados!

*Sometido por Isabel Aguilera, el Centro de Garden City*



Familias Unidas, cordialmente lo invitan asistir uno-o-más de nuestros eventos anuales. Estos eventos lo educará y lo inspirará, también son divertidos. Nuestras **Conferencias de Estatal** se sostienen en Kansas City e Garden City. Nosotros estamos invitando a los padres, profesionales y cualquiera que está interesado en ganar el conocimiento en la Educación Especial. Este evento será todo un-día y está lleno de Talleres Educativos como: La ley de Educación Especial, 504, Inclusión, la Conducta, y otros. Nosotros también, traeremos oradores conocidos nacionalmente (algunos que también tienen incapacidades) para educar, motive e inspírenos.

Nosotros también, ofreceremos una **Conferencia-Red De Padres** que simplemente es para los padres de un niño con una incapacidad. Empieza el viernes por la tarde y fines el Sábado en la tarde. Los padres recibirán un vale para el cuidado de los niños. Así ellos puedan conectar una red con otros padres, asisten a los talleres educativos y tienen un tiempo sin tension.

Nuestro más popular, es nuestro **Enriquecimiento Familiar A Fin De Semana** y eso es porque es un evento familiar. Los padres asisten los talleres educativos mientras los niños asisten actividades divertidas a lo largo del día. Los niños también tendrán un compañero con ellos a lo largo de las actividades del día. Para aprender más sobre estos eventos y otros vayan a nuestra página de web: [familiestogetherinc.org](http://familiestogetherinc.org)



## YOU'RE INVITED...TO ONE OF OUR BEST-KEPT SECRETS!

*Submitted by Isabel Aguilera, Garden City Center*

Families Together cordially invites you to attend one or more of our annual events. These events are educational, inspiring and fun. Our statewide conferences are held in Kansas City and Garden City. We are inviting parents, professionals and anyone who is interested in gaining knowledge on special education to attend. They are one-day events and are full of educational workshops on topics such as: special education law, section 504, inclusion, behavior, etc. We also bring nationally known speakers to educate, motivate and inspire us.

We also offer Parent Networking Conferences that are just for parents of a child with a disability. They begin on Friday evening and end on Saturday afternoon. Parents will receive vouchers for childcare so that they can network with other parents as they attend educational workshops and have a stress free weekend.

Our most popular event is our Family Enrichment Weekend and that is because it is a family event. Parents attend educational workshops while the children attend fun activities throughout the day. The children will have a one-on-one companion with them throughout the day's activities. To learn more about these events and others go to our web site at [familiestogetherinc.org](http://familiestogetherinc.org)

We encourage you to come and be part of a positive team of professionals, parents, youth and community partners in connecting with each other to build better futures for our youths with disabilities.

# ? Q&A



**Q.** Why is my child being promoted from grade to grade but can't read?

**A.** A child with a disability has an IEP for the purpose of helping him/her to benefit from his/her educational experience. The issue of reading should be addressed in the IEP. Measurable goals should be developed for reading so the method used can be assessed. A child operating from an IEP developed by the IEP team is not held to the same academic standards as the class. The goals and objectives in the IEP determine the child's progress, not the grading standard for the class. If reading is the only goal that the child did not attain, then it should be closely examined to determine if the method is

appropriate for the child. It is the decision of the IEP team whether the child should go on to the next grade level in school. Some considerations are:

- What benefit is it to the child to retain him/her?
- Is there a reason why the child is not learning to read (on grade level)?
- Does this child need additional help in reading?
- Can the needs of this child be met in the next grade level?

Often, the student is promoted to maintain social ties with his/her classmates. Self-esteem is very important to children and is a determining factor when a child is "socially" promoted. However, social promotion is not a substitute for learning a skill, especially reading. If the IEP team does not come to consensus on promotion or retention, then procedural safeguards necessitate review of all options considered and due process may be initiated.

## Moms & Children Needed

for an **Early Communication Breakdown & Repair Research Project**

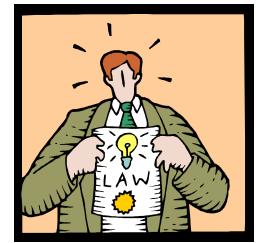
Conducted by Dr. Nancy Brady and Dr. Tammy Steeples, University of Kansas Life Span Institute

Several families have participated in the past two years, and we thank them again. We invite additional children 3-5 years old who communicate with gestures or single words and their mothers to participate from now through December 2003. We can offer you mileage (up to \$35 per trip) and gift certificates (\$20) from your choice of Wal-Mart or McDonald's. We do Saturday or evening appointments if preferred and families can participate in Lawrence or at the KU Medical Center. We especially need moms and children who live within 30 miles of Lawrence as we will be inviting some families to participate in an intervention phase of the study.

