



Family Resource Network

Helping Families Meet the Challenge

Volume 23, Issue 3, Summer 2015 Edition



Kathy Werner **Parent, Mentor, Volunteer, Friend**

On March 9th Family Resource Network lost its longest serving Board member, Kathy Werner. Kathy's sudden death has left us heartbroken but we find comfort in remembering her giving spirit and the wonderful things she did for FRN and the families we serve. Kathy served for almost 20 years on FRN's Board of Directors. Over the years she held the positions of President, Secretary and most recently Treasurer. Her voice helped guide FRN as it grew from serving primarily families with infants and toddlers to families of children through age 22 and beyond.

Kathy offered support and shared personal experiences with families raising children with Down syndrome. She worked tirelessly to ensure that her daughter experienced true inclusion in her community. She worked alongside her daughter as her daughter created her own business and they participated at various street and craft fairs throughout the region.

Kathy not only volunteered on FRN's Board but she was always the first to offer to bake cookies for a FRN fundraiser, work multiple shifts for FRN at the Asparagus Festival or use her computer knowledge to provide FRN with tech support.

FRN sends its heartfelt condolences to Kathy's husband, siblings, children and grandchildren. Her love for them was unconditional and unwavering.

We will miss you, dear friend.



Personal Advocacy: Why Families Always Will Be Their Child's Care Coordinator

by Edward Schor, MD, Lucile Packard Foundation for Children's Health

Pediatric care coordination is more talked about by health care policymakers than carried out by providers. Here's one reason why: Care coordination is routinely described as "a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes."¹ Wow! Very ambitious.

And since families of children with special needs bear the brunt of absent or failed efforts to coordinate the care of their children, it makes sense that they find it necessary to step in as the principal care coordinator.

Another reason why family members do most of the care coordination is that they know best their child's care history and needs. To date there is no technology up to the task of providing comprehensive, real time information about a child's health, let alone capable of integrating across all the various systems on which special needs children depend.

But there is one more reason why families are and always will be essential in the care coordination process. The child in question is their child. They think about their child all the time. They are always on the lookout for new services, treatments and devices that will help their child. Parents would be thrilled if they received an unanticipated call from a care coordinator or a service provider with news of something new for their child, but such calls rarely if ever happen, except in response to a parent specifically pointing out a need. Others who are involved in the child's care typically have caseloads or patient panels too large to enable such proactive assistance.

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SAVE THE DATE

Thursday, October 29, 2015
 San Joaquin County Office of Education,
 Stockton, CA

21th Annual Early Start Symposium

Presenter: Cari Ebert, MS, CCC-SLP
"The Power of Play: Effective Play-Based Therapy & Early Intervention"

Play is a powerful vehicle for learning. Creating an effective play-based early intervention program requires creativity, flexibility and an understanding of how play impacts development. Parents and professionals will find this year's Symposium provides a fresh approach which promotes cognitive, physical, social-emotional and language development when working with children birth to three in a natural environment.

Registration materials will be available in late summer. Scholarships will be available to parents of children receiving Early Start or Prevention Resource and Referral Services (PRRS) services who live in Amador, Calaveras, San Joaquin, Stanislaus and Tuolumne Counties. Limited number of scholarships available for parents of preschool age children. Registration fee for local attendees is \$35; \$50 for out of area. CEUs for speech therapists, physical therapists, occupational therapists and nurses will be available for an additional \$15. For more information contact Family Resource Network 209-472-3674, 800-847-3030, www.frcn.org



Sibshop is the recreational support group for **non-disabled siblings of children with special needs,** ages 7 through 13.

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.

Saturday, June 13, 2015
11 a.m. to 2 p.m.
Stockton Covenant Church,
1720 Oxford Way, Stockton, 95204

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

Sib Update!!! See page 6 for an article on a new online Sib group.



FRN Parent Scholarships Available

Family Resource Network has received an unrestricted grant of \$2,500 from the Stuart Foundation. FRN is using the funds to assist parents of special needs children within FRN's 5 county service area with registration fees to attend non-FRN conferences or workshops on topics related to children with special needs and their families.

This is a reimbursement scholarship which means that FRN reimburses the parent after the parent has attended the event. Parents wishing to access these scholarship funds should contact FRN **prior** to attending the event. FRN reserves the right to limit the number of scholarships for any specific event. Restrictions apply. For more information contact FRN staff.

