



Dialogue

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Consumer Spotlight Their Gift Is an Angel

Doug and Jennifer Hansen are typical parents, and yet they're not. All parents have a unique story to tell, and this is a chapter in theirs. One of them seems driven while the other seems laid back. That is apparent in their different reactions to their daughter Angel's disability. Doug went on a quest to find a specific diagnosis for her mysterious ailments, while Jen said, "She has what she has — it's Angel's way of living."

They first learned that their baby would have serious problems when Jen was five months pregnant and had a routine sonogram. Some of the doctors they met with subtly and sometimes not so subtly encouraged her to abort the baby. Jen was adamant, "God gave me her for a reason, and I'm going to keep her."

Jen and Doug now know many of Angel's specific problems, but doctors still have not been able to

determine what, if any, syndrome she has. Angel was born with physical anomalies: dislocated hips, multiple joint deformities and a missing kidney. She has hydrocephalus (fluid on the brain) and her brain is only one-quarter the normal size. Despite such enormous challenges and several surgeries, she has lived and developed beyond her doctors' expectations.

Now she is two years, eight months old, and Doug and Jen do all they can to help her develop to her potential while realizing that she probably will never walk or talk. As a participant in the Early Start program, Angel receives occupational therapy and in-home infant stimulation. Doug and Jen were thrilled when Angel rolled over for the first time at 18 months of age. By 24 months, she could roll over five times in a row. She also can occasionally grab an object with her hand.

Both parents remain optimistic about the future. Their daughter has inherited their good nature. She is content to watch the world from her chair, and she responds to Mommy's voice with an easy smile. Daddy makes her giggle as he plays a game of circling around her, carrying her favorite stuffed bunny.

Although Jen and Doug knew ahead of time that Angel would have special needs, and they were

Your Attention Please! We Need to Know ...

Do you still need to receive a copy of RCOC's Community Calendar in the mail each month? Until now, the monthly Community Calendar has been mailed to all RCOC's consumers, families and service providers. It gives details about meetings of support groups, service provider committees and RCOC board committees as well as special events, workshops, and recreational opportunities. The calendar is posted on RCOC's Web site (rcocdd.com) and can be updated with new announcements and changes, while the print version is prepared about two months ahead and may not contain all the events posted on the Web version.

Because the cost to print and mail the calendar is very high, RCOC is going to discontinue mailing it except to those who need a copy because they do not have access to the Internet. If you need to continue receiving the Community Calendar every month, call RCOC at (714) 796-5100, extension 4904, to keep your name on the mailing list. Please spell your name and give your telephone number and address on the recording.

Copies of the Community Calendar will also be available from Comfort Connection Family Resource Center if you need an occasional copy. You can pick one up at 801 Civic Center Drive West, Santa Ana, or call the FRC at (714) 558-5400 to request that a specific month's calendar be mailed to you.



Jen and Doug Hansen say of their daughter Angel, "Just having her here is wonderful."

See 'Angel,' page 10

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RCOC Legislative Update

Parental Co-Payments Are Coming

By Karen Chen, RCOC Board of Directors

You may have heard a rumor that parental co-payments for regional center services will be required in the future. Unfortunately, it's not a rumor — it is a fact. And the future begins on July 1, 2004 when the co-pay program is scheduled to start. When the state legislature approved the budget last summer, they also voted the co-pay program into law.



The new law instructed the Department of Developmental Services (DDS) to develop a program for collecting co-payments from parents of children between the ages of 3 and 17 for all regional center services they receive. (Currently the only share-of-cost parents have for regional center services is when their minor children live outside the family home — and that is on a sliding scale based on the parents' income.) DDS has gathered public input at hearings on this subject and will release two draft proposals on March 1 about the way it could implement the program. RCOC will post the documents on its Web site at www.rcocdd.com. If you don't have access to the Internet and would like a copy of the documents, call Comfort Connection Family Resource Center (FRC) at (714) 558-5400 to request them.

Once we know what DDS is proposing, we can all give feedback about the plans to our state legislators and to DDS. The only way to change or do away with this new

See "Co-Pay," page 10

From the Executive Director

A New Direction in Public Policy?

