



The Link

"Linking Exceptional Families in Contra Costa County"

Volume XVII Issue 4 Published quarterly

Summer 2010

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.

CONTENTS

Parent Mentoring...It's Just the Basics!	1 & 2
Check out the New Books in our Library.	2
What is Selective Mutism (SM) ?	2
It's a Family Affair: Family & Friends Cycle Cross Country	3
Equipment Available	3
Calendar.	4
Resources.	5
Transition to Adulthood: The Road to Self-Advocacy.	5
Pool Safety.	6
Congresso	6
CARE Parent Network needs your advice.	6
Bring Your Routine Along on Vacation.	7
Special Thanks.	7
Support Groups	8

Opinions expressed in **The Link** do not necessarily reflect the endorsement of CARE Parent Network or any of its associations. We do not recommend any treatment, therapy, institution or professional system, etc.

PARENT MENTORING...IT'S JUST THE BASICS!

BY LACEY FRIEDMAN-VASQUEZ

Seven years ago CARE Parent Network connected me, parent mentor Lacey Friedman-Vasquez, and my son, Lucas, with Victoria and Bill Criswell, parents of Tyler. Tyler had recently been born with the same syndrome as Lucas, CHARGE syndrome* (see definition on page 2). What has happened since then is a great example of why mentoring is so important! Victoria and I decided to reach out to other families, having remembered just how terribly difficult those first few years were for our families. What started out as a friendship and sharing of information about CHARGE syndrome has blossomed into a support group. Last fall five mothers met for lunch at a local shopping mall. Our first two meetings were focused on socializing, information sharing and supply sharing. Eventually, the group plans to branch out to do outreach to hospitals in the area so we can support even more families. This July, we will host the third meeting of BASIC (Brothers and Sisters in CHARGE) at a park in the South Bay. We expect 17 or more families to attend from areas as far away as Sacramento to Half Moon Bay. At the most recent meeting of BASIC, we were fortunate to have a visitor, David Brown from the CA Deaf Blind Services, a world renowned Specialist in CHARGE syndrome. Following the meeting, David shared his thoughts: "It (your group) had a profound impact on me. Very instructive and very healthy for me to hear you all remembering so much. And it has made me even more amazed that every one of these kids, even the most severely challenged, comes out with bags of strong personality, a bloody-minded determination to engage with the world on their terms...and as I looked around your circle on Sunday afternoon, what do you think happened? I failed to find a single shy,

mild-mannered, poorly informed, hesitant, unassertive, smaller-than-life mom....all this horrible stuff certainly helps (makes?) you grow in extremely positive and powerful ways. Whatever you each got personally from the meeting, please believe me that you also helped me to take your inspirational behavior and use it on a much wider scale".

Before BASIC began coordinating meetings, these families were complete strangers, but now they will forever share things in common that few others can understand. The group continues to grow and being understood is not all we have to offer. Now families have the opportunity to meet other families of children with CHARGE syndrome that they can contact for advice about doctors, therapists, medical tests, insurance, symptoms, educational rights, schools, etc. The bottom line is that parent mentoring has far reaching positive outcomes and it is **invaluable and therapeutic for all parties involved**. It's far more than BASIC to help someone else travel more smoothly through a very difficult time in their life.

Top row: Moria Bettencourt, Danya Hardwick Tiffani Lanting, Hannah Manniago, David Brown, Lacey Friedman, Nikki Harden

Bottom Row Victoria Criswell, Victoria Nelson, Tanya Rago (missing from photo: Franca Angeli)



PARENT MENTORING...IT'S JUST THE BASICS!

