



HARBOR HAPPENINGS

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A UNIQUE COLLABORATION GIVES KIDS A GREAT START

Building relationships and forging partnerships are the hallmarks of what we do at Harbor Regional Center. And our collaborations often result in creative new programs to better serve our community.

Take LEAP (the Long Beach Early Autism Program). In October 2004, this innovative program opened on the campus of Bixby Elementary School in Long Beach. A joint venture between Harbor Regional Center and the Long Beach Unified School District (LBUSD) – LEAP offers children ages two-three with autism an alternative to in-home or center-based programs. LEAP is a comprehensive approach to development of communication skills, behavioral training, and sensory and fine motor development – all key issues for children with autism.

LEAP was born from an ongoing collaboration between Harbor Regional Center and LBUSD Assistant Superintendent Dr. Judy Elliott. “The LEAP program is incredible.

It was two years of collaborative planning before HRC and LBUSD pulled it off – and we are ecstatic!” she enthuses. “It is state-of-the-art early intervention for newly-diagnosed children with autism. The monthly parent support

meetings have been attended 100%. Students are making progress and parents are happy.”

LEAP incorporates play, discrete trial training, and independent work skills to give children with autism a smooth transition from HRC’s early intervention services program into the school district. It also uses music extensively, with songs

woven into many of the children’s activities. Occupational Therapy is provided at the school’s clinic twice a week, while speech activities are integrated throughout the classroom.

“The LEAP Program in Long Beach is a beautiful collaboration of the regional center and the school district in addressing the needs of 2-3 year old children with autism.”

*Dr. Nicole Tartaglia,
MIND Institute at UC Davis Medical Center.*

HRC contracts with LBUSD and Autism Comprehensive Educational Services (ACES) to provide this program for our toddlers. Jahn Rokicki, Director of Children and Family Services, meets with all the agencies involved once a month. “We are continually trying to improve the program and to make sure that we are progressing on target,” he explains.

“We have a really close relationship with Harbor Regional Center. Everybody here is just so enthusiastic and we all really believe in what we’re doing,” adds program teacher Robin Weinberg.

She also notes the strong involvement of parents as a key strength of LEAP. Parents come together monthly to learn about topics such as sleep issues, communication, or behavior intervention techniques. The program offers training classes and home visits. Parents or other caregivers can also come to the site and observe classes that may help with a challenge at home.



Emily Walsh enjoys painting as part of the LEAP program.

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"It's state-of-the-art early intervention for newly-diagnosed children with autism."

Dr. Judy Elliott, LBUSD Assistant Superintendent



(top) Benjamin Scott works with OT Therapist Assistant Julie Harb.

(below) Teacher Assistant Yajair Adams helps Kai Johnston with his OT.

A Unique Collaboration Gives Kids A Great Start (continued from page 1)

Cindy Walsh's granddaughter, Emily, began the LEAP program last November. She is now starting to interact with her peers both in school and at home. She's also using language more and is showing imaginative play skills. According to Cindy, the parent training was extremely helpful, and with the skills she has learned, Cindy is able to work with Emily at home. Now that Emily is transitioning to the school district, it is an easier process because she has already been in a classroom situation.

The LEAP program is unique because it offers socialization opportunities that might not be available in an in-home or community-based program. The child is also in a more natural environment for learning. "Families seem to like the program a lot so we are currently working with other school districts to implement a similar model elsewhere," notes Jahn.

Bixby Elementary School Principal Donna McKeehan explains that the

program's strength lies in the collaboration of the partners, the quality of the teacher and the involvement of parents. "Everybody's focused on the children and their success," she says.

She also is pleased to note that Bixby Elementary will be able to offer a Pre-K Autism class on their campus in the fall, so when youngsters transition from LEAP, they won't have to leave the familiar Bixby site.

According to Dr. Nicole Tartaglia, of the M.I.N.D. Institute at UC Davis Medical Center who observed the LEAP program as part of the Early Start audit team, "The LEAP program in Long Beach is a beautiful collaboration of the regional center and the school district in addressing the needs of 2-3 year old children with autism. The teachers and therapists are all very dedicated and enthusiastic with expertise in the field. The classroom and the schedule are designed to address the various needs of autistic children, with inclusion of research-proven interventions. Programs like the LEAP program will make for a much smoother transition into the school system at 3 years of age and will help make a difference in the outcomes of young children with autism." ■

ADHD GENETIC STUDY NEEDS PARTICIPANTS

The University of California, Los Angeles (UCLA) Neuropsychiatric Institute is involved in a study exploring the genetic markers underlying ADHD. Researchers are looking for families that have at least two children, between the ages of 5 and 18, affected with ADHD.

Families that participate will receive – at no cost – psychiatric evaluations and cognitive assessments. Each family member will also be asked to complete a set of questionnaires and donate a small sample of blood. The identities of all those who participate will remain strictly confidential. The time commitment for this study averages five hours per person, and each individual will receive \$30 compensation for parking and travel expenses.