If you would like to be involved or get more information:

- Contact Dr. Tammy Steeples in Lawrence toll free at 866-591-3084, 312-5364 or [steeples@ku.edu](mailto:steeples@ku.edu)
- Write to us at:  
University of Kansas  
Life Span Institute  
13145 Wakarusa Drive, Suite 105  
Lawrence, KS 66049
- Let us know the best time and way to contact you, and we will get in touch with you.

Parents need to stay informed on the changes being made to the reauthorization of IDEA. For a current update, you can check our website at [www.familiestogetherinc.org](http://www.familiestogetherinc.org)



## DOWNEY SIDE

*...families for youth since 1967*

Many children between the ages of 7-17 are in need of permanent adoptive families.

These children may have mental, physical or emotional disabilities. All need a forever home.



Our mission is to match waiting children in foster care with committed caring families.

Call us or visit our website:  
913-789-8910  
[www.downeyside.org](http://www.downeyside.org)

# Family Story

## Tony and Allison Emerson

July 2003

Kaitlyn age 6, Sydney age 4, Reagan age 3

Reagan was born on June 28, 2000 just after Kansas began Universal Newborn Hearing Screening. Our family has no history of hearing loss and we almost left before the hospital was able to administer the hearing test. Our pediatrician was made aware of the results of the test and wanted to make sure Reagan saw an audiologist by the time she was six months of age. We had our first visit with the audiologist at two weeks of age. We tried to do an Auditory Brainstem Response (ABR) with her sleeping soundly, but were unable to keep her from stirring on two attempts. She went in for a sedated ABR on September 13, 2000. As the test was being conducted my husband was querying the audiologist about cochlear implants. We knew very little about them, but we had heard about them. When we left the office, we had heard the audiologist say to the ENT we were working with something about "80". We took that to mean she had an 80% loss. We didn't know she had not responded to 80 decibels.



As this news began to sink in and we were able to get more complete information on the significance of her loss, we were in shock. It was a difficult time as a parent because we were looking at all of our child's life skills, education needs and future in our hearing society when she was a mere three months old. It was very difficult, but as I look back now, it was one of the greatest gifts I have been given as a parent. I had time to position myself. I knew what I wanted for my child well before she was ready to enter those situations.

The week after the hearing loss was confirmed, we began early intervention services. There was not a seamless transition from identification to services as would be expected. Early childhood people were in no short supply, but it took some real maneuvering to get an educator for the deaf to begin working with Reagan in our home. Once we began working with the teacher of the deaf, we were bombarded with a choice for a communication method. This seemed like an ominous decision because Reagan's family is all hearing. I wanted nothing more than to give her the same opportunities that her two older sisters would have. This was the force inside me that kept me probing for more information. Most of all I wanted her to learn to use spoken language. I began sign language class soon thereafter also. I was overwhelmed at the thought of my child's ability to communicate resting upon how well I could learn to sign. The services for her to become an oral communicator we were asking for seemed atypical at best.

Reagan began wearing bilateral hearing aids at the age of four months. We had done the testing at three months, but we were seeking another opinion which was obtained at Boystown National Research Hospital in Omaha. Since our audiologist had little experience with babies, he met us for the clinic exams and testing. Their collaborative efforts were able to help us receive the best possible hearing aid fitting. It was quite a chore to keep hearing aids on an infant who was not yet sitting up. They would feedback almost constantly because she would grow before we could get new molds back from the manufacturer. She never responded to stimulus in the booth with her hearing aids.

Our quest for Reagan to learn to speak was moving forward on another front as well. She began testing in January to determine if she was a candidate for a cochlear implant. After several visits over a couple of months, we held a team meeting of all of the professionals working with Reagan. It was after this meeting that a date for cochlear implant surgery was set. I had a lot of reservation as this is a major

*continued on next page...*

invasive surgery. The many people I spoke with had a common tone. What did we have to lose? The teacher of the deaf was quite skeptical that she would receive the benefit we were hoping for. It was great to have her as part of the team because she was asking all of the tough questions and keeping us realistic.

Reagan underwent surgery on April 26, 2001. She was nine months then and the youngest cochlear implant recipient ever at the Midwest Ear Institute. She had her device activated a month later. From very early she withstood the sound she was receiving well. The audiologist would turn up the volume and sensitivity and she never turned back.