(CONTINUED)

***CHARGE** syndrome is very complex in that it affects almost every body system. Some of the most common effects include deafness, heart defects, blindness, endocrine/ hormonal imbalances, immune effects, lack of balance, behavior problems, swallowing and breathing issues, and more! "Children with CHARGE are amongst the most 'multi sensory impaired', having difficulties not just with vision and hearing but also with the senses that perceive balance, touch, temperature, pain, pressure, and smell". For more information on CHARGE syndrome visit the CHARGE Syndrome Foundation at <http://www.chargesyndrome.org>

CHECK OUT THE NEW BOOKS IN OUR LIBRARY

- 📖 "The Sibling Slam Book: What It's Really Like to Have a Brother or Sister with Special Needs" by Don Meyer
- 📖 "Thicker Than Water: Essays by Adult Siblings of People with Disabilities" by Don Meyer
- 📖 "Loving Mr. Spock: Understanding An Aloof Lover: Could it Be Asperger's" by Barbara Jacobs
- 📖 "An Asperger Marriage" by Chris Slater-Walker
- 📖 "Freaks, Geeks & Asperger Syndrome: A User Guide to Adolescence" by Luke Jackson
- 📖 "Siblings: The Autism Spectrum Through Our Eyes" by Jane Johnson
- 📖 "Siblings of children with Autism: A Guide for Families (Topics in Autism)" by Sandra L. Harris
- 📖 "Asperger Syndrome in Adolescence: Living with the Ups, the Downs and Things in Between" by Liane Holliday Willey
- 📖 "Taking Care of Myself" by Mary Wrobel



WHAT IS SELECTIVE MUTISM (SM)? BY KEVALLYN PASKOS

Do you know a child who can talk freely at home but appears frozen in other settings like at school or out in public? Do you know a child who seems so shy that they take a long time to warm up in social situations, if at all? Does it seem out of the normal range of shyness you observe in other children? If so, you may know a child with Selective Mutism.

Selective Mutism (SM), is best understood as a childhood anxiety disorder characterized by a child or adolescent's inability to speak in one or more social settings (e.g., at school, in public places, with adults) despite being able to speak comfortably in other settings (e.g., at home with family).

Affected individuals understand language use and, although they have the physical and cognitive ability to speak, they demonstrate a persistent inability to speak in particular settings due to anxiety. This differs from the developmentally appropriate behavior of a child with limited speaking and social interaction behaviors during the first month of school or daycare when he or she is adjusting to a new social environment with peers and teachers. SM also differs from shyness, which is a socially adaptable personality trait.

Whether you are a parent of a child with Selective Mutism, teacher, therapist or patient interested in learning more, our Northern California Selective Mutism support group can help. In association with <http://www.selectivemutism.org/>, our goal is to provide a local network of families and treating professionals who uniquely understand the struggles of SM. We are dedicated to sharing awareness, information, resources and support to those impacted by a child with Selective Mutism (SM). We are available for e-mail and phone support in your area. Start seeking information, develop new ideas and friendships!

Kevallyn@ureach.com



IT'S A FAMILY AFFAIR: FAMILY & FRIENDS CYCLE
CROSS COUNTRY

EQUIPMENT AVAILABLE

How far would you go for someone you love? One family will cycle 3,000 miles, from Concord to Connecticut, to help a loved one with developmental disabilities, while supporting Contra Costa ARC along the way.

Bay Area native, David M. Platter, along with his two sons and three courageous friends, launched the ride on May 29th. This ride will generate critical funding for George Miller Center in Concord, where Mike Platter, David's brother, attends the adult program. The ride will also benefit two other remarkable charities: Make-A-Wish Foundation Connecticut Chapter, and Boys and Girls Club in Greenwich, CT. These funds are especially welcome, given the current state deficit and years of budget cuts. "It's going to make a difference for all our programs", remarked Barbara Maizie, Contra Costa ARC Executive Director, regarding the Buddy Up Bike Ride campaign. "Contributions to this project will free up other funds for ARC's many programs and services."

The pre-ride kick-off, held Friday, May 28th, was a festive celebration with over 100 participants on hand in Buddy Up Bike Ride T-shirts. Everyone enjoyed music by DJ Stone, a crafts fair, BBQ lunch, and a tour of the newly-remodeled adult program building.

