



Family Resource Network

Helping Families Meet the Challenge

Volume 17, Issue 1, Winter 2009

FRN Proudly Offers Its 11th Annual Mothers Retreat



A Mother's Loving Arms

Mothers use their arms to cradle, to hug, to comfort, and to care for their children with special needs. This year's Mothers Retreat will look at the many different things mothers do to enhance the lives of their children. FRN offers a day of relaxation and fun for mothers raising children with special needs. The day will provide an opportunity for mothers to meet other mothers, and spend some time on themselves. The day will include some pampering, music, craft activity, games, fun, prizes and lots of food.

Last year some attendees said:

"I needed the break. Thanks for giving me a reason to take some time for myself."

"It was great to meet other Moms who are going through many of the same things I am."

This year's retreat will take place on **Saturday, February 7, 2009** at the San Joaquin County Office of Education. Registration starts at 9:30 a.m. and the event runs from 10 a.m. to 3 p.m. There is a \$10 fee for mothers who reside in FRN's service area of Amador, Calaveras, San Joaquin, Stanislaus and Tuolumne Counties. The fee for mothers outside of the region is \$20. While we recognize the importance of many individuals in a child's life, this event is for mothers (or the primary female providing daily care) only.

Registration forms are available by calling FRN at 472-3674 or 800-847-3030 or on FRN's website, www.frcn.org. Click on "calendar" and then on "Mothers Retreat". **Hope you can join us!**

Check Out Changes to FRN's Website

Family Resource Network has made some updates to its website, www.frcn.org. The tab bar at the top of each page has two new categories.

Resources has information on two kinds of transition. You'll find information on transitioning from Early Start in the form of the **Building Bridges – Transitioning from Early Start into the Preschool Years**

booklet. This information is available in English and Spanish. The new Resources section also has information **for students transitioning from special education to adult services**. You can download "Transition from Special Education to Adult Services Checklist" and "Suggested Steps for Investigation of Adult Service Options".

The second new category on the website is **Special Projects**. It contains information on current projects that FRN is involved with. You can learn about the **Healing Hearts Society**, which provides funds to families upon the death of their child with special needs. The site also contains the order form for FRN's **Friend In Deed certificate** which can now be downloaded at any time. There is also information on the **Little Bits Preemie Clothes Closet** and **Operation: Birthday Wishes**.



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Congrats to the WINNERS of FRN's latest drawing:

**Araceli Campos
Gabriela Elizaldi
Tricia Gougeousis**



The recreational support group for non-disabled siblings, ages 7 through 13:

**Saturday, February 28, 2009
1 to 4 p.m.
Valley Community Baptist Church,
Tracy**

Meet other siblings who have the same kinds of issues. There are games, crafts, discussion activities, food and lots of fun! There is no cost to attend.

Registration is required and must be submitted one week prior to event. Call 472-3674 or 800-847-3030 to request a registration packet.

Info on Local Support Groups

Local support groups are encouraged to email or mail flyers and information on their groups to FRN. FRN will have the information on display in the office and will share information as appropriate with families who call FRN asking for info on specific disabilities or support groups.



SPARK is an information and discussion group for families raising children with special needs. The group meets from 6:30 to 8 p.m., the 3rd Thursday evening of the month at the Sherwood Executive Center in Stockton. January's topic is Dealing with Sensory Issues presented by Debbie Link, O.T. February's topic is How Do I Know If My Child Is A Picky Eater - Promoting Acceptance of Varieties of Foods presented by Dan Lowensteiner, R.D. Topics for future meetings will be posted on FRN's website. We regret that we are unable to provide childcare. There is no cost to attend but registration is requested. You can call FRN or go to www.frcn.org and click on calendar to register.



Get All the Latest Info

FRN will email you up-to-the-minute information on news items, trainings and other issues of interest to families raising children with special needs. FRN's newsletter is published only 3 times per year so email is a great way to keep up on important information. If you would like to be added to FRN's email list, email the following info to FRNfamilies@aol.com:

- Your name
- The county you reside in
- Please indicate if you are a parent of a child with special needs or a professional working with special needs children

Training Opportunities

Jan. 13 - Building Bridges – Transitioning Your Child from the Early Start Program •
FRN Office in **Stockton**, 9:30 a.m. to 11:30 a.m., free for parents, \$15 fee for professionals, for info call 800-847-3030.