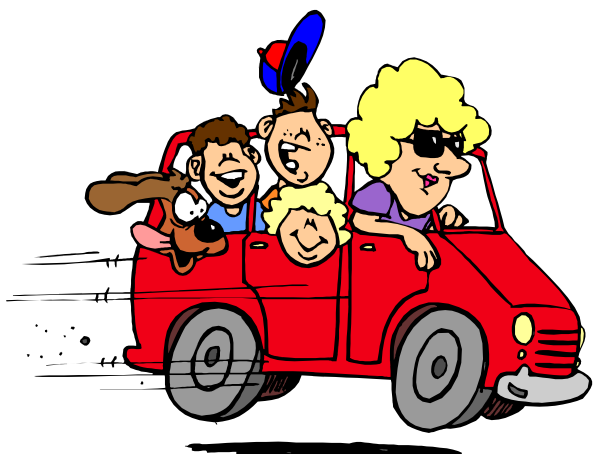
It was at this time that we began utilizing the services of St. Joseph Institute for the Deaf in Kansas City. They have a rich tradition of teaching deaf children to use their voices. They do not utilize sign language or any other visual cues as they train children to use the hearing they have as a result of hearing aids or an implant. This was the next logical step for us as we strove to maximize her benefit and encourage her to use her voice. She attended twice weekly sessions with a speech/language therapist from St. Joseph. We utilized our health insurance benefits and received some financial assistance from AGBell. Infant-toddler services in our community continued to provide the teacher of the deaf. Eventually we were so pleased with St. Joseph that we discontinued the other once weekly visit as it was unable to be scheduled at a convenient time for our family. The infant-toddler program then paid a little over \$1,000 towards our year of services at St. Joseph.

One of the most frustrating things our family has faced is not that we could not avail ourselves of the services that we wished for our child, but public funding did not support our choice for an oral education. This is an on-going battle as we have recently begun to work with our school district to develop an appropriate IEP. The

climate in our state with regard to hearing loss does not equally support families. We remain hopeful that more and more public entities will try to collaborate with families choosing the oral method.

I would say Reagan began to respond to her name within a month of activation and her progress was so steadily improving that I could not even tell you when she began to speak. One of her first really clear words was "cheese" because she would have it for a snack very regularly. She now tests at age level for expressive and receptive speech and language skills. She has pretty clear pronunciation and picks up a lot of incidental language. She knows she cannot wear her device in the swimming pool and asks to take it off. Most mornings she asks for her implant and wants to put the batteries in by herself. She is a very typical three year old.

Reagan will always be deaf. Her implant did not make her a hearing person. She will always work harder to communicate than her hearing peers. She will need people to understand that there are limitations to what she can hear and she will need to be aware of environments where communication may break down. Newborn Hearing Screening did not allow us to cure our daughter of her hearing loss. It allowed us to gain an insight at the earliest opportunity into a world many of us have little awareness of. We could not be more thankful that we knew from birth that Reagan had so much to teach us.



## WELCOME BACK REGIONAL COORDINATORS!!

**The regional coordinators  
have returned for the school year!  
They are ready to assist you!**

*Due to staff changes, the South Central Regional Coordinator's phone service may not be accessible for awhile. If your call won't go through, please call the Wichita center and they will be able to help you.*



# Leave No Child Behind!

A Statewide Conference presented by Families Together, Inc.

## Presenting... Alex Valdez

Valdez, who lost vision in his left eye at the age of 4 before losing his sight completely when he was 7, holds the title of America's first comedian with a disability. Valdez is an inspirational speaker on the hidden disabilities, multicultural issues, hospitality and diversity training.



*The following topics will be addressed: Curriculum Adaptation, Classroom Behavior, Student Advocacy, Special Education Law/Section 504, Transition, Self-determination and more!*

**For more information or to register for the conference, please call:  
620-276-6364 or 888-820-6364**

A limited number of parent scholarships are available through Families Together, Inc. Parents should call 620-276-6364 or 888-820-6364 to request a scholarship. Scholarships cover registration fee only. A block of rooms under Families Together's name is available at the Garden City Plaza Inn. You are responsible for the cost of your own room. The Garden City Plaza Inn is accessible. Individuals requiring special accommodations should contact Families Together by October 20, 2003. Lunch is included in the registration fee.

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## Register by October 20, 2003

Please submit one registration form for each person attending

Name: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ (Home) \_\_\_\_\_ (Work)

\_\_\_\_ Parent \_\_\_\_ Educator \_\_\_\_ Other (please specify) \_\_\_\_\_

Registration fee: \$30.00 for parents  
\$40.00 for professionals

*Lunch is included in the registration fee.*

\_\_\_\_ check enclosed  
\_\_\_\_ purchase order# \_\_\_\_\_

Mail to:

**Families Together, Inc  
111 Grant Avenue  
Garden City, KS 67846**

## Your Support Can Make A Difference!



- Your donation of:
- \$60... will help a family attend a statewide conference.
  - \$50... will provide toll-free line access to parents for an entire week.
  - \$25... will provide a new book for the free lending library.
  - \$10... will provide information packets to families.
  - \$5... will provide newsletters to 20 families.

Enclosed is my tax-deductible donation of \$\_\_\_\_\_.