By Bill Bowman

It's been interesting,

say the least, to observe the new state administration grapple with a multi-billion dollar budget deficit. We at RCOC definitely had concerns with the mid-year budget cut proposals that included eliminating all respite and limiting enrollment for regional center services. In December, when the governor, upon further analysis, determined that those methods were not the best way to go about saving money and withdrew those proposals, we were relieved and grateful.

Propositions 57 and 58

Now we're waiting to see what will happen after the election on March 2. Will the voters approve Proposition 57, the governor's bond initiative that offers a first step to getting our state out of its fiscal mess? If you want to read an easy-to-understand explanation of the bond issue's pros and cons, I recommend Dan Weintraub's column in the Sacramento Bee. You can access it online at www.sacbee.com/content/politics/columns/weintraub. Scroll down to the January 27 column, "Bipartisanship is great, but pitch is misleading." The explanation begins in the sixth paragraph.

Bond or no bond, cuts to regional center budgets are proposed for 2004-05. However, if the bond issue doesn't pass, the cuts will be much deeper and likely catastrophic to services. That is why I urge you to



vote "yes" on Propositions 57 and 58. As unpalatable as continued borrowing is for many of us, the reality is that the legislature and then-Governor Davis already approved \$10.7 billion in bonds last summer. Because that level of borrowing was not put to a vote of the people, it is being challenged in court. Proposition 57 would supercede and refinance that bond measure. The reason we are asking you to vote yes on both Propositions 57 and 58 is that in order for Proposition 57 to take effect, Proposition 58, the "balanced budget amendment," also must pass.

Regional Center Budgets

What the governor is proposing for regional centers beginning July 1 is a set of activities designed to put the brakes on the system's expenditure growth. The strategy can be seen as a set of "tools" to achieve savings while maintaining needed services. The tools include establishing statewide purchase of service (POS) standards and requiring that services be provided in the most cost-effective way. I see these proposals as being not so much about limiting services, but as a statement of public policy, giving guidance and direction to regional centers, families and the public about how tax dollars can and cannot be spent. It's encouraging, because it's an effort to ensure that the funding available for services is allocated to every community in the most equitable and fair manner possible — something even more critical in this time of limited resources.

Despite the fact that increases in system costs have been driven by escalating POS expenditures, the governor's proposed budget also includes deep cuts to regional center operations funding. This is cause for concern for several reasons, the

greatest of which is the serious and unintended impact on consumers and families. Two immediate consequences are longer timelines for determining eligibility and larger caseloads for service coordinators. Regional Center case management — which is funded by Operations dollars — constitutes the first and primary consumer *service*. It serves as the entry point into the system of services by establishing eligibility and developing the consumer's Individual Program Plan. Service coordinators help families select from a variety of service options and guide them to other public resources. Quality assurance is another essential *service* on the Operations side — providing fiscal and programmatic oversight to ensure that services meet the standards for quality and effectiveness upon which consumers depend. These and other essential functions provided by RCOC's Operations budget, such as the ability to pay our bills on time, develop new service resources, and authorize services, will be jeopardized if we don't have the necessary infrastructure.

We at RCOC welcome ideas that foster accountability because we take seriously our responsibility to be careful stewards of public dollars. Our hope is that the system can be improved and savings achieved without depriving consumers of needed services and supports. We are communicating with our legislators and the administration about these issues.



R.A.D.D. Review

Regional Center Has an Advocate for Consumers



Do you ever want to talk to another consumer about problems with your ser-

vices? Do you feel like another consumer can understand you best? If so, there's someone at the Regional Center waiting to hear from you. His name is Brian Story. Brian is a Regional Center consumer, too. His job title is Consumer Advocate. His job is to help you. He can be your advocate with your independent living provider. He can be your advocate with your job coach. He can be your advocate with CalOPTIMA. He can even be your advocate with Regional Center.

Here's how Brian helped someone not long ago. Brian's independent living team leader called him. He asked Brian for help with a consumer. The consumer needed a new wheelchair. Brian gave him some ideas about who to call to get one.

