

# Dialogue

Volume 18, No. 3 Summer 2004

## Consumer Spotlight Mother of Faith

isa Mitchell thought back to the ultrasound she had when she was 12 weeks pregnant.



14-month-old Faith Mitchell, shown with her mom Lisa, always wakes up happy, according to her Grandma.

"It happened so fast. They could tell that something was wrong. At first they thought it might be Trisomy 18 [a serious chromosomal abnormality] because of the large bump on the back of the baby's neck. I called my pastor and cried and told him there might be something wrong with my baby. I asked him to pray that I wouldn't be mad at God, whatever happened. The next day I woke up, and I was fine," said Lisa. She didn't learn until 20 weeks pregnant that her baby would have Down syndrome. When she gave birth to a little girl on April 23, 2003, she and her husband Michael named her Faith.

Of course there were emotional ups and downs along the way, as when Faith had to be hospitalized twice at two months of age because of an extremely high fever. The doctors thought she had an infection in her heart and were going to give her antiobiotics intravenously for three weeks, until the second blood

See 'Faith,' page 10

#### **Inside This Issue**

Legislative Update2
New Board Members Elected . 2
From the CEO 3
Consumer Advisory Team 4
Safety Corner5
Special Olympics torch run 5
Comfort Connection Update 6
Family Support Resources 6
Respite Voucher Q&A7
Down/Alzheimer's Support 7
West Nile Virus Q&A8
CalOPTIMA Update 9
Planning Ahead9
Important Things to Know 11

#### Don't Miss Out - Make Your Spotlight Awards Reservation Today

he day is fast approaching and will be here before we know it. That day is Friday, September 10, and the occasion is the eighth annual Spotlight Awards. The festivities will begin at 6 p.m. and last until midnight at the Irvine Marriott Hotel. Join the celebration and enjoy a delicious dinner, music, a basket raffle to win great prizes, dancing, and of course, the awards presentation. Awards will be given to as many as 14 people or organizations who serve as role models in providing

services, volunteering, or advocating for people with developmental disabilities.

This year we are happy to welcome back as master of ceremonies John Moschitta, Jr., the voice of *Hollywood Squares* on CBS and the new celebrity TV game show *Balderdash*, which will start airing on the PAX network in August.

Invitations have been mailed, so send back the response card and reserve your spot! Admission is \$40 if reservation is made by August 20

and \$45 after that date. If you haven't received your invitation, call Jacqui Kerze at (714) 796-5299 to request one. We hope to see you on September 10!



John Moschitta, Jr. delighted the audience with his warmth, humor and fasttalking skills as emcee at the 2001 Spotlight Awards.

#### **RCOC Legislative Update**

#### Introducing RCOC's New Legislative Committee Chairperson

By Tresa Oliveri, RCOC Board of Directors

aren Chen has taken advantage of an exciting opportunity to intern in Washington, D.C. for the summer, and



I've replaced her as chair of the Legislative Committee. I'm Tresa Oliveri, and I've been on the board of directors for two years. I have two sons, Robert and Bryan, ages 16 and 14. Bryan was diagnosed with Pervasive Developmental Disorder at age 2½ while we were living in New York. We moved to California about a year later and Bryan became a consumer at Regional Center due to his developmental delays.

#### **Legislative Committee Activities**

During my involvement with the Legislative Committee, I've traveled

to Sacramento to keep our legislators informed about not only our local issues, but also about keeping the regional center system strong and solvent. I've also addressed a Budget sub-committee related to parental copayments, Purchase of Service Standards, as well as other issues.

#### **State Budget**

As of this writing, the budget negotiations were still underway. Our best guess at the time *Dialogue* went to print was that the budgets of the regional centers would have reductions on both the purchase of service and operations (administrative overhead) sides, but the purchase of services reduction would be less of a challenge for RCOC in the coming year than the operations cut.