January 17– Writing An Effective IEP for Your Child with Special Needs •Presenters: Area VI Board and Family Resource Network • SCDD, Area VI Board • Area VI Board Office, **Stockton**, 9:30 - 11:30 a.m. FREE, **SATURDAY workshop**, reservations are required, for reservations call 800-847-3030.

Feb. 19– Writing An Effective IEP for Your Child with Special Needs •Presenters: Area VI Board and Family Resource Network • SCDD, Area VI Board • **Doctors Medical Center, Conf. Room 4, Modesto**, 6 – 8:00 p.m. FREE, reservations are required, for reservations call 800-847-3030.

Feb. 25 - Parental Rights and Advocacy in Special Education •Presenter: Ann Cirimele, Family Resource Network • FRN Office in **Stockton**, 9:00 a.m. to 2:30 p.m., scholarships for parents, \$35 for professionals, for reservations call 800-847-3030.

March 5 – Writing An Effective IEP for Your Child with Special Needs •Presenters: Area VI Board and Family Resource Network • SCDD, Area VI Board • **Tracy Sports Complex, Tracy**, 6 – 8:00 p.m. FREE, reservations are required, for reservations call 800-847-3030.

March 12– Writing An Effective IEP for Your Child with Special Needs •Presenters: Area VI Board and Family Resource Network • SCDD, Area VI Board • **CalWORKS Building, San Andreas**, 6 – 8:00 p.m. FREE, reservations are required, for reservations call 800-847-3030.

See Page 7 for info on a new workshop on Disability Benefits.

Financial and Estate Planning Workshop

Frank Quacinella, First Vice President and National Spokesperson for Families with Special Needs Planning Network for Merrill Lynch, and Mark Drobney, Attorney at Law, will once again be the presenters for FRN's Financial and Estate Planning workshop. It will take place on the **evening of February 17th** at the San Joaquin County Office of Education, Education Service Center in Stockton. Topics include:

- ◆ Understanding the importance of financial planning,
- ◆ Preparing for when you're not there to help.
- ◆ Protecting government benefits through proper estate planning.
- ◆ Special Needs Trusts – the basics of how they work and when they are appropriate.
- ◆ Conservatorship – What is it? Situations under which it should be considered and when it should be avoided.
- ◆ Personal estate planning

There is no cost to attend this workshop, but reservations are requested. Call FRN or go to www.frcn.org and click on calendar for registration information.

Merrill Lynch is offering a free interactive seminar on Special Needs at 7 p.m. on February 25th. A Merrill Lynch financial advisor as well as a 3rd party special needs attorney will be participating to discuss financial, legal and social challenges facing families raising children with special needs. Log onto epliveonline.com



IEP workshop to be conducted in Spanish

Entrenamiento en Español para la forma
IEP(Programa de Educación Individual)
El taller será presentado solamente en español

**SÁBADO, 10 de Enero del 2009
9:30 AM – 1:30 PM**

En las Oficinas de Educación del Condado de
San Joaquín
2707 Transworld Drive,
Salon Greenwood 1, Stockton, CA

El entrenamiento es gratuito pero se requiere que se registre con anticipación. Las formas están disponibles en www.frcn.org/calendar o llamando 209-472-3674.

Check FRN's website, www.frcn.org and click on "calendar" for updated information on trainings and events. Registration forms for FRN events are on the website.

New FRN Library Resources

Books

- Adults with Down Syndrome
- Autism 24/7
- The Autism Encyclopedia
- Diamonds in the Rough (Learning Disabilities)
- The Everything Book – Sensory Integration Disorder
- Feet Are Not For Kicking
- Gifts – Mothers reflect on their children with Down Syndrome
- Hands Are Not For Hitting
- Mental Wellness in Adults with Down Syndrome
- Parenting with Positive Behavior Supports
- Raising A Sensory Smart Child
- Tails Are Not For Pulling
- Teaching Children with Down Syndrome About Their Bodies, Boundaries & Sexuality
- What Did You Say? Speech Intelligibility in People with Down Syndrome

FRN thanks Emily Bauch for the donation of:

- Louder than Words: A Mother's Journey in Healing Autism

CDs

- Crash Course in American Sign Language

DVDs

- Building Relationships (Parenting)
- Correcting Misbehavior (Pareting)
- The First IEP
- Kids with Down Syndrome
- Preventing Problem Behavior
- Teaching Children Self-Control

En Espanol

- El Sentido Comun
- La Crianza Practica de Los Hijos

Visit www.frcn.org and click on Library to see a complete listing of all of FRN's library resources and to find out how to borrow resources from the library. If you don't have access to the internet you can contact FRN at 209-472-3674 or 800-847-3030.