The kick-off made news and was covered live by Bob Horn of CBS 5; John Sasaki of KTVU 2; Christie Smith of NBC 11; and Vern Glenn, sportscaster for KRON 4. The Contra Costa Times and its network of local papers, along with the Concord Transcript and the Pleasant Hill Register, published articles regarding the event.

The ride will fund a state-of-the-art computer lab and an enhanced sports facility at the George Miller Center in Concord. This will further emphasize the health and nutrition lessons that the ride has inspired.

If you haven't already done so, we hope you consider supporting Buddy Up Bike Ride! You can donate by going to www.ContraCostaARC.org. To learn more about the ride, visit www.BuddyUpBikeRide.net, where the cyclists will post frequent updates on their blog.

- ☆ 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



CALENDAR 2010



August 14, 2010: SAVE THE DATE -- Congreso Familiar. Chabot College, Oakland, CA. More information will be available in the coming months. Families in Contra Costa County, contact: Cecilia Zepeda at 925-313-0999 x108.

September 11, 2010: Connecting People to Resources, 2nd Annual Information and Exposition. Presented by Marin Autism Lecture Series. Dominican University of California, San Rafael, CA. For more information and registration: email Karen Kaplan at karensupportsu@comcast.net. (Fee)

September 22, 2010: Marin Autism Lecture Series: Teaching Parents to Become Effective Autism Services Consumers. Sponsored by the Marin Autism Collaborative, San Rafael, CA. Marin County Office of Education, San Rafael, CA. For registration: <http://signup.marinschools.org>. For more information, call or email: Karen Kaplan, 415-497-3751 karensupportsu@comcast.net (Fee).

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

October 20, 2010: Marin Autism Lecture Series: Aspergers From a Person Not Just a Textbook. Sponsored by the Marin Autism Collaborative, San Rafael, CA. Marin County Office of Education, San Rafael, CA. For registration: <http://signup.marinschools.org>. For more information, call or email: Karen Kaplan, 415-497-3751 karensupportsu@comcast.net (Fee).

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 17, 2010: Marin Autism Lecture Series: Making Life Work...A Menu of Options for Developing Life Skills for Children, Teens and Young Adults on the Autism Spectrum. Sponsored by the Marin Autism Collaborative, San Rafael, CA. Marin County Office of Education, San Rafael, CA. For registration: <http://signup.marinschools.org>. For more information, call or email: Karen Kaplan, 415-497-3751 karensupportsu@comcast.net (Fee).

January 19, 2011: Marin Autism Lecture Series: A Neurologist's Perspective on Autism. Sponsored by the Marin Autism Collaborative, San Rafael, CA. Marin County Office of Education, San Rafael, CA. For registration: <http://signup.marinschools.org>. For more information, call or email: Karen Kaplan, 415-497-3751 karensupportsu@comcast.net (Fee).

February 23, 2011: Marin Autism Lecture Series: Quality and Effectiveness of Computer-Assisted Instructional Programming for Children with ASD. Sponsored by the Marin Autism Collaborative, San Rafael, CA. Marin County Office of Education, San Rafael, CA. For registration: <http://signup.marinschools.org>. For more information, call or email: Karen Kaplan, 415-497-3751 karensupportsu@comcast.net (Fee).

March 16, 2011: Marin Autism Lecture Series: Auditory Processing Problems in Children with ASD. Sponsored by the Marin Autism Collaborative, San Rafael, CA. Marin County Office of Education, San Rafael, CA. For registration: <http://signup.marinschools.org>. For more information, call or email: Karen Kaplan, 415-497-3751 karensupportsu@comcast.net (Fee).