For more information, call (310) 825-8660 or visit the Web site at www.adhd.ucla.edu

HARBOR REGIONAL CENTER TEAMS MEET WITH LEGISLATORS

Nancy Spiegel, Director of Information and Development

Ever since Governor Schwarzenegger released his proposed 2005-06 budget in January, our state legislators have been busy reviewing and evaluating his proposals and hearing testimony from the community. To ensure that our community's voices are heard, representatives of the Harbor Regional Center community, including parents, clients, and service providers, have visited our local legislators in their offices to discuss issues which are of importance to our clients and families.

The Governor's Budget for 2005-2006 for regional centers is proposed to increase by nearly 6 percent, due to the expectation that regional centers are expected to serve more than 200,000 clients and families by next year.

The Governor's proposed budget also includes numerous "**cost containment measures**," many of which are continued from the current budget year. Several of these strategies have already been supported by the HRC Board of Trustees and have been in practice at Harbor Regional Center for some time. For example, we have continued to deliver services in a manner which we believe is most cost-effective and consistent with existing laws and regulations, and that meet the needs of the individual client and family. Also consistent with the Governor's recommendations, Harbor Regional Center continues to take into account a family's responsibility for providing similar services to a minor child without disabilities, when determining whether a service should be purchased by the regional center, and to provide some services, such as behavioral services, social recreation, and language therapy services, using a group modality when this meets the needs of the client and family.

However we do have serious concerns about some of the proposed cost containment measures which, if continued, will seriously compromise the ability of regional centers and community service providers to meet the needs of our clients and families.

- The Governor proposes continuation of rate freezes for service providers. These providers – particularly residential services and day activity services for adults – have withstood many years of rate freezes, and are having severe difficulties. Some in our area have come dangerously close to closing for fiscal reasons.
- The Governor plans to continue to prohibit the use of service development grants, to support development of new services. Continued resource development is needed to meet the needs of our clients and families, including emerging/expanding populations such as individuals with autism, young adults leaving the education system, etc.
- The Governor has proposed the elimination of pass-through of SSI/SSP Cost Of Living Adjustments (COLA) to licensed home service providers. This action, on top of multiple years of rate freezes, places even further strain on their ability to continue to operate and maintain service quality.

The Governor's Administration also plans to continue the Family Cost Participation Program which began implementation in January of 2005

While there are no new unallocated reductions to Regional Centers' Purchase of Services Budget proposed this year, those which were enacted in previous fiscal years will continue. Over the last two budget years, Regional Centers' Operations Budget has been cut by \$40 million, while at the same time we have been given several new mandates to carry out. Regional centers have advised the State that if these cuts are not fully restored, they will impair our ability



Senator Alan Lowenthal (above) and HRC's Paula Fiebert with parents and Board members Robert Irlen and Robert Bethel (below) catch up on the latest issues for our community.

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Harbor Regional Center Teams Meet with Legislators (continued from page 3)

to meet our responsibilities, and therefore will hurt our clients and families. In his May Revision to the proposed 2005-06 Budget, the Governor has included approximately \$20 million to assist regional centers to maintain caseload ratios, be responsive to clients' and families' needs, successfully implement new programs, and continue to meet federal requirements (thereby helping to defray costs to California and promote long-term sustainability of funding for the developmental disabilities system).

The Governor's Budget also proposes freezes or reductions of rates paid for Supplemental Security Income (SSI/SSP) and for In Home Supportive Services (IHSS) workers' wages. As the cost of living in safe and health environments continues to rise, these cuts threaten the ability of individuals with disabilities to live independently in the community.

The proposed budget allocations are now being reviewed by the legislature, and may be modified prior to the passing of a final budget. As our legislators continue to work on the budget and legislation, they will try to achieve the difficult task of closing the budget shortfall. Recent reports that the state economy is beginning to show improvement may help to a certain degree, and this may ultimately have a favorable impact upon regional centers and community service providers. We will continue to monitor the budget process closely and to maintain communication with our legislators and community as changes unfold.

To stay informed, don't forget to check the HRC Web site at www.HarborRC.org, or sign up for the HRC e-mail network by sending your e-mail address and a request to be added to the network list to Nancy.Spiegel@HarborRC.org. And if you would like to express your views to your legislative representatives, you can find a list of our representatives on our Web site as well (see Budget Alert). ■

HRC OFFERS NEW VIDEO ON LIVING WELL INTO THE FUTURE

There are many questions, but also many options – and as in all the other transitions families have faced, Harbor Regional Center is here to help.

To support parents, siblings and families of older adults with developmental disabilities who are facing these challenging issues, Harbor Regional Center has produced *Living Well into the Future*. It features interviews and stories of mature clients and family members living in a variety of situations.

The video offers support, information and examples of all the options available to the older adult community.

Harbor Regional Center counselors from our Older Adult team now have this tool at their disposal, to share with families. Counselors can bring copies of the video along with them to older adult clients' annual service planning meetings, and leave a copy with the family to facilitate further family discussion and future planning. The video is also available on loan from the HRC Resource Center. ■



Getting older takes us all by surprise. And for older adults with developmental disabilities and their families this transition may be the most challenging and unsettling of all, as so much in life alters.