#### **Purchase of Service Standards**

Also at the time this went to print, the Legislature had removed Purchase of Service Standards from the budget discussion, but until the final package was presented to the Governor and the budget was signed, it could not be assumed that they were gone from the conversation. By the time you read this, hopefully the

matter will have been settled. This Regional Center has not opposed the formation of standards in principle, but is committed to making sure the standards that are adopted bring equity to the system while maintaining the individuality of services that are the hallmark of the Lanterman Act.

#### **Legislation Update**

As a point of information, last year Assemblymember Patricia Bates introduced Assembly Bill 1393 in an effort to give Regional Centers the ability to more carefully consider applications for vendorization. While we still believe in its original intent, due to other considerations, the bill was amended significantly, and it now addresses another issue entirely. We thank Assemblymember Bates for her efforts on behalf of the Regional Center system.

Please visit our Web site at <a href="https://www.rcocdd.com">www.rcocdd.com</a> for late breaking news about the budget, as well as other information. I look forward to bringing you news in the future about how we can all be involved to support the Regional Center.

#### RCOC Welcomes New Members to Its Board of Directors

guyen Luu-Trong, M.D. and Lore Flavell were elected to the Regional Center Board in May and will serve until May of 2007. Joan McKinney was elected for fiscal year 2004-05 as the new Vendor Advisory Committee representative to the RCOC Board.

**Dr. Luu-Trong** is medical director of CHOC (Children's Hospital of Orange County) Health Alliance, a network of 700 primary care physicians and specialists. He is the management representative to the



CHOC board of directors and the advisory board of CHOC Health Alliance. He is a member of the CalOptima Pharmacy and

Therapeutics Committee. He also serves as an advisor to Physicians with Heart, an organization that sends medication and medical supplies to developing countries. Nguyen and his wife have two sons, one of whom receives Early Start

services through RCOC. He said he appreciates the services RCOC provides and wishes to show his gratitude with his service on the board of directors.

Lore Flavell is a high school English teacher. She and her husband have two sons, one of whom receives RCOC services. She gives



See 'Board,' next page

#### **CEO's Corner**

#### Streamlining Bureacracy Opens Door of Opportunity

By Bill Bowman, Chief Executive Officer

t the Regional Center, a lot of work on behalf of people with disabilities happens "behind the scenes."



Sometimes those efforts are so significant that they warrant being brought to light. One such case is known as the "Habilitation transfer," which occurred July 1. On that date the funding and responsibility for habilitation services moved from the state Department of Rehabilitation to the Department of Developmental Services (DDS). The Habilitation Services Program provides both sheltered workshop and supported employment services to about 2,500 adults in Orange County who have developmental disabilities. Prior to July 1, eligible people had been referred to the program by RCOC, but the services were administered and funded by the Department of Rehabilitation. The transfer of responsibility was written into the fiscal year 2003-04 Budget Bill in order to save the state millions of dollars in administrative costs.

That conversion presented a considerable administrative challenge for both regional centers and habilitation service providers. The providers went through the process to become official regional center vendors. RCOC's accounting system had to be modified to accommodate new service codes and ensure that these "new" service providers would get paid. The records for the 2,500 people receiving habilitation services had to be individually entered into RCOC's

computer system. This labor-intensive process was accomplished without any additional administrative funding to the regional centers.

The result of the diligent efforts of the many people involved resulted in a seamless transfer of the program on July 1. I want to thank the habilitation service providers who stepped forward and worked with us to accomplish this formidable task smoothly and on time. Their cooperation in the process prevented interruptions in service and inconvenience for the people who participate in the habilitation program.

The transfer of responsibility for Habilitation services to the regional centers will save the state millions of dollars and may, in time, allow more creative employment options for people with disabilities.

Another positive element of this changeover is the doorway it could open for creativity in the area of supported employment. Having community-based employment services be managed on the local level makes it easier to do new and different things. I anticipate that service providers will eventually gain additional flexibility in how they provide services in exchange for outcomebased performance. That could enhance employment benefits and potential for people with developmental disabilities. We at the Regional Center welcome the opportunity this change may give us to develop more flexible and creative employment options for the people we serve, leading to their increased independence and integration in the community.

