



# The Link

"Linking Exceptional Families in Contra Costa County"

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## What is CARE Parent Network?

We are a Family Resource Center for families of children with special needs in Contra Costa County. We provide information, referral, resources, training opportunities and family support.

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## HOW DO YOU TALK TO OTHERS ABOUT YOUR CHILD'S DISABILITY?

Reprinted with permission from PACER's Early Childhood Connection, Summer 2008. PACER Center, 8161 Normandale Blvd., Minneapolis, MN, 55437. 952-838-9000 (voice). 952-838-0190 (TTY). Email: [PACER@PACER.org](mailto:PACER@PACER.org) Website: [www.PACER.org](http://www.PACER.org)

Experience is the best teacher, as the saying goes—and one of its big lessons is how to communicate about your child's disability. For Kathy Graves, the learning began when her son Sam, then 1, was diagnosed with cerebral palsy (CP). "He was born on his due date and was healthy," she recalls. "Then he contracted meningitis when he was a week old." At the time, Sam seemed to recover and was reaching all his developmental milestones. "But at six months, he didn't crawl," Kathy remembers. Eventually, doctors discovered that the motor part of Sam's brain had been affected. "I remember well getting that diagnosis and thinking, now what? I remember not knowing who to call, who to tell, or how to tell it. There's not a road map for you," Kathy says.

Sam is now 14. Over the years, experience has taught Kathy some important lessons about communicating with others about her son's disability. As a result, she has developed a philosophy about whom, what, and how much to tell, as well as how much energy to expend on it. Here's what she's learned.

### Lesson 1: Find People You Trust

"My husband and I started slowly by calling people we could really trust and talk to without having to make them feel good," she says.

"My sister-in-law and brother-in-law both work in special education, and they felt like the right people to talk to."

"We also learned early on that you need people outside the family. Find three or four people who are always there for you, without judgment; people you want to go through this with," she says. "Stage one for us was having someone listen and not try to fix it or say 'everything will be fine,'" she says.

As time went on, they also found friends who have kids with disabilities. "There is nothing better than that. You can call them on days when you're really down. They understand."

### Lesson 2: Learn and Share—But Set Limits

"Stage two was educating ourselves about the disability," Kathy says. That paved the way for communicating with professionals. "You get further with teachers and doctors," she says, if you are knowledgeable about the disability.

"Help those closest to you understand, too," she adds, but let them know you're still learning. "When people ask questions, it can feel like pressure. Tell them, 'Hang in there with us. We'll tell you what we know as time goes along.' Plus, it's not what we wanted to talk about first all the time. It wasn't helpful for us."

What was useful was a question someone asked early on: "Well, what's the future likely to look like?" It was so helpful because it had hope in it," Kathy says. "Ask me questions about what you think our future will be like. Have it be forward looking, with hope, not grief."

"If kids ask, they're okay with a two-sentence reply," she says. "Adults will ask 'how did it

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HOW TO TALK TO OTHER'S  
ABOUT YOUR CHILD'S DISABILITY  
(CONTINUED FROM PAGE 1)

happen?' It's like a defense mechanism: they want to know how to stop it from happening to them. They're not trying to hurt you; they may just be fearful. I try to remember that in responding to them, but the honest answer, which I believe is best, is that sometimes things just happen. It's as simple as that."

Then there are people who stare and ask inappropriate questions. "One doctor told us if people stare, just stare back until they quit looking," Kathy says. "If an adult says, 'what's wrong with him,' I feel it's my job to say 'nothing is wrong. He has CP.' Their insensitivity is wrong. You don't have to tell them anything."

"You constantly have to help people understand," she adds. When someone talks down to Sam or treats him like he's a little child, Kathy finds that gentle reminders about Sam's teen activities and interests help to change the interaction.

**Lesson 4: Talk about Strengths**

"In one of my very first [Individualized Education Program] IEP meetings, there was a physical education teacher who said, 'Let's talk about what Sam can do.' That was the best advice. A lot of this world focuses on what he can't do. We just started to focus immediately on Sam's assets and what he could do. It's an amazingly powerful way to refocus yourself and your kids' future," Kathy says.