April 20, 2011: Marin Autism Lecture Series: Fostering Self-Regulation: The Zones of Regulation. Sponsored by the Marin Autism Collaborative, San Rafael, CA. Marin County Office of Education, San Rafael, CA. For registration: <http://signup.marinschools.org>. For more information, call or email: Karen Kaplan, 415-497-3751 karensupportsu@comcast.net (Fee).



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.

NAEYC: The Right Choice for Kids was created by the National Association for the Education of Young Children to inform families about the importance of high-quality early childhood education programs for young children. Here is the web site that lets parents search for programs accredited by the NAEYC (National Association for the Education of Young Children): <http://www.rightchoiceforkids.org/>

Story Time with a Speech Therapist Giggle, a children's store in Walnut Creek (1359 North Main Street, between Cypress & Duncun Ave.), has a speech therapist from The Speech Pathology Group in Walnut Creek come to read children's stories on the last Wednesday of each month they will be reading books aloud for kids. They will also be teaching parents techniques to share stories and promote learning skills. Event is free. For more information, call Giggle at: 925-746-0300 or email www.walnutcreek@giggle.com

Disabilityscoop is the first and only national news organization serving the developmental disability community including autism, cerebral palsy, down syndrome and intellectual disability, among others. Five days a week they sift through the clutter of top news stories to provide a central, reliable source of news, information and resources. Plus, Disability Scoop is the only place to find original content and series that take an in-depth look at what lies beyond the day's headlines. [Wwww.disabilityscoop.com](http://www.disabilityscoop.com)

ispeech.org is a website that reads aloud the words that you type into it. The program can be used with blogs or websites to help make them more accessible to people.

TRANSITION TO ADULTHOOD: THE ROAD TO SELF-ADVOCACY

One of the most important things a parent can do for a child facing transition is to talk to the child about his/her disability. Many children may understand that they have a disability with a name – autism, for example. What many children have a harder time doing is putting into words what the disability means *to them*.

For example, if a child has difficulty following and/or remembering verbal directions, teaching the child to ask that directions be given in writing is a significant step in helping the child take control of his/her disability. While parents may be the ones to have had that discussion with teachers, administrators, and others throughout elementary and middle school, it is important that the child learn this skill on his/her own during high school.

Understanding the impact of the disability is essential in helping our children become the self-advocates that they need to be for their future. Talk to your children about what areas they do well in and in what areas they need support. In addition, make certain that your children understands what supports are required to make them successful and how to ask for these supports.

Please contact Caroline Ortiz at (925) 313-0999 x109 if you have any questions about transition.



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



SAVE THE DATE



CONFERENCIA CONGRESO FAMILIAR

Saturday, August 14, 2010
8:30 am to 4:00 pm
Chabot College
Hayward, CA

A Conference in Spanish for Families
with Members with Disabilities

20+ Workshops • Childcare • Food •
Resource Fair •
Live Music • Friendship • Transportation

For more Information contact:
Cecilia Zepeda (925)313-0999 xt. 108
or

Visit us at www.congresofamiliar.org

**CARE Parent Network
needs your advice!**

The next edition of our
Newsletter will include a short 10
question survey. We really want to
learn your opinions. When it comes
in the mail, will you please fill it out
and mail it to our funder, Contra
Costa First 5!
We'll pay the postage!

POOL SAFETY

Here are some water safety tips for your typical child or for your child with special needs to make sure you and your family and friends stay safe when you are in or around water.

- ☆ Children should always be actively supervised by an adult while in or around a swimming pool.
- ☆ Don't consider children "drown proof" because they have taken swim lessons.
- ☆ Remove all toys from the pool when not in use. Toys will attract children back to the pool.
- ☆ Keep a constant eye on young children playing in or near ANY body of water, wading pool, public pool, bathtub or lake.
- ☆ Keep rescue equipment by the pool, as well as a phone with emergency numbers.
- ☆ Install self-closing and self-latching gates on isolation fencing around the pool. Be sure they are properly maintained and checked frequently.
- ☆ Have your child wear a brightly colored swimsuit and life vest so they are easier to see.
- ☆ All non-swimmers should always wear approved flotation devices around the water.