#### **Board** (from page 2)

lectures on autism to college education students and facilitates a high school internship program in which students spend 150 hours working with young children with autism using discrete trial training techniques. In three years, the program has grown from one student working with Lore's son to 19 interns this year. Several students have chosen career paths related to their internship experience. Lore looks forward to using her background as an educator and parent to represent the best interests of all people with disabilities on RCOC's board.

Joan McKinney has worked in the rehabilitation field for 25 years and currently serves as the executive director of California Elwyn, which provides a variety of vocational programs to people with developmental disabilities in Orange and Los Angeles counties.



Joan has a bachelor's degree in social work and a master's in rehabilitation administration. Joan is active in a variety of organizations that work to improve services for people with disabilities as well as entities that assist non-profit organizations with business issues. As Vendor Advisory Committee chair, Joan looks forward to bringing service providers' perspectives and issues before the RCOC board.

# R.A.D.D. Review

# Consumer Advisory Team (CAT) Update Report On National Self-Advocacy Conference & More!

By Michael Bailey, Chairman

I and about 25 other CAT members and RCOC consumers attended the



National Self-Advocacy Conference at the Anaheim
Marriott Hotel from May 27
– 30. It was a great conference attended by about 1,500 people from across the country and even other countries.

#### **Keynote Speaker**

CAT member Sam Durbin was the keynote speaker. Sam spoke about how important it is for all of us to be able to help and support each other. Sam also talked about the importance of making dreams a reality. Before Sam's speech, the CAT members performed a song called "Unconditional Love" to set the tone for Sam's presentation.

#### **Good Information**

I found out a lot of new stuff at the conference. For instance, the state of Vermont closed all sheltered workshops in 2002. Now everyone with a developmental disability who wants to work has supported employment in the community. If a person can't work in the community, he or she can do volunteer work like stuffing envelopes at a job site with close supervision.

New Mexico is working on a program to give people with developmental disabilities a card that they can use to pay for medical and dental care and transportation. It's kind of like an insurance card. Colorado is also working on getting the same program.

#### **CAT Meeting**

At the June CAT meeting, Stu Haskin and his staff from Project Get Safe provided training on self-defense and relationships.

#### **Fund Raiser**

The CAT team is now selling sponsor certificates to raise funds for the Supported Life Conference in October.

Donors can buy \$5, \$10 or \$20 sponsor certificates. After the conference, CAT members will host a dinner to thank people who donated \$20 or more.

#### **You Are Invited**

All consumers are welcome to come to Consumer Advisory Team meetings. 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. Support staff are also welcome. Transportation is not provided by RCOC. Please call Betty Bath at (714) 796-5263 ahead of time to let her know you will be there.

The Consumer Advisory Team (CAT) is a group of consumers that meets once a month. The group discusses issues that are important to RCOC consumers, like advocacy and independence. The CAT chairman advises the RCOC board of directors about the group's concerns.

#### Safety Stu's Corner

#### **Swimming Safety**

Hello Safety Friends,

WHEW! It is getting so hot inside the **GET SAFE**<sup>TM</sup> headquarters. Too bad we don't have any air conditioning. I guess that means only one thing. Time to hit the water and cool down. Surfing! Water skiing! *Swimming*!

Yes indeed. All the **GET SAFE**<sup>TM</sup> instructors are going to be at the beach and pools this summer, so the staff hopes to see you out there too. We also hope that we see you being safe, like we are, when you are out in the water.

Personal safety means being aware of your surroundings. It is about always looking around, spotting trouble and avoiding it when you see it. The same thing is true when near or in the water. You should always know how deep the water is,

look for objects in the water, and watch

out for strong currents! Here are some



safety tips to swim and live safely by:

**√ Buddy System** – Always take someone with you when you go swimming. Be a good buddy – if you see someone else who needs help, get a lifeguard or call 911.

✓ Water – Drink plenty of water instead of soda or coffee. The sun dehydrates you.
 ✓ Sunscreen – Wear plenty of sunscreen to avoid getting sunburned.

√ Foot Protection – Wear something on your feet so you will not be cut by broken glass or burned by the hot sand.