"There are so many things people will try to pin on your child's disability," she adds. He might not be great at geometry—"but neither is his mom," Kathy says. "Not everything is about the disability." "He's a person with strengths who also has CP," Kathy says. The disability doesn't define him, and that's a message she always communicates.

**Experience**—both good and bad—has shaped Kathy's philosophy about communicating with others about Sam's disability. Time, too, has played a role. "In the early days, I spent a lot of time and energy on it. I tried to learn everything about CP and interpret it to the world. I do that less now. Most days, I think about getting lunches packed, getting the kids off to school, getting to lessons and games—just regular, plain old life. The effort is less as time goes by, at least for us," she says.

For others, she offers this simple advice. "You have to carve out your own philosophy. Every kid is different, and you need to honor who that child is. Focus on their strengths, and let people know that to you they're no different than any other child. A diagnosis of a disability is the start of something, not the end of something."

And remember, Kathy adds, "you don't have to figure out everything at once. One day at a time is a beautiful thing."

SPECIAL EDUCATION  
WORKSHOPS AT  
CARE PARENT NETWORK

**Transition to Adulthood**

For parents of children with disabilities 16-21 years old, and planning for transition to adulthood in the IEP process. Topics include: postsecondary education options, jobs, community living, recreation and leisure.

**WHEN:** September 22, 7:00 pm-9:30 pm.

**WHERE:** CARE Parent Network Conference Room, 1340 Arnold Dr., Suite 115, Martinez

**WHO:** Cheryl Theis, Parent Advocate, DREDF

**MISC:** Participants will receive training materials. There is no fee for the workshop. Childcare is not available. Refreshments will be provided.

Registration by September 17<sup>th</sup> is required. Contact Sheri Proctor at: 1-800-281-3023 or [sproctor@careparentnetwork.org](mailto:sproctor@careparentnetwork.org)

**Understanding Special Education**

Participants will become knowledgeable about the special education process, Section 504 and IDEA laws, the rights of children with disabilities, and how to assert those rights.

**WHEN:** October 9<sup>th</sup>, 9 a.m.-12:00 p.m.

**WHERE:** CARE Parent Network Conference Room, 1340 Arnold Dr., Suite 115, Martinez

**WHO:** Ann McDonald-Cacho, Parent Advocate, DREDF

**MISC:** Participants will receive training materials. There is no fee for the workshop. Childcare is not available. Refreshments will be provided.

Registration by October 1<sup>st</sup> is required. Contact Sheri Proctor at: 1-800-281-3023 or [sproctor@careparentnetwork.org](mailto:sproctor@careparentnetwork.org)



TRANSITION TO ADULTHOOD:  
NIAD

NIAD (National Institute of Art and Disabilities) is a visual arts studio program for adults with developmental and other physical disabilities located in Richmond.

On any day, one can walk into the program and see people of all different ages and abilities at work creating art in a variety of mediums, including paint, paper, clay, and fabric. Some people have come to NIAD with a pre-established interest in art, while others have discovered this interest after starting at NIAD.

Although housed in a warehouse-type building, the atmosphere in NIAD is warm and inviting. There is a gallery in front that displays and sells the work of the artists. Five NIAD art shows are held over the course of a year and are open to the public. Client art is also exhibited and sold at other Bay Area galleries and businesses, on-line through NIADart.org and through gallery and museum shows nationwide.

While NIAD focuses on art, it also serves as a place to develop and foster personal identity and independence. Independent Living Skills classes are held on Tuesday and Friday. Clients apply their skills selling art at the Richmond Civic Center Farmers' Market and through paid jobs at NIAD. The NIAD garden is also a source of jobs and client cooking several times a month. Additionally, the program focuses on socialization and inclusion at the NIAD center, as well as on field trips to museums, art galleries, artists' studios, and community events.

For more information on NIAD, please contact Belinda Sifford at NIAD at (510) 620-0290. For more information about the CARE Parent Network Transition Center,

please contact:  
Caroline Ortiz, Transition Coordinator, at (925) 313-0999, x109.



