



# HARBOR HAPPENINGS

A PUBLICATION OF HARBOR REGIONAL CENTER

SPRING 2006

## GET FIT! NOT FAT! Endorsed by the Governor's Council As HRC and LRC Clients Continue Fitness Challenge

*Kerry Ryerson  
Wellness Project Manager*

Recently, the Get Fit! Not Fat! Project, a collaborative Wellness program of Harbor Regional Center and Lanterman Regional Center, received some exciting news when we were informed that our program has been formally endorsed by the Governor's Council.



*The Get Fit!  
Not Fat! Beach  
Volleyball Team  
shows their  
team spirit.*

“The California Governor's Council on Physical Fitness and Sports is proud to recognize the “Get Fit Games” as an event that promises to significantly contribute to the health and well-being of Californians. The opportunity for

Californians to be physically active in fun and safe community gatherings is critical to the Council's mission of establishing California as the “nation's fitness state.”

The Get Fit! Not Fat! Wellness project was met with great anticipation and excitement by clients, and the service providers who support their participation, when it kicked off last November. The goal of the Get Fit! Not Fat! Project is to improve the nutrition, fitness and overall health of adults with developmental disabilities.

*(continued on page 2)*

## THE GOVERNOR'S PROPOSED BUDGET FOR 2006-2007: Good News and Bad News

As the new year began, reports of the improving California economy and unexpected increases in state revenue caused us to be cautiously optimistic about the coming year's budget. We were hopeful that after several years of cuts and freezes, the Governor would include long-needed increases to developmental services. Although the proposed budget for Developmental Services does include modest increases in specific areas, those increases come on top of reductions so that the program overall will remain fairly level.

The good news is that there is some increase. The bad news is that California is still experiencing what the state's legislative analyst terms “structural deficit.” And what that means for regional center budgets is, at the moment, unclear. What follows is what we do know.

The Governor and California's Department of Developmental Services (DDS) report that they maintain a commitment to containing program and administrative costs, while continuing to provide an expansive array of services and supports to developmentally-disabled individuals and their families.

### **Proposed Funding for Regional Centers for 2006-07:**

The proposed budget for 2006-07 includes a net increase of \$115.8 million, including:

- **\$67.8 million to fund a 3% cost-of-living increase for the following service provider categories:** community care facilities, supported living, community-based day programs, look-alike day programs, habilitation services programs, respite and transportation services.

*(continued on page 3)*

*Get Fit! Not Fat! Endorsed by the Governor's Council As HRC and LRC Clients Continue Fitness Challenge (continued from page 1)*

HRC clients have been receiving instruction and guidance on proper nutrition, exercise and healthy meal preparation in a variety of program and community settings. In an effort to provide encouragement to the clients in the Wellness project, HRC staff members have also joined in the Fitness/Weight Loss challenge. Participants will celebrate their accomplishments this year with a sports competition between the clients of the HRC and LRC. The Get Fit! Games will be held at the Home Depot Center in Carson on Saturday, November 4, 2006.

Clients are speaking out about the benefits of their involvement in the project. "I have more energy and good eating skills," says Christin Martinez. Several participants were excited about the progress they have made in working towards a healthier weight, and as Fitu Taleni noted, "It's nice to enjoy losing weight!" Her teammates enthusiastically agree: "It's good, eating right. I cut down on junk food"... "I feel good about myself. No more sodas for me!" boast Kevin Boyer and Juan Castaneda. Matthew Tan sums it up with, "I like the program because it helps me learn to lose weight and look good."

Service providers from the Easter Seal Society in Redondo Beach report noticeable changes in the participants. Val Chavarria observes, "This class gives the clients a positive focus on choosing to eat healthy foods and participate in fun fitness activities." Ray Maestas notes that the process has not always been an easy one, but it is certainly paying off. "The clients are making better food choices, bringing salads from home instead of purchasing fast foods. When we go out for our fitness walks, they no longer complain. They now look forward to getting out and moving!"

The California Governor's Council is helping to promote the "Get Fit! Games" on their Web site, [www.ActiveCA.org](http://www.ActiveCA.org). Information about our event can be found within the Life in ActiveCA section of the site, acknowledging HRC's commitment to providing active opportunities for our adult clients with developmental disabilities. More than 100 HRC participants in Get Fit Not Fat's Fitness/Weight Loss challenge are using the Active California website to track their own fitness activities.

If you are interested in volunteering at the Get Fit! Games on November 4th, please contact Kerry Ryerson by e-mail or phone at [kerry.ryerson@harborrc.org](mailto:kerry.ryerson@harborrc.org), (310) 543-0686. The Games Committees will be forming soon and there will plenty of fun activities for everyone to be involved! ■

## DIAL 211 IN L.A. COUNTY FOR SOCIAL SERVICE INFORMATION

Have you ever needed help finding child care? Do you have a question about health care, housing, or education resources in our community? What could be easier than dialing 211 on your telephone, to gain valuable information and referrals?



Now with one simple call, you can access a comprehensive source of health and human services available in Los Angeles County. The county, United Way and Accredited Alliance of Information and Referral Services have provided assistance at your fingertips. 211 is a multi-lingual service that offers free and confidential information 24 hours a day, seven days a week.

211 LA County was created to provide an easy-to-use, caring, professional source of guidance, advocacy, and access to a comprehensive range of human services for the people of Los Angeles County. The 211 LA County database has listings for more than 4,000 agencies and over 28,000 programs and services. These listings contain descriptions of the service being provided, eligibility requirements or exclusions, target groups, service areas, application procedures, hours and any associated fees. Harbor Regional Center and our sister regional centers in L.A. County have also been included as featured agencies, as one more way that individuals and families in need of our service can find us.