Brian sets an example for other consumers. He is a good advocate in everyday

living. Sometimes he sees someone without a disability park a car in a handicapped parking space. That is against the law. Brian waits to see if the person leaves soon. If the person doesn't leave soon, Brian calls the police. The police will come and give the person a ticket. That may keep the person from parking in a handicapped space again.

Here's another example from Brian. Brian uses a wheelchair. He saw that one of the wheelchair ramps at his apartment building was too short. It was dangerous. He could have fallen out of his wheelchair. He might have gotten hurt or killed. He let his apartment manager know about it. The apartment manager had the ramp fixed.

Brian also meets with resource groups at the Regional Center. The resource groups give advice to service coordinators so they can help consumers better. Being part of these groups helps Brian with his job. He learns more about service choices.

If you think Brian can help you, call him at (714) 796-5365.

Use Tele-Friend to Make a New Friend

Regional Center consumers can join Tele-Friend to meet new people over the phone. We suggest that if you decide to meet someone in person, meet at a public place and provide your own transportation.



To put your name on the Tele-Friend list or to get a copy of the list so you can talk to someone, call (714) 796-5270 for the forms you need. You must be a Regional Center consumer or parent to respond.

Marcel of Costa Mesa ... "I am a 30-year-old man. I like to play video games, swim, dance, cook, roller-skate, bowl, drive go-carts, go to the movies, and ride my bicycle. I work at Ikea, live in an apartment with a roommate, and drive my own car."

Peter of Costa Mesa ... "I like to go to the movies, listen to music, watch DVD's, talk on the telephone, work on the computer, and use the Internet. I work at United Colors of Benetton as a stock clerk. I'm 33 years old and live with my family. I don't drive."

Toby of Costa Mesa ... "I like to listen to music, ride my bike, and go fishing. I'm a 33-year-old man, and I live in my own apartment. I don't drive."

Renee of Lake Forest ... "I'm a 47-year-old woman. I enjoy music, going to the movies, writing letters, playing board games, going out to eat, and taking walks. I work at Del Taco as a host in the dining room. I live in an apartment and ride the bus."

Consumer Advisory Team (CAT) Update

By Michael Bailey, Chairman



We have big news! The National Self-Advocacy Conference will be held

at the Anaheim Marriott Hotel on May 27-30, 2004. The theme is "California Dreamin.'" Our own CAT team member Sam Durbin will be the keynote speaker on Friday, May 28. There will be many workshops. Speakers will come from 25 states. Workshop subjects include leadership, self-advocacy, dating, independence, and more. The registration fee is

\$350 before March 15. After that, it's \$400. For a registration form, call Comfort Connection Family Resource Center at (714) 558-5400.

In December, the team had a Christmas party in place of the regular meeting. The members had a fun time. They also donated \$20 to the American Red Cross. It was to help the victims of the October fires. Members also brought canned foods to the party. They filled four grocery bags. They donated the food to Kelly's Cupboard. That's a project in the East/Central Area. Service coordinators make food boxes for low-income consumers and families at Christmastime.

The team has been busy

recently. In November we wrote a letter to Governor Schwarzenegger. We asked him to support the regional center system. We have been working with OCTA to fix problems with the fixed route and ACCESS bus systems. We also had an employment workshop.

You are welcome to come to a Consumer Advisory Team meeting. They are held on the third Wednesday of the month. The meeting time is 10:00 a.m. to noon. The meeting place is usually the RCOC East/Central office at 801 Civic Center Drive, Santa Ana. Please call Betty Bath at (714) 796-5263 ahead of time to let her know you will be there.

Safety Stu's Corner

Telephone Safety

Hello Safety Friends,

You might remember me from your safety trainings as Cautious Kyle. I'm writing this time because Safety Stu is out of the office. He'll be back for the next issue. We are just a couple of months into a new year, and I hope one of your resolutions is to stay safe. I'm sure many of you have been sharing what you have learned with your friends, so that they can **GET SAFE™** just like you!