EQUIPMENT AVAILABLE

- ☆ 1 Medium/Large Rifton Supine Stander
- ☆ 1 Medium Bailey Chimney Stander
- ☆ 1 Small Prone Stander
- ☆ 1 Medium Prone Stander
- ☆ 1 Small Activity Chair on Wheels
- ☆ 2 Adult Locking Elevated Toilet Seats
- ☆ 1 Adult Seat Belt
- ☆ 1 Tumble Form—Junior Carrie Potty Seat (weight limit 50-100 lbs)
- ☆ 1 Medium to Adult Invacare Forward Walker—2 Wheels
- ☆ 1 Toddler Guardian Forward Walker
- ☆ 1 Medium Rifton Potty Chair
- ☆ 1 Medium Walker w/ Aide Guide Bar
- ☆ 1 Small Reverse Kaye Walker
- ☆ 1 Small Mini Walk Walker
- ☆ 1 Small Pony Walker
- ☆ 1 Toddler Guardian Forward Walker
- ☆ 1 Youth Kaye Posture Control Walker—4 Wheels
- ☆ 1 Large Youth Single Quad Cane
- ☆ 2 Small Quad Canes
- ☆ 1 Large Youth to Adult Guardian Quad Cane
- ☆ 1 Set of Large Lofstrand Crutches
- ☆ 1 Medium Pink Rock-n-Roll Push Bike (need upper body strength to ride and the bike needs some gear adjustments)
- ☆ 1 Large-Tumble Form Chair on Base With Wheels—No Straps
- ☆ 1 Large Bucket Swing (Sling Only)
- ☆ 10 cases Pediasure Vanilla With Fiber
- ☆ 10 cases Two-Cal
- ☆ 3 Large Cases of Adult Size Small Diapers



## CALENDAR 2010



**September 9, 2010:** Listen Beyond Words: Communicating Nonverbally. Sponsored by We Care Services for Children. This parent education event is held from 6:30—8 p.m. For more information contact Vi Ibarra at: 925-671-0777, ext. 14 to RSVP for this event.

**September 11, 2010:** 2nd Annual Golf Event. Sponsored by Special Kids Foundation. This event will be held at the Shadow Lakes Golf Club, Brentwood. For more information visit the website at: [www.spkids.org](http://www.spkids.org) or call (925-516-9690. (Fee)

**September 12, 2010:** Wine Tasting at the Respite Inn. Sponsored by the Respite Inn. Come for an appreciation and fund raising event in support of the Respite Inn. 2 p.m.–4:30 p.m. at the Respite Inn at : 906 Lee Lane, Concord, CA 925-686-5758. Ticket prices are \$30 per person, in advance or \$35 at the door.

**September 25, 2010:** Morgan Autism Center Conference. Sponsored by Santa Clara University and Children's Health Council. One Day conference on Autism Interventions. Register online at: [www.morgancenter.org](http://www.morgancenter.org) or call The Morgan Center at: 408-241-8161. (Fee \$125.00 per person)

**September 25, 2010:** 5th Annual Children's Art, Health & Literacy Festival. Sponsored by Child Care Council, cocokids.org. 1035 Detroit Ave., Concord. Come listen to storytelling, puppet shows, Mexican Fold & West African Dance, Hands-on Art, Sand Play & Book Making, Obstacle Course and more...for more information call, 925-676-5437.

**October 7th-8th 2010:** Supported Life 2010 Conference: "The Purpose of Our Path." Doubletree Hotel Sacramento. For agenda and further information visit: [www.supportedlife.org](http://www.supportedlife.org)

**October 27-28, 2010:** Career Planning for Individuals With Autism Spectrum Disorders. Sponsored by Spectrum Training Systems. Sacramento, CA. For more information and registration: <http://www.spectrumtrainingsystemsinc.com/sacramento2.html> (Fee).

**November 18, 2010:** Music Interventions. Sponsored by We Care Services for Children. This parent education event is held from 6:30– 8 p.m. For more information contact Vi Ibarra: 925-0777, ext. 14, to RSVP to this event.