If you prefer to do your searching online, you can search for services contained in 211 LA County's comprehensive database of health and human service resources, at [www.healthycity.org](http://www.healthycity.org).

*The Governor's Proposed Budget for 2006-2007: Good News and Bad News (continued from page 2)*

- **Continuation of existing rate freezes** affecting regional center service providers (the amounts upon which the above 3% COLA is based).
- **New regional center contract requirements to control service expenditures**, with a corresponding reduction to regional center purchase of service funding of \$85.8 million over the next three years.
- **An increase of \$2.5 million (statewide) to fund activities related to expansion of the Autistic Spectrum Disorder Initiative:** for establishment and implementation of existing best practice guidelines for screening, diagnosis, assessment, and evidence-based treatments and interventions; establishment of specialized autism resource centers; and coordination of information, guidance and resources for families and professionals.

**Other Programs of Interest to People with Developmental Disabilities:**

- **Supplemental Security Income (SSI):** Last year the budget called for saving money by suspending the state cost of living increases (COLAs) to SSI for two years, or through 2007. It also approved delaying the federal increases to SSI – due in January – for three months or until April of 2006 and 2007.

In his latest budget, Governor Schwarzenegger proposes to delay the federal cost of living increase to SSI for an additional 15 months or until July 1, 2008.

While the above proposals do not relieve the long-standing strains which our system has labored under for some time, we are heartened by the proposed increases for service providers, however modest. This spring, Budget Subcommittees of both houses of the state legislature have reviewed the above proposals; both houses have taken common positions to support the proposed cost of living increase for service providers, and the expansion of autism initiatives. Both houses are also considering a lift of the ban on start-up funding for regional centers' development of new resources. The two houses have not agreed thus far concerning the continuation of freezes upon service rates and SSI cost of living increases. In the coming months we anticipate both the Governor's May revision of his proposals, and continued efforts by the legislature to reach final agreement on these budget issues.

Our regional center system is preparing to celebrate our 40th anniversary. Together we can celebrate the accomplishments of our system and our clients over these four decades, as we campaign for legislative support for the challenges we face now and in the years to come.

## **UCLA STUDY OFFERS FREE BEHAVIORAL THERAPY FOR CHILDREN WITH AUTISM AND ANXIETY**

Dr. Jeffrey Wood and Amy Drahota, M.A., in the UCLA Department of Psychological Studies in Education are conducting a research study entitled Behavioral Interventions for Anxiety in Children with Autism (BIACA). They are currently recruiting children with autism from the ages of 7-11 years to participate. Recruitment for this study will continue through mid-2007.

This study provides treatment to children with autism or Asperger Syndrome, who also experience anxiety. For those who qualify, they will conduct a comprehensive diagnostic evaluation for anxiety and autism, and provide sixteen weeks of free cognitive behavioral therapy aimed at reducing worry and shyness, and also to improve the child's social interaction and overall educational experience.

Eligible youth must: Be between 7-11 years old; Have significant anxiety; Have an IQ above 70; Have a diagnosis of Autism, Asperger Syndrome, or PDD-NOS.

If interested in learning more about the BIACA study, please contact Amy Drahota, M.A., at (310) 882-0537 or by e-mail at [adrahota@ucla.edu](mailto:adrahota@ucla.edu).

## UC DAVIS M.I.N.D. INSTITUTE LAUNCHES LARGEST BIOMEDICAL ASSESSMENT OF CHILDREN WITH AUTISM

### *Autism Phenome Project aims to redefine autism by identifying distinct subtypes*

Multidisciplinary teams of physicians and scientists at the University of California, Davis, M.I.N.D. Institute have launched the nation's most comprehensive assessment of children with autism to detect the biological and behavioral patterns that define subtypes of the disorder.

Called the Autism Phenome Project, the large-scale, longitudinal study will enroll 1,800 children – 900 with autism, 450 with developmental delay and 450 who are typically developing – who will undergo a thorough medical evaluation in addition to systematic analysis of their immune systems, brain structures and functions, genetics, environmental exposures and blood proteins. Children will be 2 to 4 years old when they begin participating in the study, and their development will continue to be evaluated over the course of several years. The first phase of the research is funded by the UC Davis M.I.N.D. Institute and philanthropic donations.

“Children with autism clearly are not all the same,” said David G. Amaral, research director of the UC Davis M.I.N.D. Institute and co-director of the project. “The tremendous variation leads us to believe that autism is a group of disorders rather than a single disorder – several autisms versus one autism. We are determined to provide the specific biomedical and behavioral criteria that accurately define distinct subtypes.”

Autism has common hallmarks: difficulties initiating and sustaining social interactions, impaired communication skills, and restricted, repetitive patterns of

behavior. However, these hallmarks vary in severity. In addition, some children with autism can have co-existing conditions such as cognitive impairments, seizures, coordination issues or gastrointestinal difficulties, while others do not. This heterogeneity has been a major obstacle to progress in autism science.

Another obstacle involves access to reliable data. Autism science includes many quality studies on specific aspects of the disorder – from genetics and immunology to behavior and imaging – that can be difficult to combine and compare. “We spent two years designing the project so that it would be both comprehensive in scope and fully capable of integrating data across disciplines,” said Amaral, a neuroscientist who specializes in brain systems involved in memory, emotion and social behavior. “Our goal is to identify specific types of autism and develop a database of biomedical information that can be shared with the worldwide community of autism scientists. This is crucial to refining our understanding of autism, and to developing targeted treatments for a specific ‘type’ of autism as early as possible so children can reach their fullest potential.”

While the Autism Phenome Project is ambitious, Amaral believes its successful completion will shorten by decades the road to discovering the causes and treatments of autism, a neurodevelopmental disorder that now affects 1 in 166 children in the United States. The unexplained rise in autism prevalence has frustrated parents and scientists trying to find answers. “The time is right for us to build a strong database of information that we can all share in order to speed the discovery process and clarify the variability that now plagues autism research. From there, we can more quickly identify causes and treatments, and by adding collaborative partners we will be able to gather as much information as quickly as possible.”