√ **Lifeguards** – Make sure you keep an eye on the lifeguards. They will help you if you get into trouble. If you can't see them, they probably can't see you. Remember, lifeguards are either sitting near the pool or in the towers at the beach.

√ **Swimming** – If you are not a great swimmer, stay where you can still touch the ground. Also, wearing a life jacket is a terrific way to keep you floating!

We at **GET SAFE**<sup>TM</sup> are looking forward to seeing you at the next training. If your friends have not had a chance to yell **BACKOFF**<sup>TM</sup>, be 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



Lisa Plahy and Randy Carroll held a banner as Orange County ARC workers with developmental disabilities lined Harbor Boulevard and Carl Karcher Way in Anaheim on June 4. They were cheering on the Anaheim Police officers participating in the Southern California Law Enforcement Torch Run® that raises money for Special Olympics.



#### **News From Comfort Connection**



# Supporting, Empowering and Educating Parents of Children With Autism

Te have exciting news for parents of children with autism! Comfort Connection Family Resource Center has been approved for a generous grant from the state Department of Developmental Services to fund a training program for parents of young children with autism. Supporting, Empowering, Educating Parents of Autistic Children (SEE PAC) is a 10-week training series that was conducted twice before receiving grant funding. The grant will allow the FRC to put together training manuals, translate the materials into Spanish, recruit and train a Spanish-speaking instructor, and videotape the training sessions to provide for wider dissemination of the content. A minimum of three 10-week training courses will be scheduled in the grant year. The training was developed through an informal partnership of staff from Comfort Connection, RCOC, Orange County Health Care Agency, For OC Kids, and Assessment and Treatment Services for Children.

The SEE PAC curriculum encompasses such issues as:

- ♦ Understanding the diagnosis of autism
- ♦ Increasing parent comfort level with their role
- ♦ Becoming informed about various therapy options
- ♦ Understanding your child's behavior
- ◆ Developing useful coping strategies

- ♦ Understanding the service delivery system
- ♦ Building collaborative relationships with service agencies
- ♦ Planning for transitions
- ◆ Taking care of yourself
- ◆ Accessing resources for ongoing support



The grant stipulates that the primary focus of the training will be parents of children under age three, and those parents will receive priority in registration. Nevertheless, the content is not age-specific and could be helpful for parents of children age 8 or 18, but particularly helpful to those with a recent diagnosis of autism.

The videotaped series will allow families who cannot attend the training sessions to check out the videos from the FRC library. The videotapes may also be shared with support groups, Special Education Local Plan Areas, service providers, and others who wish to proctor independent training sessions.

If you are interested in registering for the next training series or would like additional information, please contact the Family Resource Center at (714) 558-5400.

#### Family Support Resources

Referenced in "Consumer Spotlight" article on page 10. Here is a list of resources specifically designed to assist parents with the challenges of raising a child with special needs.

- Comfort Connection Family Resource Center, (714) 558-5400, 801 Civic Center Drive West, Santa Ana (located adjacent to Regional Center's lobby) staffed by parents of children with special needs who have a wealth of knowledge about available resources. There's also a library of resource materials.
- Parent Connection trained volunteer parents of children with special needs provide moral support and share resources over the phone with parents who request the service, provided at no charge. Call Naomi Hall at Comfort Connection at (714) 558-5400 or your RCOC service coordinator for a referral.
- Support Groups Request the A to Z support group list from Comfort Connection to find a group that relates to your experience.
- Individual or family counseling Ask your RCOC service coordinator if you need a referral. These services are usually funded by medical insurance, CalOptima (Medi-Cal if eligible) or private pay.
- Dr. Nancy McGovern at RCOC can provide individual consultation followed by referrals to other resources, if needed. Contact Nancy at (714) 796-5396.

### Respite Voucher Recipients – This is for You

nose of you who are parents vendored with Regional Center to hire your own respite caregivers recently received a letter from RCOC regarding new requirements to the program. Here is a list of questions and answers that may have occurred to you.