Send to:  
Families Together, Inc.  
3340 W. Douglas Ste. 102  
Wichita, KS 67203

*\*Families can designate an organization when they give to United Way or to the Combined Federal Campaign.*

**Thank you!**



## NICHCY

*National Information Center for  
Children and Youth with Disabilities*

**NICHCY has NEW Website!!**

Same address - [www.nichcy.org](http://www.nichcy.org)

- ★ All text-only publications have been reformatted to a new easy-to-read layout
- ★ A side-bar menu makes navigation easy
- ★ The ALL-NEW resource library featuring the Technical Assistance & Dissemination (TA&D) Network makes finding information a breeze

Call us or visit  
our website!

1-800-695-0285  
[www.nichcy.org](http://www.nichcy.org)

## A Note From the Director's Desk...



Dear Families and Education Advocates,

I hope that the summer was fun and that the school year has gotten off to a great start for you and all the students that you care so much about.

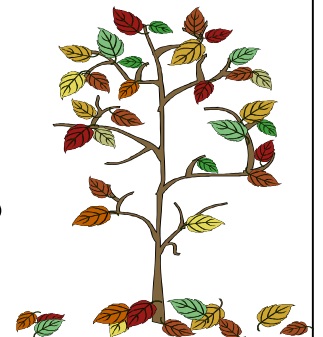
We have worked very hard this summer to plan some value packed conferences for you this school year. The flyer for the Parent Networking Conferences and Family Enrichment Weekends is included with this mailing.

The partners that we have at Families Together pay for families to be able to get this great training - free of charge!! Whenever we accept money from these partners, we have a duty to make sure that each dollar provides as much information and opportunity to as many families as possible. With that in mind, if you are planning to come to any of our conferences, please take advantage of every minute of the conference. If you are unable to attend the event for which you are registered, it is important to let the office know, so other families can come. Many of our events have a waiting list and those families are ready to take your place if you have a conflict. It costs us, through our partners, about \$225 for each family to attend a weekend/overnight event. Please help us to assist as many families as possible by letting us know if you are unable to attend.

The staff and volunteers are all anxious to meet many new families this year!! Check out the events across the state and let us know which one you can attend. See you there!!

Connie

## October is Learning Disabilities Month



# KANSAS RESOURCES

Families Together toll free numbers:

Wichita	1-888-815-6364
Topeka	1-800-264-6343
Kansas City	1-877-499-5369
Garden City	1-888-820-6364
Spanish line	1-800-499-9443
NC Region	1-866-778-7710 or 1-866-963-1734
NW Region	1-866-775-7710
SC Region	1-866-884-8810
SE Region	1-877-948-3049

## Make A Difference Information Network 1-800-332-6262

An information service for children and adults with disabilities, their families, and their service providers.

## SUPPORT GROUPS

### N.W. Kansas Association for Visually Impaired

Meets: 2nd Saturday 12:00 noon  
1105 Centennial Blvd.

Country Kitchen - 3203 Vine

**Hays** - Bob Chaffin (785) 628-2873 (H)

### Western Kansas Assoc. on the Concerns of the Disabled

Meets: 3rd Thursday  
LINK office - 2401 E. 13th

**Hays** - Gary Howard (785) 625-6942

If you have a child with xxy syndrome (sometimes known as a variant of Klinefelter Syndrome) or know a family with a child who has xxy syndrome, you can contact an international support group of xxy parents by calling Renee Beauregard at 303-766-2050 or by emailing her at [amazonb@worldnet.att.net](mailto:amazonb@worldnet.att.net).

There will be a get-together of xxy families in Colorado in July of 2004.

### Autism Society of Johnson County

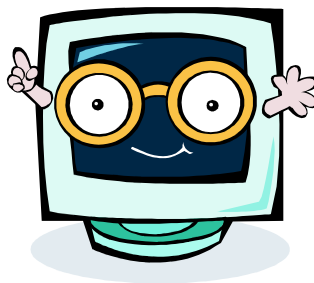
Meets: 2nd Tuesday of each month 7:00 pm  
MidAmerica Rehabilitation Hospital  
Overland Park

Contact: Kirsten Sneid (913)-987-1234

### Sign Language Bowling Club

Meets: 3rd Saturday 7:00 - 8:00 pm  
Trego Bowl, W. Hwy 40

**Wakeeney**



## Check Out these Internet Resources!

See [Does Your Insurance Company Cover Your Hearing Aid Expenses?](#) from the [Where Do We Go From Hear?](#) website. We hope some of the following information will be helpful to you who are having problems getting your hearing aid or cochlear implant covered by your health care provider.