For further information, go to [www.mindinstitute.org](http://www.mindinstitute.org). ■

## MEET OUR BOARD: Bob Bethel – Service “Above and Beyond”

One of the remarkable and enduring facets of the world of developmental disabilities is the journey that parents share together with other parents as they cope with the daily challenges of raising their children with special needs. For some, that is all they can manage. For others, the experience prompts them to get more involved in the community of disabilities to understand and to make a difference.

Then they look for ways to help.

Our Harbor Regional Center family of volunteers often grows by people recruiting other people, person to person. That was the case with Bob Bethel who was drawn into service on our Board of Trustees by friend and fellow trustee Ken Moses.

That encounter brought Bob to three terms of service on the HRC Board, including offices as secretary and treasurer. He currently serves as a member of the Retirement Committee, and is helping put into place a well-designed retirement system for Harbor employees.

A retired aerospace executive from Northrop Grumman, he brings a rich background in business to the board. Over the years, Harbor has benefited greatly from his experience and sound advice. “I had an interest in pursuing and assisting people faced with developmental disabilities – and particularly in understanding the mechanisms that provide financial support,” he explains.

He’s particularly frustrated by the fact that there have been no increases to service providers for home care in basically 20 years. “The state has fundamentally ignored the inflation process,” he says. He finds this an unacceptable situation and is exploring what can be done about it. Part of his effort involves working with board members and visiting political representatives to express concern.

He finds the most satisfying part of his work, “Helping clients so that they are not taken advantage of and have the maximum opportunity for a successful life.” He also feels that service on the board provides him insight into the political process of how the system really works in terms of funding, and who are the legislators truly committed to and interested in supporting people with developmental disabilities.

He and his wife Kathy have twin 25-year-old daughters, Katie and Marie, with developmental disabilities. The girls were both premature and weighed under two pounds at birth. Today the young women live in a supported living setting in Cerritos.



*Robert Bethel,  
HRC Parent and  
Board Member*

“It’s always a challenge – especially having two children with developmental disabilities. But I’m very blessed with having a very committed wife who’s been pivotal to the care and development of our daughters,” he shares. “She’s been the focal point and their best advocate all these years.”

Bob and Kathy also have another daughter, Amy, who’ll be graduating this year from the University of Colorado. And though retired, he is still working as a consultant for Northrop Grumman. In his spare time, he also bikes and plays tennis.

But he’s never far from his focus on giving to back to the community. His volunteer commitment extends beyond HRC to helping serve meals to the homeless, working with his church, and volunteering at Torrance Memorial Hospital.

It’s that level of “above and beyond” personal commitment that characterizes Bob Bethel, a valued member of our board who helps HRC keep “making it happen.” ■

# Client *focus*

## INTRODUCING THE ALTERNATIVE/ AUGMENTATIVE COMMUNICATION USERS GROUP

*By the AAC Users Group Participants, HRC Resource Center*



Harbor Regional Center is proud to offer a unique opportunity to a special group of clients. Twice a month, a group of seven people who use augmentative communication devices meet with Maureen Fondevilla, Speech Language Pathologist, and Elizabeth Green, Assistive Technology (AT) Specialist.

*The following article was written by members of this group using their AT devices.*

Hi! We are the AAC class at HRC. We meet on the 2nd and 4th Fridays of each month from 10:00 am to 12:00 pm. The class has 7 people in it with two main instructors. I bet you are wondering what AAC means. We are here to tell you. AAC is short for Alternative/ Augmentative Communication. What this means is that we use a device to speak for us.

**Q: What is it like to use AAC?**

**A: Barbara O'Hearn:** We need to use our communication device so people will know what we want.

**Kenneth Malveaux:** I would like to tell you what it is like to use my communication device. I love it! It takes time to learn but it really is worth all the time and effort because I can really communicate what I want to say!

**Q: What else can you do with your device besides generate speech?**

**A: Kenneth Malveaux:** I use my communication device to work on my desktop computer. My communication device tells my desktop computer to move the mouse and also sends messages to documents through the infrared system built into my communication device. It's very cool! I also control my TV with my communication device. I am just so happy!

**Stephen Kromminga:** One, I can use my cell phone. Two, I can use my computer. Three, I can use my TV. Four, I can do math with my Pathfinder calculator.

**Q: What is the class all about?**

**A: Bryan Boyd:** The class is about how to become a better user and becoming a fluent AAC communicator.

**Elissa Nadel:** It is all about myself, I want to keep going on able to communicate with the outside world.

*(continued on page 7)*



*(top photo)  
Elissa Nadel  
(middle)  
Barbara O'Hearn  
(bottom)  
Bryan Boyd*



(continued from page 6)

**Q: How many participants are in this class?**

A: **Kenneth Malveaux:** There are 7 students in the AAC Class and we would like to meet more communication device users.

**Q: Why is it important to come to this class?**

A: **Margaret Crew:** It is really important to meet with other communication device users and see and hear how other people use their devices to speak. Plus, the class is a lot of fun. Also I get to practice using my device and sharing my thoughts with my classmates. It keeps me in check. You know what I mean? Next, I get a lot of support from the teachers, the SLP and the AT specialist, plus, I get so much support from my classmates. The teachers help me understand my device better and help me to use it more effectively. My classmates are good examples of good AAC users and give me a lot of hope and motivation to work harder and talk better.

**Q: What type of supports do you get from this class?**

A: **Margaret Crew:** You know, I really do get a lot of support from this class: I get encouragement, AAC support, technical support, and homework! Believe it or not, the homework really helps me to stay focused. I am really happy that this class is here for me. Last, I feel better about myself when I come to this class. I guess because I am doing something for myself, plus I know it has something to do with supporting all AAC users by supporting this class.