Families who have cared for their child since before there was a service system must face the fact that they, too are aging and may soon be unable to care for their family member.

MEET OUR BOARD MEMBERS: George Bird

George Bird has made volunteering a way of life, from coaching little league and soccer teams to becoming a scout leader to being active in the local and county bar associations. Even so, he wanted to do more. In 1999, two events occurred that would present George with that opportunity: a close friend's son was diagnosed with autism, and he had a chance meeting on an elevator with HRC Executive Director Pat Del Monico. Both led him to Harbor Regional Center, where he's currently serving as Vice-President of our Board of Trustees.

As a board member, George feels he's found a place where he can make a difference. For example, when he became aware of the need for affordable housing for our adult clients, he became a founding member of the Home Ownership for Personal Empowerment (HOPE) Board of Directors and has been active with HOPE ever since. During the holidays, his law firm "adopts" families who have economic needs.

George feels that his experiences at HRC have changed him for the better, and given him the chance to positively influence his two sons. "My kids are now familiar with persons who are diagnosed with a disability and they will educate their peers," he explains. "My son, Cameron, has a friend at school with a disability that is always included in his school group and activities."

George has worked both as a public defender and in corporate law. He met his wife, Karen, while they were both public defenders. Today, George and



Karen practice criminal law in Torrance. He is also a certified Criminal Law Specialist and has appeared as a regular legal commentator on KNBC, KCAL, CNBC and CNN. Recently, George was named "Criminal Defense Attorney of the Year" by the Los Angeles County Bar Association.

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Despite his hectic volunteer and professional schedule, George's family remains his top priority. One of his favorite outings is taking his sons for a spin in his beloved 66 classic Mustang convertible.

The ability to touch the lives of others in a positive way is the most rewarding part of his work with HRC, and George intends to continue making a difference through his commitment to Harbor Regional Center and the clients and families we serve. ■

HRC EARLY BIRDS CATCH THE SPIRIT At Reach for the Stars 5K Walk, Run, Wheel, and Woof

Getting up early on a Sunday morning isn't easy. But on Sunday April 3rd, thirty HRC volunteers, including staff, board, clients, service providers, friends, family members and pets, were on the starting

line bright and extra early, day-light savings time, at the Achievable Foundation's 4th Annual "Reach for the Stars" 5K Walk, Run, Wheel and Woof in Century City. Harbor Regional Center joined with Westside Regional

Center, Lanterman Regional Center, and other agencies raising funds and awareness for developmental disabilities.

Our very enthusiastic group was among more than 2000 participants who came out that day to "Reach For the Stars." Hundreds of people with developmental disabilities were also among the walkers, runners, wheelers, and canine companions along the 5K course. Participants

enjoyed the opportunity to mingle with the celebrities who came out for this event, like film and TV stars Kathy Bates, Connie Stevens, and Antonio Sabato Jr., who served as Master of Ceremonies.

The proceeds of this event will directly help people with developmental disabilities to live fuller, more independent lives. 100% of the funds raised by our HRC team will be contributed to the Harbor Help Fund, for services and supports which we would not otherwise be able to offer the individuals and families that we serve. HRC was well represented by our Executive Director, staff, board, clients and service providers including: Pat & Barbara Del Monico, Rita & Benjamin Eagle, Adriana Grgas, Laura Guzman, Kevin Herink, Melody Hopewell & Frank Marmolejo, Michelle Kim & Russell Chee & Bear, William Martinez, Colleen & Tim Mock, Janeth & Ruth Monge, David Oster, Gail Parker & Scoobie, Cynthia & Vincent Pellerito & family, Elisabeth Poplin, Pha Prum, Elizabeth Ramirez, Robert Romero, Lisette Sandoval, Becky Smitha, Elizabeth Stroh, Maria Isabel Vargas, Schella Vilme, Josselyn Wheeler, Shakoya Williams, Rhiannon Acree of Cambrian Home Care, and Kristine Engels of Life Steps Foundation.

A big thanks to all of you – especially our generous sponsors, and the entire Harbor Regional Center staff – for walking and running, contributing and raising funds, volunteering or otherwise helping to make this event an extraordinary success! ■



Antonio Sabato Jr., of "General Hospital" and "Melrose Place" fame, congratulates HRC Counselor Adriana Grgas.

HARBOR AND LANTERMAN REGIONAL CENTERS HELP CLIENTS GET FIT, NOT FAT!

The California Department of Developmental Services has awarded Harbor and Lanterman Regional Centers a grant of over \$300,000 (out of a total of nearly \$1 million provided statewide to various wellness proposals), for a collaboration, Get Fit, Not Fat. This is an exciting, multi-faceted program to educate adult regional center clients how to maintain a healthy lifestyle that emphasizes exercise and nutrition. Aimed at improving health and reducing the risks of developing chronic health problems, this innovative project will provide education on healthy lifestyles to clients and their service providers in independent & supported living services, day activities, and group homes. Regional center counselors will also receive an orientation so they can help participating clients incorporate fitness-related objectives into their Individual Program Plans.