The Sound of Music

FRN offers two musical play groups for young children with special needs and their parents. **Tikes and Tunes** is for children ages birth to 36 months who are served through Early Start or Prevention Resource and Referral Services (PRRS). **Preschool Posse** is for preschool age children who are receiving special education services through an IEP. Parents will learn how they can use music to enhance their child's development. Both groups are led by Karen Sanchez, MBA MT-BC, Music Therapist. We'd love to have you join us, but space is limited so be sure to register! Registration forms are on FRN's website or you can email or call FRN to register. Both groups meet at FRN's office, Sherwood Executive Center, 5250 Claremont Ave., Suite 148, Stockton.



Tikes and Tunes

A Musical Play Group for Infants and Toddlers in Early Start or PRRS

When: The first Tuesday of the month from 9:30 to 10:30 a.m.

No Musical Talent Required.



Don't forget to register!

Preschool Posse

A Musical Play Group for preschoolers receiving special education services



Preschool Posse is taking a break for the summer. Contact FRN if you are interested in knowing when the program resumes in the Fall.



And Don't Forget that FRN has **Toy Lending Libraries** for children in Early Start and PRRS in **Stockton, Modesto and Sonora.** Contact FRN for more information.



Zero to Three's Let's Play app

Let's Play provides parents and grandparents with fun ideas for keeping babies and toddlers entertained and learning, especially during daily routines like commuting time, chores, bedtime and bathtime, mealtime, shopping. There are also "boredom busters" for any time. Parents can search activities by age (0-18 months, 18-36 months, and 3-5 years), tag favorites, and share activities via social media. All of the activities reflect children's typical skills at each age and are designed to support development in the context of play and family routines. Let's Play was developed by ZERO TO THREE, a national nonprofit organization focused specifically on the healthy development of babies and toddlers.

Disability Rights CA introduces 3 new assistive technology publications

Funding of Assistive Technology Through Blind Work Expenses (BWEs), Pub #5569.01 – This 3 page publication provides information about the following topics: What is a BWE? What is the relationship between a BWE and an Impairment-Related Work Expense (IRWE)? What are some examples of Assistive Technology expenses under BWEs? What is the relationship between BWE and a Plan to Achieve Self Support (PASS)?

Funding of Assistive Technology through Impairment Related Work Expenses (IRWEs), Pub #5570.01 – This related 3 page publication provides information on the following topics: What is an IRWE? What assistive technology can be considered an IRWE? What if I purchased an assistive device but I am making payments on the purchase? Can I deduct the payment as an IRWE? How do I deduct them? What is the relationship between an IRWE and a Plan to Achieve Self Support (PASS)? If Social Security denies an item as an IRWE can I appeal?

Funding Assistive Technology Through A Plan for Achieving Self-Support (PASS), Pub #5571.01 – This related 3 page publication provides information on the following topics: What is a PASS? What can I purchase with a PASS? How can I get a PASS? Can I get help to complete the PASS application? What if SSA does not approve my PASS? For more info go to

<http://www.disabilityrightsca.org> and click on Publications.

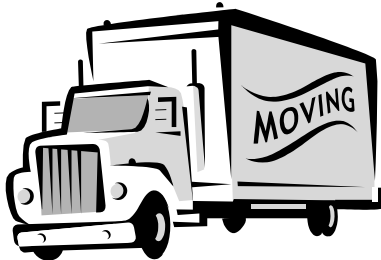
Check FRN's website, www.frcn.org and click on "calendar" for updated information on trainings and events. Registration forms for FRN events are on the website.

Save the Date

Info on upcoming event:

Family Resource Network is working on a variety of workshops in the coming months. Registration is required for many of the events and registration forms are posted on FRN's website, www.frcn.org and click on Calendar or you can contact FRN staff at 209-472-3674 or 800-847-3030.

- **June 25, 2015: Conservatorship for Your Adult Child with Special Needs**, presented by Mark Drobny, Attorney at Law, offered in collaboration with San Joaquin County Office of Education, SELPA, **Stockton**, registration required.



Moving?

If your child is receiving special education services make sure that your copy of your child's IEP is in a safe place and accessible to you when you reach your destination. It can sometimes take a school district some time to send the IEP and other school records to the new school so having your copy available could help speed up the process.

If you are relocating within FRN's five county service area (Amador, Calaveras, San Joaquin, Stanislaus and Tuolumne) we want to continue to send you the FRN newsletter. Because the newsletter is mailed via bulk mail the Post Office does not forward it to your new location. So if you want to make sure that you receive all issues of the newsletter just give FRN a call or send an email or letter with your new address.