In this issue, we will review *phone safety*. We all know that we should not talk to strangers on the street. Here is a safety question for you: Should we talk to strangers on the *phone*? **NO!**

Remember – if someone you do not know well calls you on the phone, never give them information such as your name, phone numbers, address, credit card numbers, social security number, where you work, go to school, or even things about your parents, friends or caregivers. If you are not sure what to say, you can always ask someone like your parent or care provider before speaking to anybody on the phone.

Sometimes people might call and act like they know you or even try to become your friend. Someone may even say things that sound weird to you. The best thing you can do is **HANG UP!** If you are not sure if you should hang up the phone, just let someone else know what is happening. If you live alone, it's okay to ask

the person for their phone number and call them back after you talk with staff or a parent. Always ask someone you trust if you are unsure about anything.

We at **GET SAFE™** are proud of your safety accomplishments. If your friends have not had a chance to yell **BACKOFF™**, please make sure to share your safety tips with them.



If you have a safety question for Safety Stu and the Safety Team, write to us. Send your letter to Safety Stu, c/o RCOC, P.O. Box 22010, Santa Ana, CA, 92702. If we use your question in Safety Stu's Corner, we will send you a safety T-shirt, absolutely free. Thanks for Staying Safe, Cautious Kyle in for Safety Stu



Spring Is Coming – A Time for Transitions

By Hedy Hansen, FRC Manager

For parents of children under age 22 with special needs, spring is a time of planning for the next school year through the Individual



Education Plan (IEP) process. But changing school grades is not the only transition children (and adults) with developmental disabilities experience. Crucial transitions are made at several points: from Early Start to school programs at age three, starting kindergarten at age five or six, from elementary school to junior high or middle school and then to high school, and from school to work programs. Thinking ahead about transitions can be the key to success for children in just about everything.

Check Out These Resources!

Comfort Connection Family Resource Center (FRC) and Regional Center have many support options available to help families with transition. We can also help you start thinking now about upcoming transitions. The FRC has parent support coordinators to assist with parent-to-parent support. They can also help you find print and video resources at the FRC library. Parent Connection is a program that matches volunteer parents with parents who would like the moral support of speaking to someone who has been through a similar situation. Parent Connection is jointly administered by RCOC and United Cerebral Palsy of Orange County. Call the FRC at (714) 558-5400 for more information. Dr. Nancy McGovern is a licensed clinical

psychologist at RCOC whose focus is parent support. She is available for brief consultations with parents having trouble dealing with the stresses of their child's transitions. She can refer parents to other therapists and community resources as needed. You can contact her at (714) 796-5396.

Training, Groups & Workshops

RCOC offers a two-hour training session called "Moving on at 3" for parents of children who will be transitioning out of the Early Start program in the near future. To find out about upcoming sessions, contact John Zeimantz, RCOC's Early Start Coordinator at (714) 796-5339.

The Regional Center also has resource groups made up of RCOC employees, consumers and family members. The groups meet regularly to review consumers' needs and offer advice and program options. The Education Consult Group can assist with education transitions, the Adult Resource Group can offer assistance with consumers getting ready to transition from school to work at age 22, and the Living Options Group can make recommendations for consumers wishing to move out of their family home.

Periodically the Regional Center also offers special presentations and workshops covering a variety of topics, such as Individual Education Plans, conservatorship, and estate planning.

Feel Free to Call or Visit FRC

When you are looking for information or resources related in any way to your child's disability, feel free to visit or call Comfort Connection FRC, 9:00 a.m. to 4:00 p.m. Monday through Friday, 801 Civic Center

Drive West, Santa Ana, (714) 558-5400. Our knowledgeable parent staff members will be happy to assist you in finding what you need.



TASK Offers IEP Clinics

Would you like free help working out issues in your child's Individual Education Plan? Well, here's your opportunity to sit down and talk to an expert one-on-one. Team of Special Advocates for Kids (TASK) has partnered with the Regional Center to offer parents individual assistance with their child's IEP. IEP Clinics are held at various times during the month at different RCOC area offices. Each appointment is one hour long, so the time will be focused on one or two of the most important issues. This can be useful for parents who have situations that are more involved than can be dealt with at RCOC's Education Consultation Group.