**Q: How has this class helped me to learn how to use my device in a better way?**

A: **Kenneth Malveaux:** The class helps me to work harder and I feel more motivated because when I go to class I know that my classmates are listening to hear how I am doing and how well I am doing with my com-

munication device. I feel more motivated to do better.

**Kathy Braxton:** This class has helped me to want to use my device more. This is the greatest help to me. I have increased my desire to use my device at day program and the homework keeps me thinking about how much my device helps me to communicate better.

**Q: How has this class changed my routine?**

A: **Kathy Braxton:** Well, first of all, because this class is only twice a month it hasn't affected my routine very much but on the class day I wait a little longer for the van to pick me up. Second, the class is over earlier than my normal day program schedule so when I get home I have a little more quiet time before the other clients get home. That's nice, I like that. Last, I have to get my homework done. I usually spend some time during the week thinking about my homework so that when I see my speech therapist I am ready to have her program my homework into my device. It really helps to have the assignment written out so my day program coach and home staff can remind me and help me get my thoughts out.

**Q: Why should others come to this class?**

A: **Stephen Kromminga:** Well, I am going to the class because, one, we have fun. Two, we have two great teachers. Three, we are learning a lot about our AAC devices and assistive technology. Four, also, we are learning more about HRC because the class is held there. Five, last, we get to talk a lot!

**Bryan Boyd:** It is important to have a support staff that can troubleshoot a problem with your device. If they can't solve your problem the speech staff can have the device sent back for repairs. ■

(from top to bottom)  
Kathy Braxton,  
Margaret Crew,  
Kenneth Malveaux and  
Stephen Kromminga



# FAMILY *matters*

## NEW HOPE AFTER KATRINA—HRC Provides Support for Families

It has been many months now since Hurricanes Katrina and Rita devastated communities in the Gulf Coast. Many, many families are continuing to work hard to rebuild their lives, one day at a time. Some of these families are now living here, and have been welcomed by our community. Harbor Regional Center is happy to be a source of support for some of these families.



*The Duke family settle into their new home in Torrance.*

Shavonda Duke and her three children, Darion, Jayden and Briyanna, survived Hurricane Katrina and know first-hand the life-changing impacts of a natural disaster. Born and raised in West Los Angeles, Shavonda had settled in Metairie, Louisiana, and lived there

for the past five years. She recalls that before disaster struck, life was going fine “I had my own place and was happy.”

Then, of course, everything changed. “We are one of the families that left before the hurricane actually hit. My mother came to get us, and it took us 21 hours to get to our destination. We were lucky that my aunt made reservations at a hotel in Houston, Texas. The next day, when we turned on the television, I was shocked to hear just how hard Katrina hit...I realized that I had packed like we were just going and coming right back.

We had no money and only the clothes on our backs.”

She also immediately realized that she had an even more critical emergency, for her children who have developmental disabilities. “My twins would need their breathing machine, diapers, prescriptions and supplies necessary to meet their needs. I had to borrow money from family members, and wait in lines to get medical assistance... There were so many who needed help...”

After a month of what felt like the worst of times, Shavonda’s grandmother helped her to bring her family to Torrance. She heard from those who had remained in Metairie that she had lost everything. “I have cried so much because it hurts to know you have nothing left. If it weren’t for my grandmother, we wouldn’t have anywhere to live. My grandmother has had to assist me with everything.”

“Although I have lost so much, I have also gained my love for family and our community. My children are now able to receive services from Harbor Regional Center. In Louisiana services for people with developmental disabilities are very limited. When my Harbor Regional Center Counselor described the services available, I was amazed! I am so thankful that I will have assistance in our time of need, and throughout their lives. It gives me hope for the future. I just hope other families treasure these services as I will. You never know what you have until you are forced to be without it.” Shavonda also has this advice: “Please remember, if you are a person who has a developmental disability or a parent of a child who does, be prepared, in advance, for a disaster... Be sure especially that you are prepared with medications and supplies that you will need for your disability. Remember, you may not come back the next day. Take everything you can with you. You never know when disaster will strike.” ■

## DISASTER PREPARATION AND PLANNING TIPS FOR PEOPLE WITH SPECIAL NEEDS

### Person with Special Needs

- Ask your physician for a current care plan, including what to do in case of an emergency, and for a list of current medications.
- Keep a completed health information form on your child. (A form is available on HRC's website at [www.harborrc.org/resource-information/health-history](http://www.harborrc.org/resource-information/health-history)).
- Have a two-week supply of medications and other disability-related supplies on hand.
- If you use medical equipment that requires electricity, have a back-up generator or plan.
- Tell your city's emergency management team that you have special needs, and ask for guidance in what help, shelters, etc. could be available for people with disabilities in a disaster.
- Discuss disaster plans with your child's school, day care, day activity, etc.