# Why are changes being made to the "Parent-Vendored Respite" program?

The Department of Developmental Services has proposed revisions to the California Code of Regulations (Title 17, Division 2) regarding voucher respite services. Those laws are expected to be approved and will be effective as of July 1, 2004. The changes, which require stricter record-keeping on the part of participating parents, may allow the state to obtain federal reimbursement for "parent-vouchered" respite services.

### Do these changes also apply to nursing respite?

Yes, if the respite nurse is hired directly by the parent or other family member.

Do these new requirements apply to other vouchered services, such as day care or transportation? Yes they apply to all youchered

Yes, they apply to all vouchered services, where the family requests

reimbursement from Regional Center for a service provided to their child.

#### If I can't or don't want to comply with these new requirements, is there any other way I can get respite services for my child?

Yes. You can use your vouchered respite hours for camping opportunities for your child. You may also request that respite services be provided by an agency that contracts with the Regional Center.

If you have additional questions, please feel free to contact your RCOC service coordinator to discuss.

#### Down Syndrome and Alzheimer's Disease Caregiver Support Group Available

specialized support group has been formed to meet the unique needs of family members and caregivers of people who have both Down syndrome and Alzheimer's disease. The Alzheimer's Association of Orange County, Dr. Ira Lott, Down syndrome project director at the University of California, Irvine, and Regional Center of Orange County worked together on this endeavor. The educational support group meets monthly and is designed specifically for anyone who loves and/or cares for someone who is diagnosed with both Down syndrome and Alzheimer's disease.

This group allows those involved to meet others with similar circumstances, exchange information, share methods of coping, and develop new relationships at a time of difficulty. Caregivers are encouraged to bring issues for discussion. The meetings will occasionally include presentations by medical professionals on topics of interest to group members.

The meetings are facilitated

by Carol Burgener of the Alzheimer's Association of Orange County, Eric Doran, M.S., project manager of the Down Syndrome Program, Institute for Brain Aging and Dementia, University of California, Irvine, and Jacqui Kerze, family support coordinator at RCOC. Meetings are held on the last Friday of each month from 3-5 p.m. at the UCI Medical Center in Orange, Neuropsychiatric Center (Building 3), Conference Room 101. For more information or if you plan to attend, please call Eric Doran at (714) 456-



Susan Goodman, front right: 1954-2004, surrounded by her parents and brother, (left to right) Ruth, Roy and Les Goodman. Susan's parents have been participating in the new support group.

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#### Protect Your Family and Consumers in Your Care from West Nile Virus

# What is West Nile Virus and why is it important that I know about it?

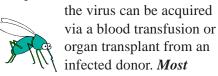
West Nile Virus is a mosquito-

borne disease that is common in Africa, west Asia and the Middle East. It was first detected in the United States in New York in 1999. Since then, West Nile Virus has spread to 46 states, including California

As of late May this year, West Nile Virus has been detected in birds and mosquitoes in southern California. In 2003, three locally-acquired human West Nile Virus cases were confirmed in Los Angeles, Imperial and Riverside counties, and the virus was detected in dead birds, mosquitoes, sentinel chickens and a horse in six southern California counties. Nationwide, there were almost 10,000 human cases of West Nile Virus, including 262 deaths.

# How do people contract West Nile Virus and how is it treated?

Individuals usually get West Nile Virus from the bite of an infected mosquito. There is also evidence that



people who are bitten by a mosquito with West Nile Virus will not get sick. People who do become ill may experience mild to moderate flu-like symptoms like fever, headache and body aches. It is estimated that less than one percent of the people infected with West Nile Virus become severely ill and require hospitalization. The elderly and immune compromised are particularly suscep-

tible to illness caused by this virus.

Currently there is no specific treatment for West Nile Virus infection. Since it is a virus, it does not respond to antibiotics. In severe cases, hospitalization and supportive care is important. If you have symptoms of West Nile Virus, call your doctor.

### How can people avoid getting West NileVirus?

You can reduce your risk of illness from West Nile Virus by doing the following:

√ Avoid spending time outside at dawn and dusk when mosquitoes are active. They are especially active for two hours after sunset. When outdoors, wear long pants, long-sleeved shirts and other protective clothing.