Although it is helpful if parents have attended a TASK workshop before accessing the clinic, it is not required. The clinics are available to parents who speak English, Spanish and Vietnamese. To make an appointment for an upcoming clinic, call TASK at (714) 533-8275 and ask for Tiffany Nurminen if you speak English, Yolanda Cruz for Spanish, and Linh Nguyen for Vietnamese.

Get Assistance With Special Needs Estate Planning

If you have an adult or even a young child with a developmental disability, you may have wondered, worried, or avoided thinking about what will happen to your beloved when you are gone. Who will take care of him? How will she survive on SSI? Where will he live? Who could possibly love her and watch out for her interests the way that you do?

You don't need to wonder, worry or avoid any longer. You can take advantage of abundant helpful resources to plan for the future and lift the burden of concern from your heart. If you don't know where to begin or what you need to do, you might want to start by calling or visiting Comfort Connection Family Resource Center, (714) 558-5400, 801 Civic Center Drive West, Santa Ana.

The staff of caring and knowledgeable parents can guide you to organizations, individuals, Web sites, and/or publications that can answer your specific questions or provide the services that you need. In addition to financial planning and the accompanying legal issues, it's important to consider and document issues relating to your child's quality of life preferences and day-to-day care needs with a letter of intent and/or videotape.

To help you begin to think through this process, here is a list of some of the topics related to special needs planning along with resources that might be helpful to you.

Wills/Special Needs Trusts

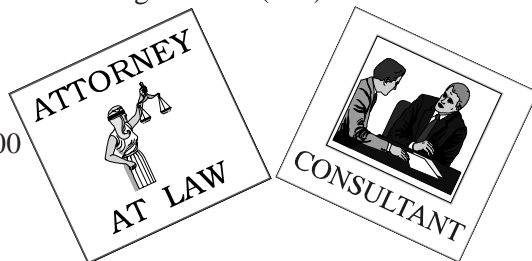
Comfort Connection FRC has numerous books, articles and fact sheets. Call (714) 558-5400 or visit Monday through Friday between 9:00 a.m. and 4:00 p.m. at 801 Civic Center Drive West, Santa Ana.



The Inland Counties Master Trust provides the benefits of a trust account to families that may not have the means to establish an individual trust. In addition, as trustee of the account, Inland Regional Center has the necessary knowledge and expertise to administer the trust assets in accordance with the laws and in the best interests of beneficiaries with developmental disabilities. For more information, see Inland's Web site at www.inlandrc.org, then click on "Info & Support" and "Master Trust," or call (909) 890-3000 for more information.

Conservatorship, Trusts and Wills for People with Developmental or Other Disabilities: A Guide for Families is a booklet written by an attorney in family-friendly language and available from Protection and Advocacy, Inc. You can download the publication in English or Spanish at www.pai-ca.org or call toll-free (800) 776-5746 to request a copy.

NICHCY, the National Center for Children With Disabilities, has a 20-page publication called *Estate Planning* that you can download at www.nichcy.org, click "Publications," then enter "Estate Planning" in the Search box, or request by calling toll-free (800) 695-0285.



MetDESK is a service of Metropolitan Life Insurance Company that provides special needs planning assistance and information. Check their Web site at www.metlife.com/desk or call toll-free (877) 638-3375.

The ABC's of Special Needs Planning Made Easy is a book available for \$34.95 from Bart Stevens Special Needs Planning. Also available in early to mid-March will be a Special Needs Planning Kit for \$395. See www.bssnp.com or call (888) 447-2525. Mr. Stevens can also provide fee-based one-on-one consultations for parents.



Conservatorship/Guardianship

The FRC has a one-page fact sheet called "The Difference Between A Guardian and a Conservator," as well as a more detailed paper called "Overview of Conservatorship," and can provide a list of attorneys in Orange County that specialize in conservatorships.

See *Conservatorships, Trusts and Wills...* under "Wills/Special Needs Trusts," above.