The program will use education and hands-on instruction in exercise and nutrition; implement regular peer support programs; and offer clients of Harbor and Lanterman Regional Center the opportunity to compete against one another in organized "Get Fit Games." The program will also include development of a cookbook that integrates healthy menus, budget-conscious planning, shopping, and safe food handling and storage practices.

The Get Fit, Not Fat project will start in January 2006, and run the entire year. By its end, clients will have received the information and training they need to develop good exercise and nutrition habits to increase their health and fitness for life.

Adults who are HRC Clients and interested in the Get Fit, Not Fat program should contact your HRC Counselor. ■

PRADER-WILLI HOME FINDS UNPRECEDENTED SUCCESSSES

At close to 300 pounds, Corinne Quimson found it difficult to walk even a few feet without becoming winded. Today, she weighs 154 pounds and feels great. The Carfax Home where Corinne lives specializes in assisting people who are diagnosed with Prader-Willi syndrome and helped her reach her goal.

Prader-Willi syndrome is a very unique and challenging disorder that can cause insatiable appetite, chronic preoccupation with food, and extreme, potentially life-threatening weight gain. Common behavior challenges for individuals with this rare syndrome include stealing food and trash in the attempt to satisfy an uncontrolled need for food. Resources to support individuals with Prader-Willi have also been very rare, but HRC has been fortunate enough to work with the Carfax Home to develop a very specialized and successful residential program. Today, Corinne and the other three HRC adult clients diagnosed with Prader-Willi who share the Carfax home are healthy, active and feeling good. For these individuals, this is an amazing accomplishment!

What is the secret to the Carfax Home's success? Everybody exercises daily by either walking or using videos for aerobic exercise. The staff monitor food intake and plan menus that are primarily high fiber with fruits, vegetables and lean meats. Menus are written out in advance so each client knows what foods, and what size portions, are in their meals.

To deal with the compulsive behaviors associated with Prader-Willi, the program is designed to take extra precautions in



(l-r) Corinne Quimson, Betty Stone and Keith Yuhl prepare a healthful dinner.

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Prader-Willi Home Finds Unprecedented Successes (continued from page 7)

safeguarding food and other temptations, while a behavior plan for each client helps staff to intervene when clients sneak food or have tantrums. Paula Fiebert, Director of Adult Services at Harbor Regional Center, points out that the program has reoriented these individuals so successfully, that they now willingly seek out rewarding activities that do not involve food. "They have begun to internalize their individual behavior programs at a higher level, and this is really remarkable!"

Cerritos College twice a week. Audrey's mother, Lucy, knows how difficult it is for Audrey to maintain her weight. Lucy describes how when Audrey was living at home, she needed to be monitored 24 hours a day or she would raid trash cans, even when out in the community. Since she has been living at the Carfax Home, Audrey has not only lost and maintained her weight, but she no longer raids trash cans and is much better able to resist the temptation to sneak food.

Lucy feels that the best part of the Carfax Home is the support structure. "I really feel comfortable with the staff at the home and I know that Audrey's in good hands," she says. "It is a blessing." ■



(lr) Betty Stone, Audrey Ong and Corinne Quimson enjoy feeding Betty's pet rabbit.

All four clients have had dramatic weight loss. In 2000, Keith Yuhl was at his peak of 238 pounds. Today he is a svelte 145 pounds. He feels that the staff at the home really help him with his weight goals, adding that he feels so much better and lighter.

Audrey Ong was 180 pounds in 2002; today she weighs 118 pounds and attends

Today, the four HRC adult clients diagnosed with Prader-Willi who share the Carfax home are healthy, active, and feeling good. For these individuals, this is an amazing accomplishment.

RECOGNIZING EXTRA EFFORT!

HRC is dedicated to providing **support, information and choices** to our clients and their families. Our staff, from the receptionists to our psychologists, strive to demonstrate our core values through their interactions with you.

You can help us recognize those individuals who have provided you with outstanding care and service. When you see an HRC staff member who is **demonstrating respect by treating people considerately, working collaboratively, looking for ways to be helpful, responding quickly and explaining any delays, listening, sharing information, or any other assistance you found helpful**, simply fill in this form and mail it to: **Office of Information and Development, 21231 Hawthorne Blvd., Torrance, CA 90503 or by e-mail at cheryl.perez@HarborRC.org**

We will make sure that the HRC counselor, support staff, clinical staff, Resource Center staff or other members of the HRC team receive your note along with our special recognition.

Name of person you wish to recognize: _____

Your name: _____

How that person demonstrated outstanding service or fulfillment of our core values: _____

We appreciate your support in helping us acknowledge these outstanding individuals.

YOUNG SIBLINGS FIND SUPPORT, SHARING

Harbor Regional Center has traditionally offered parents of children with disabilities a variety of support groups where they can share experiences and gain emotional support from other parents who share their concerns. These groups often also target adult siblings of people with disabilities, especially those who are caregivers.