Best wishes to you in your new home!

Attention All PRRS Families



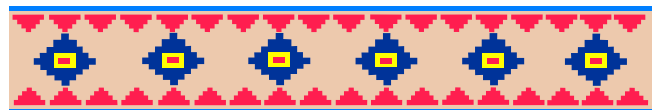
Effective January 1, 2015 the eligibility criteria for California's Early Start program has been broadened. The new criteria means that your child, who is currently served through Family Resource Network's Prevention Resource and Referral Services, might now be eligible for Early Start services. In order to receive Early Start services your child will need to be assessed by staff from Valley Mountain Regional Center (VMRC).

If you have concerns about your child's development and would like your child to be assessed by VMRC for possible Early Start eligibility please contact FRN staff and we will take your information and submit the referral to VMRC. You can contact FRN via phone (209-472-3674 or 800-847-3030), fax (209-472-3673), email (FRNfamilies@aol.com) or by coming into FRN's office (office hours: Tuesday through Friday, 8:30 a.m. to 2:30 p.m., 5250 Claremont Ave., Suite 148, Stockton, CA 95207). It will take about 10 minutes to gather the information we will need from you in order to make a referral to VMRC.

There is no requirement for you to have your child assessed by VMRC. It is totally parent choice. If at any time before your child's third birthday you have concerns about your child's development and would like your child assessed by VMRC for possible Early Start services just contact FRN staff and we can take your information and submit the referral to the Regional Center.

The PRRS program funding ends on June 30, 2015. At this time we do not know if funding will be renewed. Updates on the PRRS program will be posted in future newsletters.

If you have any questions about PRRS, the Early Start program or any other way that FRN can be of service to you please contact FRN staff.



Congrats to the WINNERS of FRN's latest drawing:

- ♥ Lydia Barrera
- ♥ Leap Nhim

It's not too early to Save the Date!!



We hope moms can join us on Saturday, February 6, 2016 for the 18th Annual Mothers Retreat. Registration information will be available in December.

Thanks

FRN has received donations from:

- ♥ Sue Allyn
- ♥ Emily Bauch
- ♥ Natalie Cruzat
- ♥ Lisa Drake
- ♥ Graham Ultch Charitable Trust
- ♥ PEDS
- ♥ Efrain Rosas
- ♥ Diane Tamayo
- ♥ And Anonymous Donors

Thank You Student Volunteer
Jester Ramos



Want to be In The Know?

Send your email address to FRNfamilies@aol.com to receive email updates on topics of interest to parents of children with special needs. There is no fee to be on the email list and FRN

does not share your email address with anyone, ever.

Remembering Kathy Werner

The following have made donations to FRN in memory of Kathy.

- ♥ John & Monika Bertke
- ♥ Sue Chinchio
- ♥ The Cirimele Family
- ♥ Lisa Culley
- ♥ The Mikita Family
- ♥ Colleen Okura
- ♥ Mrs. Wendall Parker
- ♥ Gwenda Simms
- ♥ Susie Wong and Brian Connelly



Thank You

Asparagus Festival Volunteers!

Raymesha Bilbo
David Chavez
Necose Cook
Elvin Estrada
Victoria Estrada
John Forrest
Sotero (JR) Herreria, Jr.
Jason Kissane
Andrea Rios
Gilbert Rodriguez
Joseph Rontel
Susie Wong





Announcing Sib20!

Sib20 is a [Facebook group](#) where twenty-something sibs of people with disabilities connect with others who “get it.” It’s sibling support from a young adult perspective.

Sib20 is also a community—a remarkably thoughtful, nonjudgmental community of sisters and brothers who share concerns, challenges, insights, and joys that only other sibs are likely to understand. And we share information about services, resources, and strategies that help members advocate for their brothers and sisters, themselves, and their families.

Like the greater sibling community, Sib20 has a diverse membership. We come from all economic, religious, and cultural backgrounds. We have sibs who have autism, intellectual disabilities, cerebral palsy, Down syndrome, spina bifida, fragile X, and other disabilities. Some of us think that having a sib with a disability has enriched our lives. Others of us find having a sib with a disability has been a source of distress. And for many more, it has been a mixed bag. All of these experiences are valid and all views are welcome on Sib20.