Periodically, RCOC offers **estate-planning workshops** presented by knowledgeable professionals. **The next presentation is scheduled on Thursday, April 22 from 6:30 to 8:30 p.m. at RCOC's Santa Ana office, 801 Civic Center Drive West.** Joe Sahabu of Metropolitan Life's MetDESK will be accompanied by estate-planning attorney Chris Poulos. Please call (714) 796-5100, extension 5904 to make your reservation.



Thank You, Generous

Regional Center of Orange County conducts the Wish Tree program annually to help make Christmas and Hanukkah brighter for those with developmental disabilities who do not have families to give them gifts, or whose families simply do not have the resources. Cards containing gift wishes are distributed to businesses, other organizations and individuals throughout the county. Generous donors purchase gifts or make monetary donations to fill the wishes. Gifts are collected and wrapped at each of the Regional Center's four Orange County locations, then delivered by RCOC staff to their intended recipients. The gifts range from toys to clothing and holiday meal gift certificates.

This program could not succeed without the kindness and generosity of hundreds of individual shoppers as well as several organizations whose employees shop and share with those less fortunate.

We at Regional Center of Orange County want to say THANK YOU to everyone who participated in the 2003 Wish Tree Program. We appreciate the discounts given for Wish Tree shopping by Wal-Mart and Factory-2-U. The major donors were:

- AECOM, third largest global architectural & engineering firm in the U.S.
- American Suzuki
- City of Brea – Judy Campos, community services director
- Brea Methodist Church

- Brea Senior Center
- Carden Academy
- Casto/Orange Unified School District
- Christ Presbyterian Church, DV8 High School group
- Costco of Garden Grove – Bruce Greenwood, manager
- Girl Scouts of Saddleback Valley Service Unit One – Kathy Lauderdale, coordinator
- Kohl's
- Lexus of Mission Viejo
- Mattel



Children in one of the preschool classes at The Learning Experience and Director Pauline McCall (right) presented bundles of gifts to RCOC's Patrick Ruppe (seated).



Marty Haynes (left) of American Suzuki delivered a vanload of presents from Suzuki employees to RCOC and was greeted by RCOC's Jacqui Kerze and Jason Jolivette.



Wish Tree Donors

- Micro Specialties
- Orange County Interfaith Shelter
- Pacific Life
- Beth Richards
- 7-Eleven
- Soroptimist International of Newport Harbor
- The Spraker Family
- Starlight Children's Foundation
- The Learning Experience – Pauline McCall, director
- UCI Pediatrics/Genetics
- Wildermuth Environmental, Inc.
- Winways

Girl Scouts Megan Murphy and Jocy Keider along with parent volunteer Gail Holmes helped deliver and wrap dolls, games and clothes contributed by Saddleback Valley Service Unit One Girl Scouts.



Vietnamese Christmas Party Provides Cheer

The Vietnamese staff members of Regional Center of Orange County hosted their 19th annual Vietnamese Christmas Party on December 5, 2003, which was attended by more than 350 consumers and their families. This year's party featured a delicious dinner at the Emerald Bay Seafood Restaurant in Santa Ana. Highlights of the evening included pictures of all guests taken with Santa Claus, a magic show, gifts distributed by Santa and his elves, and singing by Master of Ceremonies Phuc Bui and several dinner guests. RCOC's Karen Hua also served as master of ceremonies.

Members of the planning committee worked hard to make the event an enjoyable

time for all who attended. They are Phuc Bui, Tinh Cao, Van Chau, Duc Hoang, Karen Hua, Becky Ly, Binh Nguyen, Costa Nguyen, Nga Nguyen, Nelly Ninh, Kandyse Tran, Lucille Tran, Quang Tran, and Truy Tran.

The committee members are deeply grateful to the RCOC and community volunteers who assisted at the party as well as the monetary and in-kind donors who made the party possible.



The Pham family was among those who enjoyed the festive evening. From left: Grandmother Nam Ho, Jessica (back) and MaryJo Pham, Santa Claus, Tanya and Jason Pham.

Angel (from page 1)

able to manage the mixed emotions of joy and sorrow that came with her birth, they would have appreciated coming home from the hospital a little more prepared. They said that the nurses and the social worker at the hospital were caring and supportive, but they would have liked a list of resources — people or organizations they could have called or looked up on the Internet to ask questions or seek help. They were called by the Regional Center shortly thereafter, but no one told them ahead of time about Regional Center or any other resources. They didn't know what to expect or where to turn in those first days and weeks.