It is crucial that you and all of your child's caretakers can swim and know how to perform CPR in an emergency. For more information you can contact:

- Drowning Prevention Foundation at:
www.drowningpreventionfoundation.us,
- www.ndpa.org, or call 707-747-0191



BRING YOUR ROUTINE ALONG ON VACATION

Part of the fun of travel is experiencing new things, taking the old boring routine and throwing it out the window, right? For a child with special needs, that's not the fun of travel -- that's the horror of it. When routine is your touchstone, your way of making it safely through the world, having it removed can be more terrifying than exciting.

There's a degree to which routine disruption can't be helped when you're on the road. But to the degree that it can be, do so. Keep things as predictable as possible for your child. If your child has a difficult time with transition or change, show him/her pictures of where you are going. Create a social story so that the stress of the unknown is alleviated.



Bring things that will make the trip easier on your child:

- Bring familiar bedroom items like a stuffed animal, favorite blanket, pillow, and beloved toys.
- Keep bedtimes and wake-up times as close to normal as possible, allowing for time changes.
- Consider staying in a room with a small kitchen so your child doesn't have to deal with restaurants first thing in the morning, and you can have an occasional at-home dinner, too.
- Try to bring some entertainment item your child enjoys -- videos, video games, computer -- for some decompression time.
- Keep a consistent schedule from day to day if you can -- a trip routine -- even if the specific activities change.
- Talk to your child each morning about what you'll be doing, and each night about what you've done.

Also, many car rental companies offer vehicles that have been modified for use by drivers or passengers with mobility issues. These may not be available in all locations, so you'll want to check ahead and make sure that an appropriate car will be available and accessible when you arrive. Start by checking the car-rental company web sites for information on what they offer and what they require.

What many people don't realize is that there are tour operators and travel agents who specialize in working with travelers with disabilities and who can help families plan vacations suited to their interests and needs. Two websites you might check are www.access-able.com and www.sath.org (Society for Accessible Travel & Hospitality).

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

- | | | |
|---|--------------------------------|---------------------|
| ☆ Suzanne Anthony | ☆ Vi Ibarra | ☆ Claudia Ronaldson |
| ☆ Bonnie Arnwine | ☆ Bob Jacobsen | ☆ Joann Rossi |
| ☆ Julie Barazza | ☆ Gina Jennings | ☆ Laurie Soman |
| ☆ Sharon Bardy | ☆ Christine Keene | ☆ Teresa Tijero |
| ☆ Olivia Beretta | ☆ Mary & Jon Livesay in Memory | ☆ Rosa Valledor |
| ☆ Erika Buckman | of Mark Schneiders | |
| ☆ Stephanie Chapralis | ☆ Mimi Lou | |
| ☆ East Bay Services for
Developmentally Disabled/
Concord | ☆ Hilda Mariscal | |
| ☆ Denise Guilliams | ☆ Hannah Michaelson | |
| | ☆ Blanca Peraza | |
| | ☆ Hector Rivera | |

 *Merci*



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	C. Zepeda	2nd Friday morning	Spanish-speaking parents of children with autism
Caminemos Juntos	San Pablo	H. Mariscal (peer facilitator)	2nd Thursday morning	Spanish-speaking parents, all disabilities
Nuevo Grupo	Pinole	C. Zepeda	2nd week of the month in the afternoon	Spanish-speaking parents, all disabilities
Alas de Angel	Concord	Blanca Peraza (peer facilitator)	2nd Tuesday morning	Spanish-speaking parents of transition age, 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.

Non-Profit Organization
U.S. Postage
PAID
Permit #177
Concord, CA

Return service requested

CARE Parent Network,
A program of Contra Costa ARC
1340 Arnold Drive, #115
Martinez, CA 94553