[www.listen-up.org/haidfund.htm](http://www.listen-up.org/haidfund.htm)

Free or discounted prescription medication  
[www.makoa.org/freemedicine.htm](http://www.makoa.org/freemedicine.htm)

Social Skills and Autism  
[www.teachervision.fen.com/lesson-plans/lesson-26105.html](http://www.teachervision.fen.com/lesson-plans/lesson-26105.html)

For safety tips for children with special needs, check out [www.safekids.org](http://www.safekids.org) under Safety Tips.

On-line Medical Dictionary  
Allows you to search for information on any medical term through a wide search. This site can also link you to a multilingual dictionary and a drug database.  
[www.graylab.ac.uk/omd/index.html](http://www.graylab.ac.uk/omd/index.html)

Childhood and Neurodevelopment  
This is a useful overview of key early childhood web sites and resources prepared by the National Governor's Association.  
[www.nga.org/HotTopics/ECIssues.htm](http://www.nga.org/HotTopics/ECIssues.htm)

Services for Children with Special Health Care Needs  
[www.kdhe.state.ks.us/shs/](http://www.kdhe.state.ks.us/shs/)

United Cerebral Palsy of Kansas  
[www.ucpa.org](http://www.ucpa.org)

Spina Bifida Association of Kansas  
[www.wichitaeagle.com/connect/sbaks/](http://www.wichitaeagle.com/connect/sbaks/)

NAMI Kansas (National Alliance for the Mentally Ill)  
<http://ks.nami.org>

Autism Society of Johnson County  
[www.asjck.org](http://www.asjck.org)



# Sound Beginnings

## ***Newborn Hearing Screening in Kansas makes the grade!***

*Submitted by Kim Sykes, KDHE*

**A** State Report Card published by the Deafness Research Foundation and National Campaign for Hearing Health checks to see if states are making the grade on infant hearing screenings. Kansas made the grade with an excellent rating for screening 95% of infants. Each year more than 120 infants in Kansas, or one in 300, are born with a hearing loss and 10 to 40 of these infants are profoundly deaf. Hearing loss is the number one birth defect in the United States. Kansas mandates newborn hearing screening for all infants prior to hospital discharge to detect hearing loss. Early detection is vital to diagnosis and intervention. The age of the child when a hearing loss is diagnosed is crucial to the development of the child's speech, language, cognitive, and psychosocial abilities.



universal newborn hearing screening, hearing loss is usually found when a child is 2 to 3 years of age. All infants who screen positive for hearing loss should have an audiological evaluation **before 3 months of age**, or as soon as they can. Infants who have hearing loss should have a complete medical evaluation. All infants with hearing loss should receive early intervention services **before 6 months of age** (medical, audiologic, educational and support services). Health care professionals will give families information about the full range of intervention options so they can make the best choices for their child.

**Plus** ~ if at any time you are concerned about your child's hearing, have a hearing test as hearing loss may occur later in childhood even if your baby passed the screening at birth.

Remember the EARLY in EHDI (Early Hearing Detection Intervention), 1-3-6-plus, and ask your child's provider to report their findings to KDHE Sound Beginnings. For additional information contact Sound Beginnings at [www.soundbeginnings.org](http://www.soundbeginnings.org) or 1.800.332.6262, 785.296.6135. A resource guide is available for families of infants and toddlers who are deaf or hard of hearing.

**The key is "1-3-6-plus" for early hearing detection and intervention.**

***All infants should be screened before 1 month of age***, ideally before they leave the birth hospital. Without

Sources: Sound Beginnings May 2003, CDC, EHDI Program, My Baby's Hearing, Boys Town National Research Hospital & NIDCD

# Get to know your Legislator!!

*Submitted by Connie Zienkewicz, Wichita Center*

**T**here are several committees of the legislature that meet between sessions to prepare for the upcoming year, or research legislation that had been "tabled" in the previous session.

Recently, Families Together was asked to provide testimony to an Interim Committee. The Budget Committee is discussing a bill to reduce the number of Community Developmental Disability Organizations (CDDO) from the current 28 to 15. Those who support the reduction think that less money spent on administration of the program will put more money at the service level and give families a more objective picture of the services in a given area of the state. Those that oppose the reduction think that services provided by smaller organizations, closer to the persons that are served, make the services more responsive to those persons. Each family will have their own opinion about how this change in service provision will affect their situation.

If you are concerned about the Parental Participation Fee for families who have children on an HCBS waiver, talk to your legislator. This is a likely topic that the legislature will discuss in the upcoming session, too.

The best way for your legislator to know how to vote on these issues next session is to have your perspective to draw on. Please contact your senator or representative this fall and tell them how you feel about these issues. They are less busy now than during the legislative session when they are in meeting all the time. They will appreciate your valuable information as a family who uses the services that they fund.