 $\sqrt{}$  Apply insect repellent containing DEET according to label instructions.

 $\sqrt{}$  Make sure that doors and windows have tight fitting screens. Repair or replace screens that have tears or holes.

 $\sqrt{}$  Eliminate all sources of standing water that can support mosquito breeding.

## How can the spread of West Nile Virus be stopped?

California has a long history of conducting surveillance for mosquito-borne viruses and has taken active steps to ensure early detection of West Nile Virus. Due to ongoing collaboration among more than 70 local mosquito and vector control agencies and state public agencies, California is well prepared to detect,

monitor and respond to West Nile Virus. These agencies use a variety of scientific techniques and products to control mosquitoes in their earliest stages and play a key role in reducing the risk of West Nile Virus. Also, California has launched a statewide public education effort about personal protection measures and reporting dead birds.

## Is there anything I can do to help?

You are encouraged to assist in the efforts to detect and monitor West Nile Virus by calling the California Department of Health Services' West Nile Virus hotline if you find a crow, raven, magpie, jay or hawk that has

been dead for about a day. Birds play an important role in maintaining and spreading

this virus. Mosquitoes acquire the virus from infected birds, and then transmit the virus to people. Evidence of the virus in dead birds is often the first indication that West



Nile Virus has been introduced into a new region.
The toll-free hotline to report dead

birds is (877) West Nile Virus-BIRD or (877) 968-2473. More information can be found on the Web site at <a href="https://www.westnile.ca.gov">www.westnile.ca.gov</a>.

Information from the California Department of Health Services

#### **News From CalOPTIMA**

#### **Program Changes**

By Chanté White, CalOPTIMA Liaison

Greetings from the CalOptima Desk! Here is an overview of changes implemented in an ongoing effort to improve the quality of



health care services.

Open Enrollment: Starting June 15, 2004, members have a three-month Open Enrollment Period during which they can request a change of their Health Network for any reason. The open enrollment period is from June 15 to September 15 of each year. Every year by April 15, members will receive a letter from CalOptima advising that the open enrollment period is approaching. At the end of the open enrollment period, members will remain with their selected Health Network for the next 12 months. The

12-month period begins October 1 and ends September 30 each year. Members can still change their Primary Care Physician (PCP) every 30 days, as long as the PCP is contracted with their current Health Network.

Pharmacy Home: This program applies to CalOptima Direct members that have been identified as using four or more pharmacies within a two-month period. The members are directed to select one "Pharmacy Home" for all prescription medication needs for a period of 12 months. This reduces any risks of polypharmacy (injury from overmedication and/or drug interactions).

Health Network Changes: United St. Joseph's Mission Network will no longer be affiliated with CalOptima as of July 1; however, there are three new Health Networks!

United Care Medical Network (UCMN): (877) 225-6784

Memorial/Talbert Health Network: (800) 297-6249

Monarch Family Health Care: (888) 656-7523

Medical Supplies: This program applies to CalOptima Direct (COD) members identified as utilizing medical or incontinent supplies. A letter was mailed to those members advising that beginning August 1, 2004, all COD members must use one of the following contracted vendors:

- 1) A-Med Health Care Center: (866) 833-2442
- 2) Caremax Pharmacy: (800) 626-2600
  - 3) Modern Health: (866) 500-3070
- 4) Schrader's Medical Supply: (800) 258-9145
- 5) Shield Healthcare: (800) 372-6205

Members have been advised to call CalOptima, one of the contracted vendors or their doctor if they're using a vendor other than those listed above and/or need assistance with ordering more supplies in a timely manner.

If you have any questions about any of the changes listed above, please call CalOptima Customer Service at (888) 587-8088 or me at (714) 796-5213.

#### **Planning Ahead**

e all know the old adage that the only certain things in life are death and taxes. Sometimes people plan ahead for their own end of life by purchasing burial plots or making funeral arrangements so that their family members won't be burdened by those decisions and costs while in the midst of grieving for their loved one. The same kinds of planning can be done for people with developmental disabilities. Planning ahead can ensure parents and other family members who may pass away first that their relative with a disability will be

properly taken care of when he or she passes away.