### You/Your Family

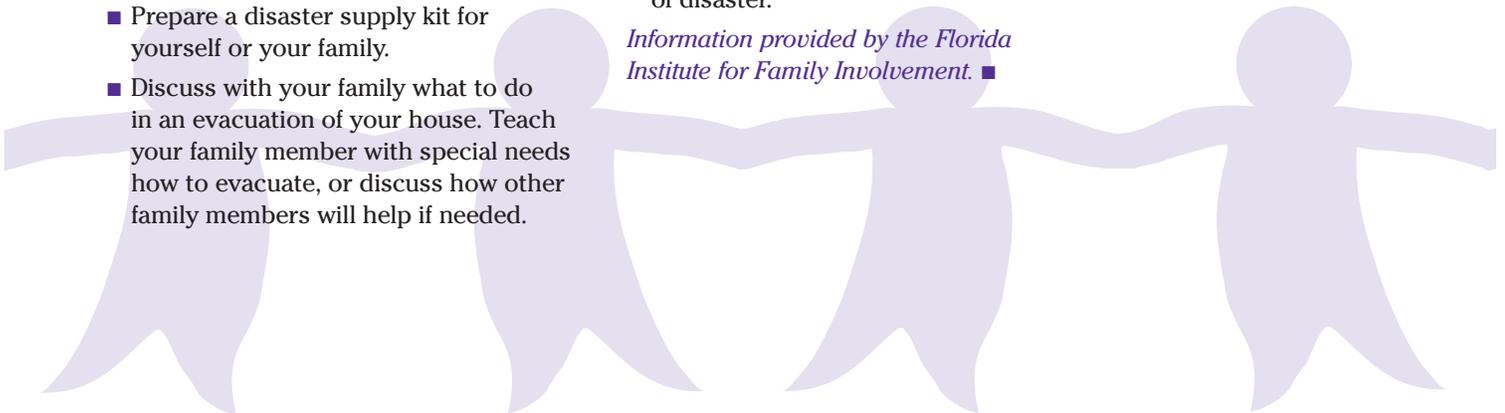
- Discuss how disasters can affect all family members and how you will address your family member's special needs.
- Teach children how and when to call 9-1-1 for emergency help.
- Prepare a disaster supply kit for yourself or your family.
- Discuss with your family what to do in an evacuation of your house. Teach your family member with special needs how to evacuate, or discuss how other family members will help if needed.

- Pick two places to meet if you are separated, such as outside your home if there is a fire, or outside your neighborhood, and how to contact one another.
- Ask an out-of-area friend to be your "family contact." After a disaster, it's often easier to call long distance than local numbers. Other family members should call this person and tell them where they are. Everyone should memorize this number or keep it with them.
- Show your children pictures of emergency workers (such as workers in uniform, fire suits and protective face gear).
- Make plans for your pets, including friends or kennels that might care for them if you were not able to stay in your home, and a disaster supply of pet food, etc.

### Your Home

- Check your home for materials and items that might pose a hazard during a disaster. (Don't forget the outside.)
- Post emergency telephone numbers by phones.
- Locate and teach family members how and when to turn off water, gas, and electricity at the main switches.
- Keep smoke and carbon monoxide detectors in your home with working batteries.
- Keep necessary resources such as a water hose, fire extinguishers, generators, etc. on hand.
- Talk with your neighbors on how you will assist one another in case of disaster.

*Information provided by the Florida Institute for Family Involvement. ■*



## HARBOR REGIONAL CENTER PARENT AND FAMILY SUPPORT GROUPS

Come and enjoy informative presentations and lively discussions.  
Share resources and information. Enlarge your circle of support. Come join us!!!

**Autism, South Bay: for parents who are raising a child with autism**

2nd Tuesday, 6:30-8:30; A2, HRC Torrance  
Arwen Davis (310) 792-4508, Kristina Kilmer (310) 792-4509

**Autism and Schools, Long Beach: for parents with school-aged children with autism**

2nd Thursday, 6:30-8:30; HRC Long Beach  
Brian Lockhart (310) 543-0605

**Down Syndrome: for parents who are raising a child with Down syndrome**

2nd Thursday, 6:30-8:30; A2, HRC Torrance  
Kerry Ryerson (310) 792-4712

**A Few Friends: for parents who are raising children who have a rare genetic disorder**

4th Thursday, 6:30-8:30; A2, HRC Torrance  
LeAnn Taylor (310) 792-4530, Niima Radford (310) 792-4588

**Unidad y Fuerza: meetings are held in Spanish with topics focusing on developmental disabilities**

4th Wednesday, 6:30-8:30; Miller Children's' Hospital Resource Center  
Pablo Ibanez (310) 792-4558, William Martinez (310) 543-0627

**Single Parents: for single parents who are raising a child with a developmental disability**

1st Thursday, 6:30-8:30; HRC Long Beach  
Ed Swan (310) 792-4547, Betsy Jennings (310) 792-4529

**Adult Siblings: for siblings who are caregivers of a disabled person**

4th Thursday, 6:30-8:30; A1, HRC Torrance  
Kent Yamashiro (310) 543-0687, Audrey Clurfeld (310) 543-0616

**Familias Amigas: for families of children who are at risk and/or have a developmental disability**

Now in Development  
Olga Sanchez-Farah (310) 543-0691

**Dads: for dads raising a child with a developmental disability**

Now in Development  
Gunnar Swanson (310) 543-0673, Pablo Ibanez (310) 792-4558

**Sibling Club: for siblings, ages 6-16, of HRC clients**

For more information, please contact your HRC counselor.

Meetings are for parents and caregivers of Harbor Regional Center clients. All meetings are free. For more information about a particular meeting please contact the facilitator indicated.

Limited childcare is available by calling Gail Parker at (310) 543-0643. For information about other area support groups please contact the HRC Resource Center at (310) 543-0691. ■

## PLAYFUL PALS A Sibling's Labor of Love

*Audrey Sunu, HRC Sibling*

Nowadays, kids are growing up at lightning speed. My little sister Andrea is not like other boy-crazy cell-phone-addicted kids her age, and she seems more like seven than fourteen. I should, however, mention a minor detail: she has mental retardation and autism. When I was younger, her diagnosis used to be a huge roadblock for me. Ironically, it now gives my life a sense of direction and purpose.