That, in part, has inspired them to try to help other parents in similar situations. Thus was born the idea of "Angel's Run." On April 3 Doug will run and walk for 24 hours straight to raise money for the Hansen family's new charity (see sidebar for details).

He said, "We'd like to be able to present CHOC with a big check."

Angel's RCOC service coordinator, April Carroll, enjoys working with the Hansens. She said, "They

are so open and honest, as well as understanding and accepting of Angel's disability. I know it's hard for families to go through that grieving process and accept their child's disability. They have done very well with that. It also helped that they found out before Angel was born about the problems she was going to have. The family is happy that she has made as much progress as she has, and they celebrate that."

According to Jen and Doug, taking care of Angel is relatively simple on the one hand, and difficult on the other. She has a feeding tube, and feeding her is easy, but they never know when she may throw up, and when she does, it's a big mess.

As Doug put it, "It's a process, it's stressful. The number of bath towels you have to wash! And you feel sorry that she's just lost a meal and doesn't feel good. Giving her a bath is a production. It's also not an easy process to grab her and go someplace. The time commitment is the challenge. It's all the extra stuff around the activities."

On February 2, the family's second child was born, a healthy boy named after his father. Doug and Jen look

forward to seeing the interaction between brother and sister.

In addition to finding strength in each other, these parents strive to have a positive outlook on life. Doug summed it up this way, "Whether you have a child with special needs or just have children, you have to try to make life fun, and laugh. It's an everyday thought process you go through. That's how we cope."

Angel's Run

What: Doug Hansen will run/walk for 24 hours to raise money for Angel's Charity, a 501(c)(3) non-profit named for his daughter

When: Saturday, April 3, 2004, starting at 8:00 a.m.

Where: The track at Corona del Mar High School, 2101 Eastbluff Drive, Newport Beach

To donate: Send checks made out to Angel's Charity to P.O. Box 10325, Newport Beach, CA 92658

For more information: Visit angelsrun.com or call (949) 650-2757

Co-Pay (from page 2)

program is for the governor or the legislature to repeal the law that established it. Maybe they will do that if the outcry is loud enough.

Some people have the mistaken idea that regional centers proposed the co-pay program. Nothing could be further from the truth. RCOC has been advocating on behalf of families in this situation. One of the primary concerns at RCOC is that the co-pay program be administered in the most equitable way possible. The people at RCOC know that if the program gets carried out in certain ways, it may prevent some families from obtaining

needed services for their children. They don't want that to happen.

An RCOC board member who has a child receiving regional center services went to Sacramento in December to testify at a DDS hearing on the co-pay issue. She also wrote a letter to DDS outlining the thoughts that she and others have about how the program should be structured. The main points were:

- ◆ the additional costs families incur as a result of having a child with a disability should be included in calculating the family's share-of-cost,
- ◆ exceptions should be made for financial hardship,
- ◆ respite care should be exempted

from the co-pay program, and

- ◆ the program should be set up to end when the state's financial crisis is over.

I encourage you to look at the co-pay program proposals and then contact DDS, the governor and your state legislators to give your input about what you think is good and what needs to be changed about how the program will be administered. RCOC will provide contact information on its Website and with copies of the proposals requested from the FRC. Please let our elected officials know how this program will affect your family.

Important Things to Know...

Apply for RCOC's board of directors ... The Regional Center of Orange County's board of directors is made up of people with developmental disabilities, family members of people with developmental disabilities, and other interested residents of Orange County who can offer business, financial or legal expertise. Board members volunteer their time at board meetings every other month and at monthly committee meetings. The board sets policies that provide direction for RCOC's operations. Board members serve three-year terms. If you are interested in applying to serve on RCOC's board, you can obtain a Board Membership Application from RCOC's Web site at www.rcocdd.com or by calling RCOC's Executive Office at (714) 796-5205. The board's recruitment committee evaluates all membership applications and interviews applicants to select candidates who are elected by the full board.