Low-cost burial plans are available and can even be purchased by the person with a developmental disability with his or her own money.



Several options may be considered, including a burial insurance plan that allows for monthly payments and

provides services if the person passes away before the plan is paid in full. Consumers can set up a bank account with up to \$1,500 that is specifically designated for a burial account, and their SSI benefits won't be affected as long as the funds are not withdrawn. A burial plan can also be considered if a consumer receives a lump sum payment or inheritance.

If you would like more information about this subject, please contact your RCOC service coordinator to schedule a meeting to discuss the options that may be available.

#### Faith (from page 1)

test came back negative. Despite the initial uncertainty of baby Faith's future, her parents had a deep sense of peace that they attribute to their faith.

Lisa said, "People find this hard to believe, but I've never been angry with God or disappointed because Faith has Down syndrome. The way I see it, it's not a mistake. Faith is who she's supposed to be. There's nothing I could have done to change it. It's just about life. People get all kinds of things [during the course of life]. They get cancer, they get in car accidents. There's no mistake."

Shortly after Lisa came home with her newborn, the Regional Center contacted the family. The hospital had made a referral to RCOC because babies with Down syndrome are considered at high risk for developmental delays.

Lisa said, "To be honest, hooking up with the Regional Center has been the most scary part of all of this. We've had a great experience [with Regional Center] and everyone's been really nice, but you just get home with this brand new baby, and you're happy, and they want to start therapy right away. When they send out all the paperwork, it's very overwhelming. You don't realize all the great things they have for your child. As parents, we have a tendency to make it all about us when it's about the child."

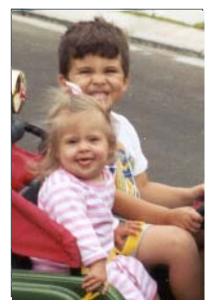
Initially Faith attended an early intervention program for infants. The babies rotated to different stations that involved music, experiencing various textures, blowing bubbles, speech therapy, and cognitive stimulation, where the therapist hides toys and has the baby try to find them. Currently Faith attends the Intervention Center for Early Childhood two days a week where she receives physical therapy.

Faith, shown here with her grandma, Diane Carpenter and her mother Lisa, goes everywhere with her family, including church, swim lessons and the park. She's even been to New York.

Lisa commented, "I am not someone who pushes for a lot of therapy. It helps them do a lot, but sometimes people think the therapy is a fix-all. For a child, I think the best thing is connecting with their parents. When your parents believe in you, everything just seems to go so much smoother."

Pam Jones has been
Faith's RCOC service coordinator for more than a year. She said of Faith's parents, "They exemplify what I encourage all my families to do: expose their children to anything and everything that they would any other child so they can grow to their potential. It's important not to magnify the child's disability. They are human and they do have potential."

Of course, disabilities that children have vary in severity and the challenges they present. Factors such as fatigue, family dynamics, and emotional support enter into each person's ability to manage the feel-



Faith loves her big brother Matthew and tries to do everything he does.

ings and difficulties they experience. It's important to seek assistance when feeling overwhelmed. (See the list of Family Support Resources on page 6.)

Lisa doesn't minimize what other people go through. When Faith was first born, Lisa was uncertain how long she might live, but she determined, "Whatever short time you have with a child, you can still enjoy her. Her grandparents can still love her."

Faith has a big brother – four-and-a-half-year-old Matthew. He loves her, and she adores him and tries to do everything he does. Having another child first made it easier for Lisa to know what to expect developmentally with Faith. She said, "I try things with her at the same age that I did with him."

One of Faith's doctors tried to tell Lisa what limitations to expect in Faith's development because of her disability, and Lisa told him, "I have dreams for Faith, just like I dream that my son will be president. They're just dreams." In other words, those fantasies don't have to come true, but it's still important to imagine the possibilities for your children. Lisa said, "We have big dreams and little dreams for both of our children.

continued next page

### **Important Things to Know...**

Art Exhibit ... through August 7, Viento Y Agua Gallery at 4007 E. 4<sup>th</sup> Street, Long Beach, presents "Was, Is, Will Be," a show featuring artwork from Arts and Services for the Disabled, Elan and First Street Galleries. Call for gallery hours: (562) 434-1182.