It all changed a couple of years ago, when Andrea threw a physical tantrum at the mall. Never before had she made such a head-turning, thunderous display of her frustration. For the first time, I had to deal with it all on my own – my parents weren't there to clean up the mess my sister had made. The embarrassment was asphyxiating. Thereafter, I longed to find a way for her to live more "normally." To merely stand by and accept her was not enough. Too many people, myself included, were misunderstanding my sister. I learned that children with intellectual disabilities often express themselves via tantrums because they don't know how else to communicate their wants and needs, but I believe they can improve by learning and honing social skills.

I drew from my volunteer experiences at the HRC Resource Center, Best Buddies, and Camp Escapades, to start Playful Pals. It is a non-school-affiliated club dedicated to enriching the social skills of kids with developmental disabilities, spreading community awareness, and basically having a great time. So as not to detract from the activities of the wonderful Best Buddies group at my high school, I recruited kids from church and from my sister's intermediate school. At the time of this writing, our membership is up to about 18! Our pool of about 25 volunteers has been recruited from my classmates, churchmates, my friends, and anyone

else I know. I'd love to have more! Every couple of weeks, we get together with an agenda focused on specific social skills to practice as a group of "pals" and volunteers. In the past we've had a blast bowling, attending a disability rights fair, picnicking at the beach, decorating clay pots, and more.

The results of this project have been beautiful and deeply moving. Friends who once felt uncomfortable around persons with disabilities have learned to show their concern appropriately. Pals who were once shy have come out of their shells to socialize better. Playful Pals volunteers have also offered parents their services as babysitters.

Parents are grateful not only because every event means more leisure time for them, but also for their children's smiles. It is by far the most gratifying, joyous feeling to watch the kids touch others' hearts, just as they have touched mine.

Next year, when I go off to college, I am hoping to pass on the leadership of this group to one of my volunteers. I'm worried about the future of the group, but I'm proud of how much has been done thus far, nonetheless. I have one outstanding wish: for everyone to experience both the humbling pain and pleasure of sharing life with someone who lives day-to-day on simple innocent terms – someone who doesn't necessarily experience life in the same way that others do. I'm not a perfect "special friend" as Andrea likes to call me. I do have those moments utterly devoid of sisterly magic, but my approach to her disability – or different abilities – has evolved. I've learned more from that fateful day at the mall than from twelve years of education. My love and understanding for my sister have blossomed, and I've found new ways to express it. ■



*(top photo) Sisters Andrea and Audrey share a special bond.*

*(below photo) Playful Pals "have a blast" with an art activity.*

## PREPARING PROFESSIONALS Students Gain Invaluable Experience at HRC

*By Kristin Martin, Assistant  
Manager, HRC Resource Center*



*Interns Lani Donnelly  
and Stuty Jain check  
out the latest children's  
software for the  
Computer Lab.*

HRC has had a long history of working with students to prepare them for a future in the health, education, and helping professions. From high school to medical school and beyond, students have worked with our staff, families and clients to develop an in-depth awareness of individuals with developmental disabilities. They also gain knowledge of the services and supports that are available. Interns experience working with clients

and families, and leave HRC with an appreciation of the everyday life of the individuals that we serve.

HRC's Physician Sri Moedjono has been working with doctors in their residency programs for the past 20 years. Doctor Moedjono strongly believes that "it is necessary for these residents to see what happens outside the four walls of the hospital." Doctors make monthly visits to HRC from Harbor UCLA's Family Medicine and Pediatrics departments, where they are encouraged to meet HRC's own staff of clinicians, visit some of the programs that serve our clients, and focus on how much people with developmental disabilities are able to do, despite their disabilities. Doctor Moedjono notes that as many as 800 doctors across the nation have gained awareness at HRC.

HRC Nurse Lewiette Wilkins coordinates fieldwork experiences at HRC for undergraduate nursing students from California State University Long Beach (CSULB), where they hear from key HRC staff regarding the roles of developmental

service professionals in the regional center and the services provided in the community. Student feedback indicates that this provides an invaluable learning experience for both their professional and personal growth, and over the past year the program has grown from 20 students to now nearly 60 students per semester. Selected undergraduate nursing students participate in a more in-depth clinical experience, learning to do nursing assessments for individuals with special health care needs, and gaining insight into the role of the nurse consultant as part of a developmental services team. Most importantly, upon completion of this clinical experience, the student will have a greater understanding and awareness of special health needs and services.

HRC's Marguerite Phillips, Director of Federal Revenue Programs, has been working with interns since 1984 and reminds us that interns have been with HRC since its inception. Interns in the field of social work currently spend a full school year at HRC, participating in support groups, individual client therapy sessions, and other activities that provide valuable support for our clients and families. Marguerite encourages students to "develop a commitment to become ambassadors and advocates for people with special needs – whether a developmental disability or other special needs."

At the HRC Resource Center, we are joined by two California State University students as well as one international student from Mumbai, India. Intern Lani Donnelly notes that "there is so much variety, even with the clientele...there is so much to grasp." Lani has been working with our Resource Center staff to update resources and coordinate special events. Future special education teacher Danielle Russell has been helping in the design and instruction of the specialized curriculum for our clients in HRC's Computer Lab, including our "Plan Your Day" and "Driver's Training" classes. Stuty Jain, who is specializing in business and information technology, will be assisting with community outreach and assistive technology

*(continued on page 13)*

*(continued from page 12)*

programs. Resource Center Manager Barbara del Monico says, “The resource center is so pleased to have these three outstanding interns who bring to us excellent skills and an eagerness to assist us in delivering services to our patrons. We are hopeful that the intern program will continue to grow at the Resource Center.”

HRC continues to be a source of support and training for future professionals in

the health, education, and social services fields, to complement the professional development of people who may one day be working directly with HRC clients, families, and support professionals. These professionals can play an equally important role in the future, in recognizing clients and families who can benefit from our services and guiding them to the regional center. You never know – your doctor, your nurse, your child’s teacher, may just have spent some time in the halls of HRC. ■

## GUEST COLUMN: Valuing What We Have

*Diane Anand, Executive Director  
Frank D. Lanterman Regional Center*

Very often in communicating with our community, we focus on the challenges we face as a system and on what we can do to further our vision of creating a truly inclusive society. It occurs to me, however, that sometimes in our effort to improve, we forget to pause and reflect on how remarkable the regional center concept truly is.