In contrast, child siblings of boys and girls with disabilities have had much more limited access to structured settings in which they may express concerns and learn more about the disabilities with which they must cope.

Research has shown that these children share a range of concerns, such as:

- Embarrassment about the sibling's behaviors or appearance that may attract other people's attention, and guilt about being embarrassed.
- Feelings of loss and isolation due to not having the companionship that would be associated with a non-disabled sibling; being neglected by parents whose major focus is on the disabled sibling; and not having peers who understand the experience of having a disabled sibling.
- Increased care-giving demands, particularly on older sisters.
- Over-identification with the sibling, causing them to worry that they share or will develop the sibling's disability.
- Feeling pressure to achieve in academics, athletics, or other areas to compensate for the inability of their disabled sibling to achieve.

And these concerns are rarely addressed directly. Support resources for siblings have been limited, and usually short-term. But this year, Harbor Regional Center has developed a team of 20 specially-trained staff volunteers to be sibling support group facilitators, allowing us to offer many more opportunities for siblings to get together with one another

and deal constructively with some of these concerns. According to Kristin Martin, Assistant Manager of the HRC Resource Center, "Having this wealth of staff volunteers has enabled us to currently offer nine ongoing support groups...and because we have more groups, we can offer the groups in multiple locations, and tailor them for a whole range of age groups."

Children are able to meet other children who have a brother or sister with a developmental disability and share experiences and express concerns. They also share strategies for dealing with the disabled sibling and for responding to situations outside of the family home, such as other people's reactions to the disabled sibling. Most of all, they have fun.

Donis Leonard, age 6, has always asked a lot of thoughtful and probing questions about why his brother does the things he does, and he was anxious for the opportunity to talk about his brother with other kids his age. Now he proudly tells his classmates at school, "I've got to go – I've got my group meeting today." Mother Mei-Ling Leonard adds, "He's taken such ownership of this opportunity to learn more about his brother's needs, and it's helping him to build that bond."

Carol Radke wasn't sure how her daughter Molly, age 11, would respond to the sibling support group experience, but "She loves it. I was pleasantly surprised. She has never liked to be too scheduled or structured, but she's very diligent about making sure I get her to this group on time." Molly tells her mom that what she likes about the group are the friends and the fun activities, but Carol senses that she also likes knowing that these kids are dealing with the same things she is facing.

Molly sums it up best, "Everybody needs their own support group." ■



Donis Leonard works with sibling group facilitator Michelle Mendoza.

FAMILY *matters*

FAMILIES COPING WITH AUTISM: Working Together to Make a Difference



According to Lisa Davidson, “When your child is diagnosed with autism; if you are resistant the whole way it will be a real uphill battle. To gain positive outcomes, tap into the support and information available from your HRC counselor and the school district using your child’s interests and strengths.”

And many HRC families are doing just that, with wonderful results.

Ryan Davidson was 2 1/2 years old when he was diagnosed. The news was really tough for both Lisa and her husband, Matt, and wading through all of the information and research she could find on autism was overwhelming. But through education and the support of her HRC counselor, Carol Hovda, Lisa says she now feels up to the challenge of seeing Ryan reach his individual potential.

Efrat Gutman had some doubts about working with a service system when her son, Peleg, was diagnosed at the age of two and referred to HRC. After an initial period of depression, Efrat began working with her Harbor counselor, Pat Moore, to see what could be done.

The HRC early intervention program was an important first step. Both Ryan and

Peleg were enrolled in an array of early intervention and therapy programs, including intensive early autism intervention. Both families also received parent training and support in how to utilize applied behavioral analysis and behavior management principles in the home to support their children’s development. Efrat feels that a parent needs to “get their hands dirty” by using what’s learned from the therapists at home. In fact, Efrat consistently uses her new skills to help Peleg have positive outcomes in new situations. When he flew for the first time, Efrat used techniques such as reading age appropriate books about traveling, visiting the airport, and watching planes take off. When it was time to fly, Peleg had a great time.

When going on a family outing, Lisa and Matt also use what they have learned. “We try and pick a place that will interest Ryan and he will be comfortable. We then have a positive family outing,” Lisa relates. Lisa and Matt believe that if traditional activities don’t make Ryan happy; they need to be okay with what he can do. They don’t want to fit a square peg into a round hole.

Both boys have come very far since their initial diagnoses. Ryan now attends the LIFT preschool program, through the Redondo Beach Unified School District, and is much more aware and engaged at home. He recently started verbalizing, playing with toys, and taking turns. Peleg is attending Tuvia Preschool where he is fully included with typical children. He is making friends and can participate in the community without incident. Once he hardly spoke, and now he can converse in full sentences.

With continued work and a positive attitude, these families can’t wait to see how far their boys will go. And HRC is looking forward to their bright futures as well. ■

(top) The Davidson family in their backyard.

(l-r) Ryan and brother Matthew having fun in their sandbox.