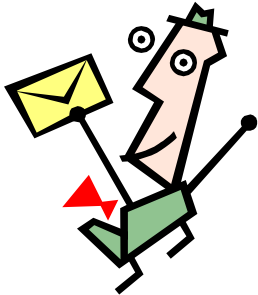


# Education Advocate Update

Submitted by Darla Nelson-Metzger, Education Advocate Co-coordinator



Have you heard the saying, “the more things change, the more they stay the same”? At this time, it seems an appropriate quote. Karen Snell has taken a new position within Families Together as the Regional Center Coordinator and will no longer be working with the education advocate program. I have increased my hours and Alisa Walker and I will co-coordinate the program. Kari Herr, who has been with Families Together for a long while, will step in to offer assistance to us.



A couple of reminders to education advocates since school is back in session... check up on the student(s) to whom you are assigned, visit the classroom, and introduce yourself to the principal and the new teacher(s). Remind them that you are the educational decision-maker for this student and are afforded all the same rights as a biological parent, including the right to receive regular progress notes and grade cards. Based on the surveys you returned to us this past spring, this was an area of concern —nine out of ten of you did not receive progress notes and grade cards every nine weeks. If you have any questions or concerns, please feel free to contact Alisa or myself at 1.800.264.6343 or 785.233.4777 or by email at [edadvocate@familiesinc.org](mailto:edadvocate@familiesinc.org). Thanks for your continued efforts on behalf of Kansas students!

## Family Voices

Submitted by Susan Arnold, Topeka Center

Fall is here, and our legislators are back at work on many promising opportunities for families of children with special health care needs.

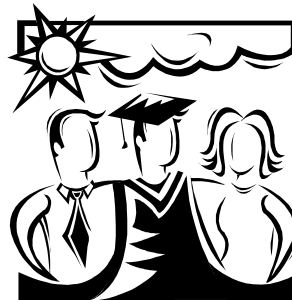
The Family Opportunity Act (S. 622, H.R. 1811) is still under consideration. The FOA legislation would secure a Medicaid Buy-In Option for middle-income families. This is an important issue for families with private insurance who are experiencing higher insurance premiums and out-of-pocket expenses for home-health care, therapies, mental health services, durable medical equipment, supplies, and so on. Families could then use Medicaid coverage to supplement, not replace, their private health insurance. For information on the status of this legislation, check <http://thomas.loc.gov>, click the search engine, and search S622 or HR1811.

On another note, Medicaid reform may affect families of children with special needs. EPSDT (Early and Periodic Screening, Diagnosis and Treatment Program of Kan-Be-Healthy), a mandatory Medicaid benefits and services for Medicaid eligible children and adolescents under age 21, is designed to ensure children access to early and comprehensive periodic health care and treatment. EPSDT continues to be a benefit within Medicaid that attracts attention for potential reform. Families of children with special health care needs should be aware that this is under consideration.

Let your Congressmen know how you feel on these issues and how it would affect your family.

## Statewide Self-Determination and Transition Conference

Submitted by Dorrene Sprecker, Wichita Center



Families Together, Inc. invites parents and their young adults (ages 13-21) to attend our statewide Self-Determination and Transition Conference to be held Nov. 8, 2003 at the Holiday Park Motel, 3030 S. Santa Fe, Chanute, Kansas.

We encourage parents from across the state to attend this conference designed to educate parents and students on self-determination, the process of transition from school to a quality adult life, and information on special needs trusts, wills and financial planning.

See our website for online registration or call Dorrene Sprecker (Wichita Center toll free- 888-815-6364 or local- 316-945-7747).



# Fall 2003 Calendar of Events

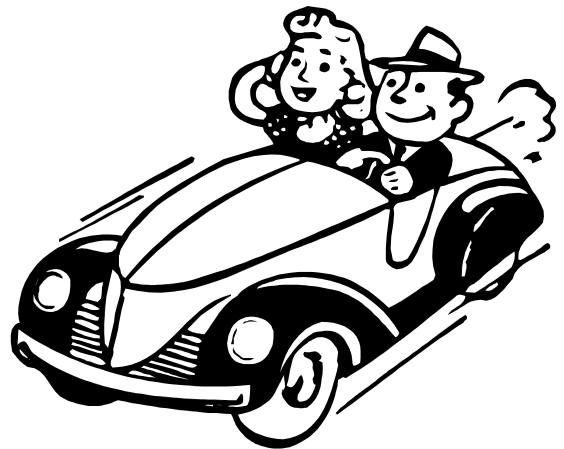
Date	Event	Contact
Sept. 24-25, 2003	Parents as Teachers State Conference, Wichita	316-973-5160
Oct. 1, 2003	Joshua Child & Family Development Center Conference "Those <i>Darn</i> Inflexible Kids!" , Topeka	816-763-7605
Oct. 10-11, 2003	<i>Families Together Parent Networking Conference, Kansas City</i>	877-499-5369
Oct. 21, 2003	<i>Families Together IEP Development Workshop, Topeka</i>	800-264-6343
Oct. 22-25, 2003	20th Annual NADD Conference, Chicago, Illinois	845-331-4336
Oct 25, 2003	<i>Families Together Statewide Conference, Garden City</i>	888-820-6364
Oct 27, 2003	<i>Families Together Mini-Conference, Topeka</i>	800-264-6343
Nov. 8, 2003	<i>Families Together Statewide Transition Conference, SE KS area</i>	888-815-6364
Nov. 13, 2003	Seventh Annual Mid-America Conference on Children with Special Health Care Needs, Kansas City	816-931-8687
Nov. 17-18, 2003	Kansas Head Start Conference, Wichita	913-422-1700
Nov 19, 2003	KITS Head Start/Children with Disabilities Workshop, Wichita	620-421-6550 ext. 1768
Dec. 5-6, 2003	<i>Families Together Parent Networking Conference, Wichita</i>	888-815-6364
Dec. 5-6, 2003	Parent Involvement Conference, Wichita	www.kpirc.org