Recently, an article in “The Wall Street Journal” described the difficult choices faced around the country by parents of children – particularly adult children – with developmental disabilities.

The piece offered example after example of the lengths to which parents are forced to go to ensure that their children receive the help they need – lengths such as a father moving out of the family home so that a son with autism can have in-home care, or a parent dropping off an adult child with mental retardation at a shelter because only the homeless can get into a group home.

Nationwide, in state after state, we hear of long lists with literally thousands of people waiting for in-home assistance or a place in a group home. The numbers are staggering, and thinking of the individuals and families behind those numbers is even more distressing.

And that certainly reminds me that the regional center system – so clearly an innovative and effective approach to supporting people with developmental disabilities and their families – is a rarity in the nation. We in California enjoy the benefits of a system that is a model for improving the lives of individuals with developmental disabilities and their families.

Despite the many challenges we face, and the need to continuously improve the service delivery system in California, the regional centers still represent the best approach to empower and enable those with developmental disabilities to live full, productive and satisfying lives as active members of their communities.

As we approach the 40th anniversary of the regional center system, we indeed have much to celebrate. As we continue to evolve, we hope that the best of what we have accomplished in California will find its way into the service delivery systems of the rest of the nation.

*Frank D. Lanterman Regional Center is one of the two original “pilot” regional centers. This year we celebrate its 40th anniversary, and that of the regional center system. ■*



*It occurs to me, however, that sometimes in our effort to improve, we forget to pause and reflect on how remarkable the regional center concept truly is.*

Diane Anand

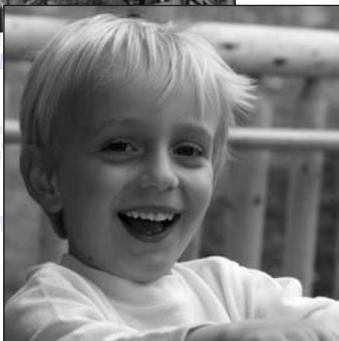
## A TREEHOUSE FOR ALL TO ENJOY

*Kerry Ryerson  
Public Information Specialist*



*(above) Torrance Mayor Dan Walker welcomes visitors.*

*(below) Visitors of all ages and abilities enjoyed the Treehouse on opening day.*



“Imagine living your entire life on one level.” Wallis Annenberg recalls hearing this suggestion from a young woman in a wheelchair, as her inspiration. About this time, she read about a non-profit organization called Forever Young Treehouses, Inc., dedicated to building accessible treehouses that can be enjoyed by all, particularly children and young adults with special needs, and funded entirely by donations. Thus far they had created 11 amazing, accessible treehouses in seven states, and hoped to build at least one in every state.

The Annenberg Foundation generously granted \$300,000 to Forever Young Treehouses, to build a universally accessible treehouse – their 12th – in a public park in California. A city search throughout the state was conducted. We are very fortunate that Charles Wilson Park, in the City of Torrance, was selected as the home of the first treehouse of its kind to be built in California.

Pediatric Therapy Network of Torrance was recruited to serve on an advisory committee, as were high school students from around the city, to participate in the planning and development phase of the treehouse. More than 1000 volunteer hours went into the development.

The opening ceremonies were held on April 10th, 2006, at the site of the beautiful new treehouse. The hosts included Wallis Annenberg; the Honorable Dan Walker, Mayor of Torrance; and Bill Allen, Founder of Forever Young Treehouses. Harbor Regional Center was invited to join

the City of Torrance, Pediatric Therapy Network, other volunteers, and representatives of several television and news outlets to witness this momentous occasion.

The magnificent 12-foot high treehouse blends in with the serenity of Wilson Park’s pond and gazebo area. Brightly painted bird houses and other lively art pieces decorate the house and surrounding trees. Two whimsical roofs adorn it from either side. There are 2,500 square feet of meandering paths complete with handrails. Ramps are 4-6 feet wide, allowing plenty of room for wheelchairs and strollers. The spaciousness of the paths and open areas will encourage people of all ages and abilities to enjoy the treehouse, and the setting in which it was built.

Phil Duthie, Program Coordinator for the City of Torrance Community Services Department has already seen Harbor Regional Center clients and service providers visibly enjoying the treehouse, and wants to spread the word for all to enjoy it. Terri Nishimura from Pediatric Therapy Network summed it up perfectly, “PTN was thrilled to be a part of this. I think it’s incredible for people of all ages...for mothers with children in strollers, older stroke patients, people who use walkers or wheelchairs, kids with mobility issues, and just regular kids...everyone’s going to love it!” You can see Torrance’s new Treehouse, and others at [www.treehouses.org](http://www.treehouses.org). ■



*Olivia Delgado and Brandon Tanioka take part in a work party, with help from Joan Jacobs of PTN.*

# MY HEART BLEEDS FOR THE COLORED BLOCKS

*Jennafer Kohlwey,  
Sister of an HRC Child*

*He holds Jenos hand at the Walk  
Now Cure for Autism,*

*Looking around I now know that  
I'm jealous of the special people.*

*He tells Jenos something but all it  
comes out as is gibberish with  
a hint of Swahili,*

*Watching, as the greatest people on  
earth race against the clock for  
money for the Crayola colored  
awareness.*

*He whines at Jenos when he has  
desires for a drinkie,*

*Yes he may be obsessive compulsive  
about his three horns and  
other dinosaur paraphernalia,  
but at least it aint guns.*