**The Libraries in Contra Costa County have many events for children at different library locations.** Below is a list of some of the free events happening at a library near you. For more information go to the website: [www.ccclib.org](http://www.ccclib.org)

**September 30, 2010:** Pleasant Hill Library, 4-4:45 p.m., Junkology with Dr. Recycle, (create art from household items), 925-646-6423

**October 20, 2010:** Pajama Math at the Walnut Creek Library, 7-7:45 p.m., 925-977-3340

**October 26, 2010:** Halloween Stories and Crafts, at the Moraga Library, 4p.m., 925-376-6852

**October 27, 2010:** Halloween Party, at the Brentwood Library, 4:-4:45 p.m., 925-516-5290

**November 12, 2010:** Mad Tea Party, at the San Ramon Library, 6:30-8:30 p.m., 925-973-2850

**November 16, 2010:** Children Learning Through Play with We Care Services for Children at the Concord Library; Families are invited to enjoy arts and crafts, group social play, and developmental screenings for children 1 month to 5 years. Child developmental specialists will be available to answer your questions about your child's development. (Free program)



**Following is the schedule for the 2010-2011 Marin Autism Lecture Series.** The lectures are sponsored by the Marin Autism Collaborative, Marin County Office of Education, San Rafael, CA

For Registration go to: <http://signup.marinschools.org>

For more information, call or email: Karen Kaplan, 415-497-3751 [karensupportsu@comcast.net](mailto:karensupportsu@comcast.net)

Fee for each lecture is \$20 for non-professional, \$35 for professional

**Sept. 22, 2010:** Teaching Parents to Become Effective Autism Services Consumers

**Oct. 20, 2010:** Asperger's From a Person Perspective, Not Just a Textbook.

**Nov. 17, 2010:** Making Life Work... Developing Life Skills

**Jan. 19, 2011:** A Neurologist's Perspective on Autism.

**Feb. 23, 2011:** Computer Assisted Instruction for ASD

**Mar. 16, 2011:** Auditory Processing Problems in Children with ASD.

**Apr. 20, 2011:** Fostering Self-Regulation: The Zones of Regulation.

**May 18, 2011:** Parenting Children with ASD



## RESOURCES

**211** is a national, toll-free number you can call 24 hours a day for information about local health and human services information. Our local 211 agency is the Contra Costa Crisis Center where you can get information on vital resources in our community quickly and easily. The staff speak English and Spanish. They also have an online database that can be accessed at [www.211contracosta.org](http://www.211contracosta.org).

**AbleCloset** is a 501c3 non-profit organization that was founded on the vision of providing children with special needs a resource for borrowing needed equipment. AbleCloset hopes to provide another resource for families that find themselves in these situations, allowing them to browse and then borrow from a “library” of equipment. AbleCloset acts as an interim between families and organizations, accepting donations of equipment that children may have outgrown or no longer need, and then lending them out to families with children that could greatly benefit from their use. For information visit [www.AbleCloset.com](http://www.AbleCloset.com) or call: 650-539-4437

**Miglet’s Gluten-Free Cake Shop** is a bakery located in Danville that specializes in making only gluten free products for those who are allergic to wheat, barley, rye and other gluten products. Katie Taylor opened this bakery after spending time in her own kitchen creating recipes for her mother to enjoy after her mother was diagnosed with Celiac Disease. Visit Miglet’s at: 480 San Ramon Valley Blvd., Danville, or call: 925-831-9016

**Special Needs Youth Basketball Camp** is sponsored by United Cerebral Palsy and the Alhambra High School Girls Basketball Team. Saturdays, September 11, 18, 25th from 2p.m. to 4p.m. at the Oak Park Christian Center Gym in Pleasant Hill. The Alhambra Boys Basketball Team will be providing guidance and instruction. Contact Doug Senz if you want to have your child participate & include your child’s t-shirt size. Doug Senz at: [desenzswim@aol.com](mailto:desenzswim@aol.com) or call: 925-890-8088