## Regional Cruises

*Submitted by Leia Holley, Kansas City Center*

To bring awareness to the unique abilities individuals with disabilities offer our communities, Families Together has joined with area "classic" car clubs to host statewide "regional" cruises in August 2004 throughout the state of Kansas. Regional cruises will be held in cities where Families Together, Inc.'s four offices are located: Kansas City, Topeka, Garden City and Wichita.

Families Together aims to involve all community members in this event. First and foremost, families of children with disabilities would be encouraged to ride in the cruise. In an effort to recognize community businesses and organizations that support employment of all members of the community, the cars will stop at pre-determined locations along the cruise route, which employ individuals with disabilities. Families Together also intends to target the members of Kansas car clubs as the "driving" force for this event to draw interest not only to the event, but also to Families Together's mission. Finally, Families Together hopes to bring in local sponsors in an effort to spark community-wide interest. Watch future newsletters for more details on this exciting event!





### **Please check your mailing label**

You can help us keep our mailing list current and save postage by letting us know:

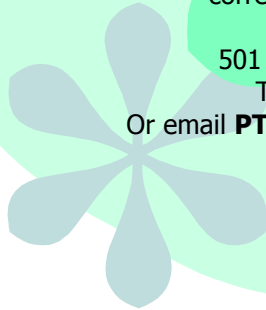
- if your address has changed or is incorrect;
- if you are receiving duplicate copies; or,
- if you would like to be removed from the mailing list.

Please send your label with corrections to Susan at the Topeka Center.

501 SW Jackson Ste 400  
Topeka, KS 66603

Or email **[PTP@familiestogethrinc.org](mailto:PTP@familiestogethrinc.org)**

**Thanks!**

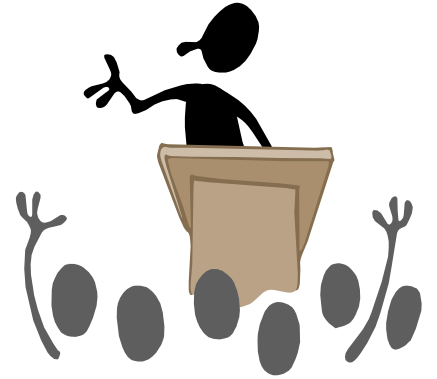


Families Together, Inc.  
501 Jackson, Suite 400  
Topeka, KS 66603

Non-Profit Organization  
U.S. POSTAGE  
PAID  
Permit No. 849  
Topeka, Kansas

# OVERNIGHT EVENTS

At the overnight events, you will learn how to successfully manage your child's educational program. The workshops will help you learn how to create a functional IEP. Parent discussion groups will help you with new ideas and you will get the chance to learn about community service providers.



FAMILIES MAY REGISTER FOR AND ATTEND ONLY ONE OVERNIGHT EVENT PER SCHOOL YEAR.

Families Together & its funding agencies pay for hotel & meals for families that attend all sessions.

## Family Enrichment Weekends

Family Enrichment Weekends are overnight events for families that include a child, birth through 21, who has a disability. Parents attend workshops and discussion groups while the kids participate in fun, age-appropriate activities. The kids are matched with a volunteer, usually a college student studying special education, to assist them throughout their day. Families must submit their application early as these events fill up quickly. Applications will be accepted on a first come, first served basis, with a preference given to families who have not yet attended an overnight event. Families will be placed on a waiting list after the first 30 applications are received.



## Parent Networking Conferences

Parent Networking Conferences are fun get-aways for parents only. Leave the kids at home and enjoy an educational overnight stay at a hotel. You will participate in workshops and discussion groups, gaining lots of good information and getting the support you need from other families and Families Together staff.