Client focus

PROMOTING UNDERSTANDING AND AWARENESS: Louise Brown Honored by LA & National Down Syndrome Associations

by Frank and Pat Brown

Editor's Note: This spring, the Down Syndrome Association of Los Angeles and the National Down Syndrome Society selected Louise Brown as a recipient of their Voices Award, which is given to persons in the media who have made contributions to the Down syndrome community. Her fellow honorees include film director Bill Smitrovich, actor Chris Burke of "Life Goes On," and other actors with Down syndrome who, like Louise, have appeared in film, television, and commercials.

Louise Brown was born August, 10, 1961 in the historic city of Verdun, France, the fourth child of Frank and Pat Brown. Her parents were completing four years in Alsace-Lorraine and Louise would return with them and her three older sisters to the United States in the fall to live in Littleton, Massachusetts. With her new younger sister and brother, Louise's expanded family moved to Arlington, Virginia, where she attended St. Coletta's, George Mason school and special classes at the National Institutes of Health which produced the first Down syndrome documentary film in which Louise appeared. The year 1969 found Louise on Southern California's Palos Verdes Peninsula. She was the first child with Down syndrome

to enter primary school and to graduate from Rolling Hills High School – with her kid brother.

Louise reads widely and well. She is highly verbal, possessing an expansive written and oral vocabulary, which enabled her to be a keynote speaker on two occasions.

Her American Sign Language fluency resulted from formal study in California, a summer seminar scholarship for the hearing impaired in Belfast, Maine, and much dedicated self-study. Lulu – her nickname – appeared in a half dozen short and commercial films and a McDonald's commercial, all of which promoted greater public understanding and acceptance of Down syndrome. Her many screen appearances make her eligible for Screen Actors Guild membership. Last year, Louise ended a 19-year career with a sheltered workshop to go to Canyon Verde School in Redondo Beach. There she's learning to unlock the mysteries of computers. Louise finds time to use her ASL fluency to sign during Catholic Mass for the deaf at St. Margaret Mary's Church in Lomita. She also serves an altar girl.

Louise is a joiner. She belongs to More Opportunities for the Developmentally Disabled, (the "MODD Squad"), and the Going Out Group. Louise has an active social life with her family. Since her 40th birthday, the family devises unique annual celebrations which kicked off with her 40th at the Palos Verdes Art Center attended by her former teachers, speech specialists and medical professionals. Today, Louise Brown remains a well-known and popular figure in the Palos Verdes community. ■



EXPANDING AWARENESS OF DEVELOPMENTAL SERVICES: HRC Provides Outreach for Student Nurses

Donnabelle Salonga and Chris Koettel are student nurses from California State University, Long Beach. To fulfill a volunteer requirement for graduation, they both recently spent 36 hours at Harbor Regional Center.



Donnabelle Salonga and Chris Koettel chat with Arlington group home resident Charlene Galle.



Donnabelle and Chris demonstrate the proper way to wash hands.

Donnabelle was not familiar with Harbor when she first arrived here. Now, when a patient has a need for HRC's services she will know where to send them. Chris is planning to become an emergency room nurse. His time working at HRC, "...gave me a deeper understanding and insight into the abilities and challenges of the clients that HRC serves."

Part of their experience was to spend an afternoon at the Arlington group home. During their time there, Donnabelle and Chris worked with the staff on preventing the spread of infections and administering medication safely. Later, staff and clients had fun making healthy snacks.

In addition to working directly with the clients and group home staff, the nursing students helped organize a medical directory in the HRC Resource Center, and learned about managed care and Medical issues. They also spent time with HRC's clinical staff. As Donnabelle relates, "My experience at HRC has been a real positive one for me."

Both Donnabelle and Chris feel that the collaboration between the CSULB nursing program and Harbor provides an important learning opportunity because it gives students a special glimpse into the lives of people with developmental disabilities that they may not have the chance to gain through the classroom. ■

REACHING OUT ALL YEAR LONG

"There are a lot of worthwhile charities, but HRC has impacted our lives in such a positive and important way."

Randy Wagner, parent

Last November, David Brown saw a flyer for the HRC "Adopt a Family" program and thought that he would like to participate. A lawyer and member of the Southbay Law Association, he adopted the Yerena family. After visiting the family, whose son, Andrew has a diagnosis of severe cerebral palsy, David called HRC and asked how he could help all year long. "My friends and I are blessed with financial means and I feel it is important to give back," David relates. Since the holidays, he has visited the family and is currently looking into purchasing Andrew some therapy items.

The employees of Northrop Grumman have been adopting HRC families for many years now. After the holidays, Lori Robertson from Northrop heard about a Harbor adult client with young children who needed new carpet and furniture. Ever-creative, Lori spoke to Todd Caldwell from EyeDeal Interiors. He agreed to supply beautiful new carpet for the whole house if Lori could find a way to pay the installation. Rallying her fellow employees, she collected enough money to have the carpet installed. When Todd went to see the finished job he brought along a sectional couch and recliner chair for Elisha Williams and her three kids. "Harbor Regional Center does such wonderful work for disadvantaged families, and it was our pleasure to assist," says Lori.