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Save the Date!

Saturday, April 18, 2009

8th Annual Autism Collaborative Forum

Keynote Presenter: Jeannette McAfee, M.D.
San Joaquin County Office of Education, Stockton

SibParent

Where parents of kids with special needs can talk about their "other" kids!



On the Internet, there are hundreds of listservs where parents can talk about their kids who have special needs. But there is only one listserv where parents can go to talk about their "other" kids! SibParent, sponsored by the Sibling Support Project, is a new, innovative listserv where parents can discuss the joys and concerns experienced by their typically developing children.

As many SibParent participants are also parents of kids who attend Sibshops, SibParent is also forum for parents who want to support the Sibshop movement. (And in case Sibshops are new to you, they're lively peer support and education programs for school-age sibs. You can find much information about Sibshops at www.siblingsupport.org)

Like the Sibling Support Project's other listservs, SibParent is a warm, thoughtful community. If you're a parent who's concerned about the well being of *all* your kids, we hope you'll join us!

SibParent is hosted by Andrea Congdon, a mom of children with and without special needs and a Sibshop provider and enthusiast. Don Meyer, director of the Sibling Support Project, hangs out on SibParent too!

Joining SibParent is easy and free: just visit www.siblingsupport.org or visit <http://groups.yahoo.com/group/SibParent/join>



FRN extends its thanks to the following for their generous donations:

- Bank of the West Employee Giving Program
- Melinda Barrera
- Charlot Derrick
- Lisa Drake
- Jane Frederick
- Beverly Klunk
- Lisa Kramer
- Deborah Mehlaff
- Wayne Morisaki of Cambridge General Agency
- Pat Murray
- Patrick O'Connor
- PEDS
- PIP Printing
- Shannon Todd
- Irene Valdez

FRN Volunteers Are the Greatest!

Anthony Bossana
 Jessica Bossana
 Joe Cirimele
 Susan Ireland
 Sophie Price
 Corky Sanborn
 Krissie Schlagenhaut
 Jeremy Werner
 Roger Werner
 and Rugby, The Service Dog



FRN thanks these great student volunteers:

*Carissa Balcao
 Jessica Burdge
 Darien Fields
 Jordan Fisher
 Sarah Islas
 Dana Macabales
 Mikaela McCarthy
 Katie Olagaray
 Nahir Patel
 Justin Sanborn
 Allie Watts*



Healing Hearts Society

Many, many thanks go to those listed below who so generously donated to **FRN's Healing Hearts Society**. Funds from these donations are given to families to assist with burial expenses upon the death of their child with special needs.

Healing Hearts Society Members include:

- Kathy Barnes
- Brookside RoadRunners
- Judy Sterling



FRN extends heartfelt thanks to Mr. Russell Dietrich and Family for designating FRN as recipient of gifts in memory of their beloved wife and mother, Virginia Dietrich. The following made donations in honor of Mrs. Dietrich:

- All Baby & Child
- Joan Bennett & Family
- Cassie Bisbikis
- Judy Blankenfeld
- Olivia Bradley
- Vanadeane Brooks
- Bruce & Karen Carson
- CoCaLo
- Louis A. Delmonico
- Frank & Lisa Drake
- Kay Gaedeke
- James & Joyce Gillan
- W. Faye Giovenetti
- Angie & Eric Gragg & Family
- Joanne and Jim Grant
- Herren Family Trust
- Sally & Tom Lowe
- Elizabeth Manoyan
- PEDS
- The Pepys Trust
- Jackie Pizitz
- Yvonne Ramirez-Ortiz & Family
- Peter & Patricia Scheuer
- Judith Schneider
- Charles S. Wilke



Caring for Individuals with Developmental Disabilities During Hospitalizations

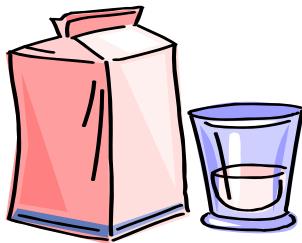
Information provided by

Doreen Bestolarides, Special Needs R.N., St. Joseph's Medical Center, Stockton

Obtaining baseline information on individuals is crucial to delivery of care as this information can gauge the hospital's individualized care planning. Most of the time, when a patient with a developmental disability is admitted to the hospital, the social worker, nurse or other hospital staff members make phone calls to collect necessary information. In many cases this important information is not as timely as it could be. Families can help this situation by gathering together the information below, and making it available to hospital staff.