Frequently Asked Questions about Sib20:

Who hosts Sib20? Sib20 is co-hosted by [the Sibling Support Project](#) and [Sibs’ Journey](#). Don Meyer (of the Sibling Support Project) and Claire Nuchtern and Renee Frederick (of Sibs’ Journey) co-moderate Sib20.

Must I be in my twenties to belong to Sib20? Sib20 is intended for sibs in their twenties—more or less. If you are a sib 18 to 30, Sib20 is for you!

I belong to [SibNet](#), the Facebook group for adult sibs. May I also belong to Sib20? Sibs in their early thirties or younger may belong to Sib20—and are welcome to belong to SibNet as well.

I belong to [SibTeen](#), the Facebook group for teen sibs. May I also belong to Sib20? If you are 18 or 19, you may belong

to Sib20—and you are welcome to belong to SibTeen as well.

Can my friends and family see what I post on Sib20? Sib20 is a closed group. This means that others can see that you belong to Sib20, but *only* Sib20 members can see what you’ve posted to Sib20.

How do I join? Simply search “Sib20” in the Facebook search bar. Due to the limitations of a closed Facebook group, there’s not much to see until you’ve joined.

Join [The Sibling Support Project’s family of online communities: \[SibTeen\]\(#\) \[Sib20\]\(#\) \[SibNet\]\(#\) \[GKSN\]\(#\) \(Grandparents of Kids with Special Needs\)](#)



Save the Dates September 17 & 18, 2015

For the 1ST Annual Best Practices in the Education of Children with Down Syndrome Conference. This event is presented by Dignity Health and supported by Family Resource Network and The Brighterside of Down Syndrome of San Joaquin County. The event will take place at University of the Pacific. The speaker will be Kathleen M. Feeley, Ph.D., BCBA. Dr. Feeley is an Associate Professor at Long Island University, NY and the Founding Director of the Center for Community Inclusion. Topics for the event include: An Overview of Down Syndrome, Rational for Inclusive Programming, Applied Behavior Analytic Interventions, Strategies to Enhance Appropriate Behavior, Modifications and Accommodations Across Curriculum. Registration fee is \$25 per day or \$40 for both days. Lunch and parking are included. There are a limited number of scholarships available for local parents who have children with Down syndrome. For more information contact Wanda Farinelli-Mikita at 209-915-6612 or deltaflower@sbcglobal.net.



Personal Advocacy: Why Families Always Will Be Their Child's Care Coordinator

by Edward Schor, MD, Lucile Packard Foundation for Children's Health

Continued from page 1.

Individualized, proactive care coordination is a form of advocacy. This kind of advocacy, focused on a single child, is essential to maximize access to critical services and to optimize children's health and well-being. If it were available from outside of the family, it would also reduce the stress that family members experience. But it's not. However, families can and should be supported in their role as their child's principal care coordinator as well as the principal care provider.² Offering that support is not a new role for health care providers, but it could stand some strengthening. Here are several ways in which the role of families as care coordinators can be supported within hospitals and medical practices, depending on the organization and location of their medical home:

- Designate a specific staff member or professional to serve as the central contact point for the family and members of the extended team of professionals serving them
- Engage in collaborative goal setting with the care team and the family
- Train health care providers to be teachers, coaches and partners in care
- Establish planned visits with all members of the care team to discuss care plans and planning
- Teach and use the five core self-management skills of problem solving, decision making, resource utilization, forming a patient-provider partnership and taking action
- Use peer or mentor families to help families learn to navigate the systems of care for CSHCN
- Develop easy-to-use and regularly updated databases of community services available at a centralized location within the community

- Jointly develop a written care plan that all essential members of the team, including the family, are able to access and update
- Use mechanisms to promote and streamline communication among members of the care team, including group visits, communication technologies such as video-conferencing and mobile applications, and shared access to medical records

Most of these functions and activities at least require collaboration among all of the various professional and community-based services upon whom the child and family depend. Some require programs and policies within the community. It takes a family to raise a child, but it takes a village to support families so care can be coordinated.

ABOUT THE FOUNDATION: The Lucile Packard Foundation for Children's Health works in alignment with Lucile Packard Children's Hospital and the child health programs of Stanford University. The mission of the Foundation is to elevate the priority of children's health care through leadership and direct investment. The Foundation is a public charity, founded in 1997.

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1 Antonelli R.C., McAllister J.W., Popp J. Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework. The Commonwealth Fund, May 2009

2 Henry H., Schor E. Teaching Families to Fish: How to Support Families as Care Coordinators. Lucile Packard Foundation for Children's Health, July 2013