Having a son diagnosed with autism, Randy Wagner has long been associated with Harbor Regional Center. He feels that without Harbor's support, his son Cole would not be doing so well today. Cole is fully included with non-disabled students for half of his classes at school,

and is active in the theatre. Last year Randy decided he would run the Los Angeles Marathon and donate any money raised to the Harbor Help Fund specifically for children in need. Randy took on the daunting task because he felt it was important to be a good role model for his son, raise money for a great cause, and to also honor a close friend. On March 6, 2005, Randy ran the 26.2 miles in 4 hours and 34 minutes and raised over \$1,500 for HRC's disadvantaged kids. Randy states, "It was worth it because there are a lot of worthwhile charities, but HRC has impacted our lives in such a positive and important way."

Elides Yereno and her son Andrew chat with David Brown.



All these wonderful individuals and organizations continue to make a difference to our families in need, not just during the holidays, but all year long. HRC thanks you for your kindness and generosity. If you would like information on ways you can support clients and families in need through participation in the Harbor Help Fund, please contact Nancy Spiegel at (310) 543-0658. ■



(middle) (l-r) Jose and Todd from EyeDeal Interiors with Elisha Williams and her children.

(bottom) (l-r) MaryLou, Cole and Randy Wagner

resource center

WHAT'S NEW AT THE RESOURCE CENTER?

By Dominique DeBorba, HRC Parent & HRC Resource Center Family Support Assistant

Today, people with Down syndrome are enjoying long and healthy lives, and participating in all aspects of family, school, work and community life. Although the world has come a long way toward providing the same opportunities as for those who were not born with this genetic condition, there is still work to be done before all individuals diagnosed with Down syndrome see full inclusion opportunities in their communities. The HRC Resource Center has three recent books that candidly address issues surrounding Down syndrome.

Common Threads: Celebrating Life with Down Syndrome *by Cynthia S. Kidder and Brian Skotko*

This beautiful book is an essay and photographic celebration of inspirational accomplishments of people of all ages with Down syndrome. It received the 2002 National Media Award for print publication by the National

Down Syndrome Congress, as well as the Excellence in Media award from the State of Massachusetts.

Down Syndrome: Visions for the 21st Century

by William I. Cohen, Lynn Nadel and Myra E. Madnick

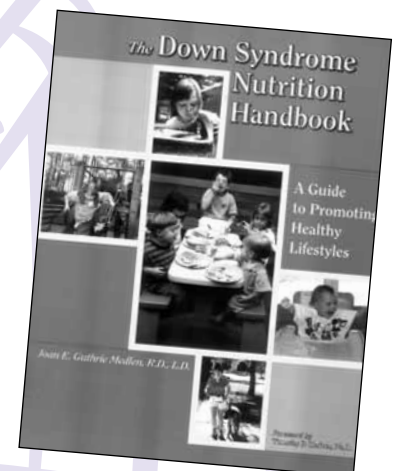
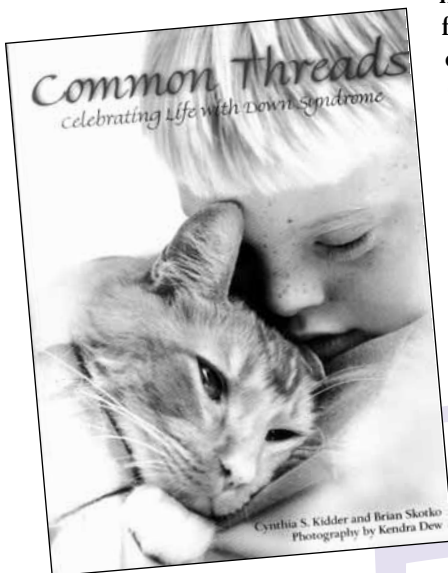
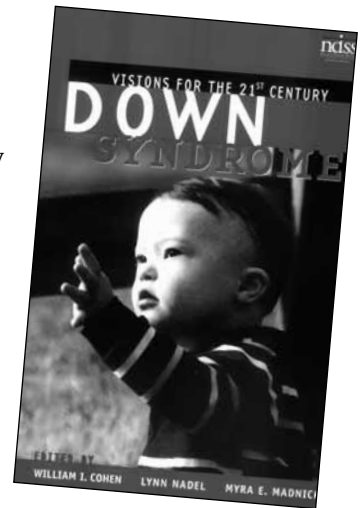
This book offers a comprehensive and up-to-date treatment of the clinical, educational, developmental, psychosocial, and transitional issues relevant to people

with Down syndrome, as well as the needs of family members, caregivers, and professionals alike. Edited in association with the National Down Syndrome Society, it also incorporates the newest developments concerning sexuality, inclusion, transition into adulthood and legislation, as well as a discussion of the Human Genome Project and the sequencing of chromosome 21.

The Down Syndrome Nutrition Handbook

by Joan E. Guthrie Medlean, R.D., L.D.