**Poss-I-Bowl** is for those who want to enjoy the bowling experience and are unable to bowl the traditional way, This event is sponsored by Special Olympics Northern California. Come to Diablo Lanes, 1500 Monument Blvd, Concord, 925-671-0913, on September 11, 18, & 25th starting at 1:30 p.m. for an opportunity to bowl with a special ramp and a switch. This special event is for school aged children, teens and adults to enjoy. To register for the event please call: Laura Cartwright (Special Olympics) 925-944-8801, ext. 211 or for further details contact: Cynthia and Mike Shim (Coach-Parent Volunteers) 925-942-0454

**National Dissemination Center for Children with Disabilities** has launched a new version of their website that has been translated into Spanish. The website includes all of the disability fact sheets developed by NICHCY on disabilities in children, early intervention, and the special education process in Spanish. For more information visit: [www.nichcy.org/spanish/pages/default.aspx](http://www.nichcy.org/spanish/pages/default.aspx)

### SPECIAL THANKS: *IT TAKES A COMMUNITY TO PROVIDE SUPPORT.*

☆ Suzanne Anthony

☆ Luz Arciniega

☆ Bev Ault

☆ Lilo Cazier

☆ Stephanie Chapralis

☆ Alicia Coleman-Clark

☆ Makayla Cook

☆ Steve Dale

☆ Lalo Duran

☆ Ruvi DeGuzman

☆ East Bay Services for  
Developmentally Disabled/  
Concord

☆ Denise Guilliams

☆ Dawn Heider

☆ Vi Ibarra

☆ Bob Jacobsen

☆ Gina Jennings

☆ Laura Kahapea

☆ Hilda Mariscal

☆ Hannah Michaelson

☆ Hector Rivera

☆ Yadira Rodriguez

☆ Paul Schneiders

☆ Laurie Soman

☆ Teresa Tijero

☆ Rosa Valledor



## WHAT IS PERTUSSIS?

There recently has been a dramatic increase in cases of Pertussis, known as whooping cough, in the Bay Area and statewide. This severe respiratory disease (which includes coughing fits) has already claimed the lives of five infants in other parts of California so far this year. Fortunately, there have not been any deaths in Contra Costa County but we are seeing the disease throughout our county. Children can get Pertussis from adults so everyone 65 and under who are around infants should get the Tdap vaccine, even those who were immunized as children need a booster shot.

Pertussis is a contagious disease that creates sticky, thick mucus in the airways, which makes it hard to breathe, eat, and drink. Infants with Pertussis can have trouble breathing and turn blue. Pertussis is also known as whooping cough because people with the disease often make a loud “whoop” sound as they struggle to breathe through their narrowed airways between coughing spasms. It can sometimes present as a mild cough which is often misdiagnosed as a common cold or bronchitis.

You can protect yourself by doing the following:

**Get Vaccinated.** If you work around children under 1 year of age or with parents/family members of children under 1, get vaccinated and encourage co-workers to get vaccinated. You can go to your regular health care provider to get the Tdap vaccine.

Information on Pertussis is available in both Spanish and English at: <http://cchealth.org/topics/pertussis/> or call: 888-959-9911.

## DONATE TO CARE PARENT NETWORK

**To Donate Online go to:** [www.careparentnetwork.org](http://www.careparentnetwork.org)

### To Donate by check:

Send your check to:  
**CARE Parent Network**  
1340 Arnold Drive, Suite #115  
Martinez, CA 94553  
Make your check payable to:  
CARE Parent Network

### Matching Gifts:

Does your employer have a matching gift program? If so, you could double, or even triple, the size of your donation to CARE. Simply contact your Human Resources Dept and send in the information to us!