Free Tax Assistance Available ... The Internal Revenue Service offers free tax assistance through Volunteer Income Tax Assistance (VITA) and Tax Counseling for the Elderly (TCE). Volunteers prepare federal and state income tax returns for low income, senior, physically challenged, and non-English-speaking taxpayers.

RCOC has a list of the sites where this service is available, so you can call your service coordinator to find the location nearest you. You can also call IRS Customer Service at (800) 829-1040 to ask for the VITA or TCE site near you.

Note: Consumers or their families may be eligible for an Earned Income Tax Credit. VITA and TCE volunteers are trained to assist people with claiming Earned Income Credit.

Down Syndrome Program at UCI Seeks Participants ... The Down Syndrome Program in Development, Aging and Dementia at the University of California, Irvine is interested in receiving referrals for individuals with Down syndrome over 40 years of age with any of the following symptoms:

- √ Requires more prompts than previously to carry out daily living activities
- √ Loss of memory or episodes of confusion
- √ Symptoms of depression
- √ Social withdrawal from daily activities
- √ Changes in sleep patterns
- √ Alterations in eating habits
- √ Increased agitation
- √ Changes in language usage or speech delay
- √ New onset of seizure disorder
- √ Difficulties in walking or balance
- √ New onset of bladder or bowel incontinence

The program provides state-of-the-art diagnostic and treatment services as well as opportunities for participating in a National Institutes of Health-funded clinical trial for dementia in Down syndrome.

For more information and appointments, please contact Eric Doran, M.S., Down Syndrome Program manager, at (714) 456-8443 or Ira T. Lott, M.D., project director, at (714) 456-5333.

Research study ... Children with Down syndrome between the ages of 8 and 14 and their parents are wanted to participate in a university study examining parents' perceptions of their child's ability to put together jigsaw puzzles. The study involves a one-time session of about 75 minutes that can take place at the family's home or UCLA.

The study researcher is especially seeking Asian participants that speak and read some English, but others are also welcome. For participating, parents receive \$15 and children receive a \$10 gift card to Blockbuster Video. For more information, contact Tran Ly, Ph.D. at (310) 871-2968 or by e-mail at trannie@ucla.edu.

Fuerza, Inc. is a nonprofit organization made up of Spanish-speaking family members of people with developmental disabilities. The group offers support, information and guidance to families as well as special events and a monthly meeting in Huntington Park that provides education on a variety of subjects. Annual membership costs \$20 but the fee is waived for families who cannot afford it. For more information, call (800) 200-4323 or (310) 391-7153.

Parent Links is a program for families of children from birth to 36 months that have a hearing loss. Information is available in English and Spanish. To learn more about services offered, call toll-free, (877) 322-7299.

Board of Directors 2003 - 2004

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Christian Dubia, Jr. ❖ Joyce Hearn ❖ Tresa Oliveri
Jud Robert ❖ Steven Tanner ❖ Kim Vuong

2003-2004 Board Meetings:

Mar. 4 ❖ May 6

*The board of directors meets at 6:00 p.m. at 801 Civic Center Drive West, Santa Ana.
The public is welcome.*

The Regional Center of Orange County has four locations to serve you:

Orange Office

3111 N. Tustin Street, Suite 150
24-hour phone no.: (714) 685-5555
TDD: (714) 685-5575

San Juan Capistrano Office

26311 Junipero Serra Road, Ste. 180
24-hour phone no.: (949) 234-8800
TDD: (949) 488-3399

Santa Ana Office

801 Civic Center Dr. West
24-hour phone no.: (714) 796-5100
TDD: (714) 667-6021

Westminster Office

13950 Milton Ave., Suite 200
24-hour phone no.: (714) 889-7200
TDD: (714) 889-7234

RCOC Web site: www.rcocdd.com

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*The Regional Center of
Orange County is a nonprofit,
private agency that contracts with
the California Department of
Developmental Services to provide
services to individuals with
developmental disabilities.*

Important Information
from the Regional Center
enclosed

Regional Center of Orange County
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Dialogue Newsletter

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