This comprehensive book looks at all aspects of nutrition, and educating individuals with Down syndrome about healthy lifestyles, from birth through young adulthood. It also provides numerous hands-on and fun activities to teach and practice nutrition concepts. ■



LOS HERMANOS Y LAS HERMANAS ENCUENTRAN APOYO AL COMPARTIR

Tradicionalmente, el centro regional "Harbor Regional Center" ha ofrecido a los padres una variedad de grupos de apoyo donde pueden compartir sus experiencias y recibir el apoyo emocional de otros padres con sus mismas inquietudes. Con frecuencia, estos grupos también se dirigen a los hermanos y hermanas adultos de las personas con incapacidades, especialmente a quienes están a cargo de su cuidado.

En contraste con ello, los hermanos y hermanas que son niños han tenido un acceso mucho más limitado a los entornos estructurados para expresar sus inquietudes y aprender más sobre las incapacidades a las que se deben enfrentar.

Las investigaciones han mostrado que estos niños comparten una variedad de inquietudes, como:

- Vergüenza por la conducta o la apariencia del hermano o la hermana, que puede llamar la atención de otras personas, y culpa por sentirse avergonzados.
- Sentimientos de vacío y de aislamiento por no tener la compañía que podría ofrecer un hermano o una hermana sin incapacidades; sentimiento de abandono por los padres, cuyo enfoque principal es el niño con incapacidad; y no tener compañeros que entiendan sobre la experiencia de tener un hermano o una hermana con una incapacidad.
- Mayor exigencia de cuidar al hermano(a), particularmente a las hermanas mayores.
- Identificarse excesivamente con el hermano o la hermana, sintiendo la preocupación de que desarrollará la misma incapacidad.
- Sentir presión por desempeñarse bien en lo académico, en el atletismo o en otras áreas para compensar por la incapacidad de desempeño que tiene el hermano(a).

Y es raro que estas inquietudes se aborden directamente. Los recursos de apoyo para los hermanos ha sido limitado y generalmente son de corto plazo. Pero este año, el centro regional "Harbor Regional Center" ha

creado un equipo compuesto por 20 miembros del personal que ofrecieron sus servicios voluntarios y que están especialmente capacitados para moderar un grupo de apoyo para los hermanos y las hermanas de los niños con incapacidades. Esto nos permite ofrecer muchas más oportunidades para que los hermanos se reúnan y resuelvan de manera constructiva algunas de estas inquietudes. Según Kristin Martin, sub-gerente del Centro de Recursos de HRC, "contar con esta abundancia de voluntarios entre los miembros del personal nos permite actualmente ofrecer nueve grupos de apoyo continuos...y al tener más grupos, podemos ofrecerlos en diferentes lugares y ajustarlos a diferentes grupos de edades."

Los niños podrán conocer a otros niños que tengan un hermano o hermana con incapacidades del desarrollo, y podrán compartir sus experiencias y expresar sus preocupaciones. También compartirán estrategias para ocuparse de la persona con incapacidades y para responder ante las situaciones ocurridas fuera del hogar de la familia, como la reacción de otras personas ante el hermano(a) con incapacidades.

Donis Leonard, 6 años de edad, siempre ha hecho muchas preguntas sagaces y de reflexión sobre la razón por la que su hermano hace lo que hace, y sintió mucho entusiasmado al tener la oportunidad de hablar sobre su hermano con otros niños de su edad. Ahora con orgullo les dice a sus compañeros de clase: "Debo irme, hoy tengo reunión con mi grupo." La madre, Mei-Ling Leonard, agrega: "Ha aprovechado tanto esta oportunidad para aprender más sobre las necesidades de su hermano que esto lo está ayudando a crear lazos con él."

Principalmente, se divierten.

Carol Radke no estaba segura cómo respondería su hija Molly, de 11 años de edad, ante la experiencia del grupo de apoyo para hermanos, pero: "Le encanta. Fue una agradable sorpresa para mí. A ella nunca le había gustado demasiada programación o estructura, pero es muy diligente en dar por seguro de que la llevaré puntualmente a este grupo." Molly le dijo a su mamá que lo que a ella le agrada del grupo son los amigos y las divertidas actividades, pero Carol cree que también le agrada saber que estos niños están enfrentándose a las mismas cosas que ella.

Molly lo sintetizó mejor, "Todos necesitamos tener nuestro propio grupo de apoyo." ■

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BOARD MEETINGS

July 19, 2005 – 6:30 p.m.
No Meeting in August
September 20, 2005 – 8:00 a.m.

The Board of Trustees of the Harbor Developmental Disabilities Foundation, Inc. meets regularly once a month on the **THIRD** Tuesday of the month.

Board meetings alternate between morning and evening times to provide opportunity to people in the community to participate. Morning meetings are from 8:00 a.m. to 10:00 a.m. and evening meetings are from 6:30 to 8:30 p.m. The Board does not meet in June, August or December.

All regularly scheduled business meetings of the Board are open to the public and visitors are welcome to attend both morning and evening meetings of the Board. The meetings are held in Conference Room A1 & A2 at Harbor Regional Center. ■

Harbor Happenings is a publication of Harbor Regional Center, a program of the Harbor Developmental Disabilities Foundation, Inc.

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