*CARE is a 501(c)(3) non profit corporation. All donations are fully tax deductible.*

The newsletter you are reading is available via email!  
Contact us to start receiving The Link via email.  
Call: 925-313-0999 or 800-281-3023  
or email Sheri: [sproctor@careparentnetwork.org](mailto:sproctor@careparentnetwork.org)



## PREPARING FOR PRESCHOOL AND KINDERGARTEN

### Evaluating Preschool Programs:

- ☆ Are classrooms, playground, bathrooms, stairs, and other facilities clean, safe and accessible and adapted for special needs?
- ☆ Are there opportunities for your child to interact with peers without special needs? What kind of opportunities? How many? For how long?
- ☆ Does the teacher seem responsive, comfortable, and warm with the children? Is he or she flexible and able to adapt the curriculum and schedule to meet individual needs?
- ☆ Are children encouraged to communicate their needs?
- ☆ Are there enough adults to provide proper supervision and individual attention?
- ☆ Do the children receive individualized instruction for their unique needs?
- ☆ Are the children's different learning styles recognized (visual, tactile, auditory)?
- ☆ Have activities been planned to teach specific skills?
- ☆ Are parents welcome to participate or observe in the classroom?
- ☆ How does the teacher keep in touch with the parents (notebooks, phone calls, parent/teacher conferences, home visits)?
- ☆ Does your child require medication during the school day and if so, who will dispense it?
- ☆ Does the teaching staff need training in how to handle your child's medical needs, such as seizures?
- ☆ How will your child get to school? Your car? School bus?
- ☆ If your child will go by bus, how long will he or she be on the bus?

### Preparing for Kindergarten:

- ☆ **Contact your school district for information on kindergarten registration procedures and requirements and to find out when kindergarten registration will be held.**
- ☆ Contact your school district by the beginning of January of the year in which your child will enter kindergarten. For example, if your child will enter kindergarten in Fall 2010, contact the district at the beginning of January, 2010. School districts often post kindergarten registration information on their web sites.
- ☆ Your district may require that you complete the kindergarten registration process even if your child is currently receiving special education preschool services from the district.
- ☆ Kindergarten registration is generally held sometime between January and May. The registration period differs for each school district, so be sure to check with your district to determine when it will be.
- ☆ For kindergarten registration, school districts require that you provide your child's original birth certificate, documents proving that you live within district boundaries, and proof that your child's immunizations are up to date.
- ☆ **Many schools hold a spring open house. It is a great time to visit a school with your child.**
- ☆ At an open house, families can visit classrooms, meet teachers and see examples of students' work.
- ☆ Check elementary school calendars and newsletters for open house announcements, or call schools.
- ☆ Even if you don't know which school your child will attend, a visit to your neighborhood school during an open house can provide information that may be useful to you when the IEP team discusses your child's kindergarten placement.



## CARE PARENT NETWORK SUPPORT GROUPS

NAME OF GROUP	LOCATION	FACILITATOR(S)	SCHEDULE	PURPOSE
Just for Fathers	Walnut Creek	Bob Jacobsen (peer facilitator)	1st Wednesday evening	All disabilities
Support for Moms	Brentwood	L. Schneiders	1st Tuesday morning	All disabilities
Support for Moms	Martinez	L. Schneiders	1st Thursday evening	All disabilities
Support for Parents of Teens	Martinez	L. Schneiders	2nd Wednesday evening	All disabilities
Padres Latinos	Brentwood	A. Gattis	1st Friday morning	Spanish-speaking parents, all disabilities
Grupo de Autismo	Brentwood	Luz Arciniega (peer facilitator)	2nd Friday morning	Spanish-speaking parents of children with autism
Caminemos Juntos	San Pablo	H. Mariscal Rosa Valledor (peer facilitators)	2nd Thursday morning	Spanish-speaking parents, all disabilities
Pinole (Transition)	Pinole	Cecilia Zepeda	3rd Wednesday of the month in the afternoon	Spanish-speaking parents with teenagers, all disabilities
Alas de Angel	Concord	Cecilia Zepeda	1st Tuesday morning	Spanish-speaking parents, all disabilities

**If you are interested in attending a support group, please contact CARE Parent Network at 800-281-3023 x 101 or 925-313-0999 x 101.**

**Return service requested**

**Non-Profit Organization  
U.S. Postage  
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A program of Contra Costa ARC  
1340 Arnold Drive, #115  
Martinez, CA 94553**