A Day at the Ballpark is August 15 for Down Syndrome Association of Orange County (DSAOC) at Angel Stadium to see the Angels challenge the Detroit Tigers. DSAOC has reserved a section of seats for the game, and the Angels are donating all profits from those seats to DSAOC. The group will meet under the Big A for a no-host tailgate party before the game, which starts at 1:05 p.m. On that day, a child with Down syndrome will serve as honorary bat boy or girl. Tickets are \$10 if purchased through DSAOC. Call (714) 547-2895 for more information.

The first annual WALK NOW Orange County charity event to benefit Cure Autism Now will take place at the Arrowhead Pond on Sunday, August 29. The event will include a 5K fund raising walk and a resource fair. The resource fair will

feature helpful family resources and fun activities for children of all ages. For more information, call (323) 549-0500 or toll-free at (888) 8AUTISM or go to <a href="https://www.walknow.org">www.walknow.org</a>.

Accessible park ... the City of Irvine has a new public park that includes a wheelchair-accessible play area. Bill Barber Park is located at 4 Civic Center Plaza, adjacent to the Irvine Civic Center at the corner of Barranca Parkway and Harvard. Three large play structures connected together are accessible by ramps. The play area features playhouses, swings, monkey bars, rock climbing walls, and slides. A sandy area includes a water spout that allows children to make sand castles. The park also contains picnic shelters and barbecues. For more information, call (949) 724-6759 or (949) 337-5962.

The Social Security Administration (SSA) offers a Disability Starter Kit on its Web site as a tool to help individuals prepare to participate in a disability interview or complete an online application for benefits. Kits are available for adults and children. Each Disability Starter Kit contains a fact sheet that answers questions about applying for disability benefits, a checklist of documents and information SSA will request during the application process, and a worksheet to help applicants gather and organize the information they will need. Disability Starter Kits are available at www.ssa.gov/disability/disability\_starter\_kits.htm.

Community Action Partnership of Orange County is an organization

that brings together private and public resources to assist low-income families and individuals. The Partnership provides a variety of emergency services as well as programs that assist people to gain knowledge and skills to overcome poverty. The weatherization program assists with making homes more energy efficient, thereby saving on utility costs. The LEAP program focuses on eliminating lead in older homes. Lead poisoning can result from exposure to lead-based paint chips and may cause learning and behavior problems as well as hearing and nervous system damage. For more information, call (714) 839-6199 or toll-free at (800) 660-4232 or look at the Web site at www.capoc.org.

#### Faith (continued)

But if my husband and I are still at the toddler pool with Faith when we're in our 70's because that's what she's capable of, that's where we'll be. Faith is here for a reason and she will touch people's hearts."

Lisa's mother, Diane Carpenter, added, "Faith brings us a lot of joy. She's extremely happy all the time. We just feel she's going to be able to do a lot in her life. You just have to see with your heart. If you can't see

with your heart, you can't see."

Lisa believes that it's important not to impose limitations on people. Nobody knows what someone else is capable of doing or being. She and Michael have a 25-year-old niece with autism who works as a missionary at an orphanage in Mozambique.

Lisa said, "You can't put boundaries on people. I'm happy with my little girl. She's a gift and I thank God for her everyday."



Faith has taken swimming lessons since she was 12 months old and can now hold her breath under water for 10 seconds.

Regional Center of Orange County is a nonprofit, private agency that contracts with the California Department of Developmental Services to coordinate services for approximately 13,500 children and adults with developmental disabilities in Orange County.

Dialogue is published four times per year by the Regional Center of Orange County for people with developmental disabilities, their families, service providers, and members of the community.

Dialogue can be read online at RCOC's Web site: www.rcocdd.com.

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Meetings start at 6:00 p.m. and are held in the Regional Center Board Room at 801 Civic Center Drive West, Santa Ana. The public is welcome.

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