- Patient name and date of birth.
- Patient's living situation including address and daytime and nighttime phone numbers (include info on whether patient lives with family, in group home, etc.).
- Height and weight (for calculating drug dosages and watching fluid intake).
- Medications currently being taken (include prescription and non-prescription drugs).
- Names and contact information of patient's doctors.
- Type of disability (Down Syndrome; Cerebral Palsy; Seizure disorder, etc.).
- Cognitive function/level of understanding (understands simple communication or understands but nonverbal, can read, etc.).
- Form of communication (can speak, uses sign language, uses a picture exchange system).
- How stress is handled (becomes nonverbal when scared or not feeling well).
- Can/cannot feed self (can/can't drink from a straw).
- Ambulatory/uses walker or custom wheelchair/non weight bearing.
- Visual or auditory deficit (Legally blind, wears eyeglasses or hearing aides).
- Toileting issues (continent/incontinent, uses diapers).
- Likes/dislikes (likes TV or videos and stuffed animals).
- Who can sign medical consent forms (ie: parents; patient; VMRC rep; conservator; family members?).
- Any other pertinent medical info such as "temperature is usually subnormal", "constipation requires daily medication", "typically aspirates and uses adaptive feeding utensils" etc.
- If Valley Mountain Regional Center client, list name of Service Coordinator and contact info.
- conservated/unconserved (i.e. if patient is an adult, have legal rights been restricted or removed by the court?).

This is not an exhaustive list. Feel free to add any other items you think will help hospital staff better serve your loved one. You could include a recent picture so that hospital staff knows the patient's usual appearance. Make several photocopies of this information so that it can be taken with the patient to appointments and/or the hospital. The info could be kept in the patient's backpack and on file at the patient's school, day program or place of employment.



Parents Can Now Request Schools to Serve Soymilk

The U.S. Department of Agriculture announced that parents or legal guardians may request in writing soymilk as an alternative to cow's milk for children receiving National School Lunch and Breakfast Program meals. This change caters to the growing diversity of participants in the School Nutrition Programs and allows children with lactose intolerance, dairy allergies or cultural diet restrictions to have an alternative source of calcium at school mealtime.



Friend In Deed!

Congratulations to

♥ Douglas Green ♥

who was honored with Friend in Deed certificate for his exceptional caring and commitment toward children with special needs and their families.

If you would like to order a Friend In Deed certificate for someone who has made a difference in the lives of a person with special needs you can go to www.frcn.org and click on Special Projects for more information.



Future Horizons

Learning About Disability Benefits as Children with Special Needs Become Adults

This workshop, presented by Ignacio Chavez from DRAIL (Disability Resources Agency for Independent Living), will take place on Thursday, January 22, 2009 from 6:30 to 8:30 p.m. at the Learning Institute in Modesto. Topics will include Social Security Definitions, How employment affects Social Security and Medi-Cal, and information on Disability Benefits 101. The registration form for this workshop is available at www.frcn.org and click on "calendar" or by contacting FRN.

A Letter From a Parent to Parents

FRN received the letter printed below from a parent who wanted to share some of her experiences with other parents.



November 11, 2008

Dear Parents of Young Children with Special Needs,

In 1990, my son was born prematurely and diagnosed with cerebral palsy. Last month my son joined the ranks of freshmen at UC Davis. In between these two events were eighteen years of therapies, IEPS, doctors, alternative therapies, workshops, medical equipment, counselors, teachers, aides, assistive technologies, mediations, and hearings. As I'm sure you know, the list goes on and on.

Sometime, early on, someone directed me to Family Resource Network. Through this dedicated group of people, I found others like me, trying to balance life with a special needs child. I attended many of their workshops, arming myself with knowledge of laws; learning the keys to successfully deal with school personnel, regional centers, and medical professionals. I borrowed books and movies. I met other parents at retreats, on the phone, through support groups. We worked hard, our family, to give our son every opportunity to reach his greatest potential. I am proud to say he graduated as salutatorian of his high school class and was accepted into Davis as well as UC Berkeley.

I want you to know that life will never be "normal" (whatever that is), and that you have a lot of work ahead of you. I want you to take advantage of all that FRN has to offer. You need tools to help you build this new lifestyle. Never be afraid to ask for help. These people at FRN have been where you are; they can help you to move to the next step and the step after that. I wish all of you and all of your children the very best that life has to offer.

Gail Bunge