# 2003-04 FAMILIES TOGETHER EVENT REGISTRATION FORM

*PNC (Parent Networking Conference)*

*FEW (Family Enrichment Weekend)*

## **CIRCLE THE ONE EVENT OF YOUR CHOICE:**

PNC.....Oct. 10-11.....Kansas City  
PNC.....Dec. 5-6 .....Wichita  
PNC.....Jan. 30-31.....Hays  
PNC.....Mar. 5-6.....Salina  
FEW ..... Mar. 19-20 .....Garden City

PNC ..... Apr. 2-3 .....Coffeyville  
FEW..... April 16-17 .....Lawrence  
FEW .....May 14-15 .....Wichita  
PNC .....Spring .....Hutchinson  
(date to be announced)

Name(s) of Parent(s)\* \_\_\_\_\_

Mailing Address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Home Phone \_\_\_\_\_ Business Phone \_\_\_\_\_  
(if we can contact you at this number)

*\*Single parents are welcome to bring a friend or relative who is involved with your child and is eager to learn more through the workshops provided.*

Friend's or relative's name \_\_\_\_\_ Relationship to you \_\_\_\_\_

*Please fill out this information on your children.* Please indicate, by checking the box, if they **will** be attending an FEW.

Name \_\_\_\_\_ Age (at time of event) \_\_\_\_\_ Disability \_\_\_\_\_  
Date of Birth \_\_\_\_\_ Sex \_\_\_\_\_ Special diet /accommodations \_\_\_\_\_

Name \_\_\_\_\_ Age (at time of event) \_\_\_\_\_ Disability \_\_\_\_\_  
Date of Birth \_\_\_\_\_ Sex \_\_\_\_\_ Special diet /accommodations \_\_\_\_\_

Name \_\_\_\_\_ Age (at time of event) \_\_\_\_\_ Disability \_\_\_\_\_  
Date of Birth \_\_\_\_\_ Sex \_\_\_\_\_ Special diet/accommodations \_\_\_\_\_

Name \_\_\_\_\_ Age (at time of event) \_\_\_\_\_ Disability \_\_\_\_\_  
Date of Birth \_\_\_\_\_ Sex \_\_\_\_\_ Special diet /accommodations \_\_\_\_\_

May the above information be used on a participant list? Yes No (business phone will not be included)

*Siblings ages 16 and older may be asked to be companions for the younger children at the Family Enrichment Weekends. If your older child is **not** interested in being a companion, please indicate on this form. Thanks.*

Please provide me with a (circle one) \_\_\_\_\_ smoking \_\_\_\_\_ or \_\_\_\_\_ non-smoking room.

On what topic does your family need more information? \_\_\_\_\_

Mail application to: Families Together, Inc. • 501 Jackson, Ste 400 • Topeka, KS 66603

Families Together Inc., Presents  
**PLANNING FOR THE FUTURE**

Parenting Children with Special Needs Workshop

\*Long Term Planning-Legal & Financial Planning & Transition from School to Adult Life\*

\*Special Needs Trusts, Guardianship laws and Wills\*

\*Overview of HCBS Services\*

\*Special Guest Speakers\*

**Washburn University-Memorial Union Building (Main Level)**

1700 College Ave.

Topeka, KS 66621

**October 18, 2003 from 9:00am to 4:00pm**

**Families Together, Inc.-Independent Living Resource Center**

3033 W. 2nd

Wichita, KS 67203

**November 15, 2003 from 9:00am to 4:00pm**

This day brings a unique opportunity to parents. With a dedication to serving these individuals with disabilities and their families, the people involved will speak from personal examples and testimonies in their own lives and businesses. These people have experience in providing services and direction for families. The strategies you will discover during this day could help you find the resources you have been seeking as well as safeguard your son or daughters eligibility for government benefits. Several speakers have assisted families with estate and financial planning issues while others have a personal story to share that will enlighten you to the opportunities they have created for their families.

**Group Session Speakers**

\*Families Together, Inc. - *Kansas Parent Training & Information Center*

Planning for the Transition from school to adult life

\*Chad Koehn, *CMFC, Senior Financial Advisor - Brother of 2 siblings with disabilities*

Financial Planning

\*Eric Anderson, *Attorney at Law*

Special Needs Trusts, Guardianship laws and wills

\*Don & Dawn Merriman - *Parents of a Son with a Disability*

"How we bought Craig his own home"

**\*Lunch will be served at a cost of \$5.00 per person\***

**\*Please indicate if you will NOT be joining us for lunch\***

**To Register Call: (785) 827-3606 ext 137 or (800) 887-2423**

**All other costs have been paid for by the following sponsors:**

Choices Payroll Management Systems, Inc.-A.J. Boyer, President

Families Together, Inc.

Chad Koehn, CMFC, Senior Financial Advisor, Waddell & Reed, Inc.

Eric Anderson, Attorney at Law