*He calls Jenos when he wants ice  
cream, because puppy dog eyes  
will only get him one scoop with  
Mommy,*

*For his "disease" has made him  
the purest of 5 year olds I know.*

*He rants at Jenos when he wants to  
go, so he can be on schedule for  
one more drinkie and Speech,*

*Maybe one day he'll be the next  
Bill Gates, or Woody Allen, or  
maybe Andy Warhol, too!*

*He probably will call for Jenos  
later when he learns how babies  
are made,*

*Yet keeping it simple, for the fact he  
is only 3 and a half in mentality,  
yet I'd like to see a 3 year old  
open a locked gate with no key.*

*Both funny and tragic I wish at this  
time I had this "disease" to be rid  
of the scary facts of the world,*

*Yet for now he'll call Jenos his  
favorite sissy.*

## 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](mailto: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: \_\_\_\_\_

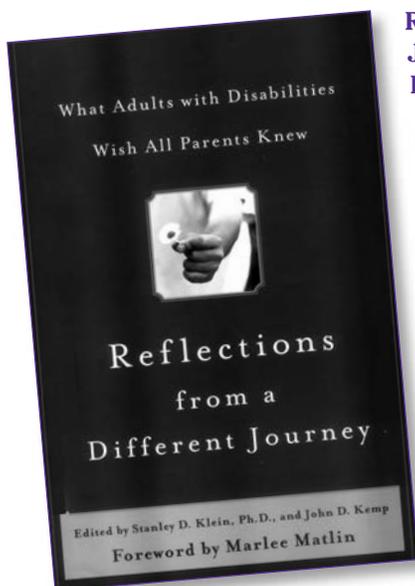
\_\_\_\_\_

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

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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

# resource center



## Reflections from a Different Journey: What Adults with Disabilities Wish All Parents Knew

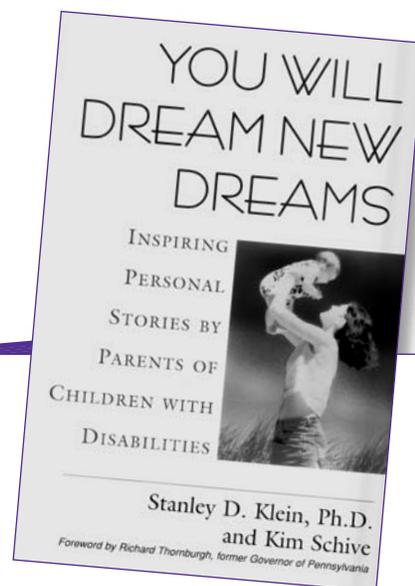
Hearing from people who have lived the disability experience can provide all parents, regardless of their children's age, with essential information about the possibilities for their children. This book comprises forty inspiring essays written by successful adult role models who share what it is like to grow up with a disability.

“Advice to parents about how to raise and guide their children with disabilities is rarely offered in such a compelling and insightful way as it is in *Reflections from a Different Journey*. Nobody says it better than people with disabilities themselves when topics such as risk-taking, social acceptance, envisioning a life of greater independence, and all the challenges confronting any parent arise. These

essays will educate, inform, and entertain every parent who wants to know how to be the very best parent he or she can be.” Senator Robert Dole

## You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children with Disabilities

Over sixty short essays by “veteran” mothers and fathers of children with varying disabilities, telling the stories they wish they could have heard when they learned their own child's diagnosis. The essays share words of validation, affirmation, support and encouragement.



## SAVE THE DATE!

Harbor Regional Center and the HRC Resource Center invite you to a Special Event for families, to meet author Stanley Klein.

**Saturday, August 5th, 2006, 10:00 a.m.-Noon**

Harbor Regional Center, Conference A1 & 2, Building A, first floor  
21231 Hawthorne Blvd. Torrance, CA

Please join us for this special presentation and book signing with author and award-winning advocate Stanley Klein. The event will include a guest lecture as well as a panel discussion with HRC adult clients. This event is a wonderful opportunity for parents with children of any age.

To register for this event, please contact the HRC Resource Center at (310) 543-0691.

Limited childcare will be available during the event by reservation only, by calling Gail Parker at (310) 543-0643. ■

## HOOP DREAMS

*George F. Bird, Jr.  
HRC Board Vice President*

Did you see the CBS news story on the 17-year-old high school student from the Greece Athena High School basketball team from Greece, New York?

Jason McElwain, who is autistic and did not begin to speak until he was five years old, is the towel boy, water boy, and manager for the high school basketball team. Jason apparently also serves as the most enthusiastic cheerleader and all-around motivator for the team. The coach allowed Jason to suit up for the final home game of the season. With four minutes to go in the game, the coach sent Jason in to allow him to have a chance to play in an actual game. Although Jason missed his first two shots, he went on to make six three-point shots and a two-pointer for a total of 20 points before he was carried off the court on the shoulders of his teammates.

At first blush the amazing part of the story is that the autistic 5'6" team manager would be given an opportunity to play a few minutes for the team that he had been supporting by providing towels and water from the sidelines. The fact that Jason scored seven baskets in four minutes, with six of them being for three points each, is in itself unbelievable.

But the most inspiring and magical part of the story is not the challenges of a young man with autism, but the celebration of what he accomplished when given the chance. Jason had always participated as a cheerleader and motivator for his high school basketball team. His

father was concerned at many games that Jason would be called for a technical foul, given the enthusiastic nature of his cheering for his team. What was the coach thinking when he selected Jason to be the manager of the basketball team, and how was he able to predict the valuable life lessons that Jason would teach the rest of the team members? Just imagine what Jason taught all those in attendance that magical night when he hit his final three-pointer at the buzzer, only to be carried off the court by his teammates. Jason brought down the roof, and was quoted later as saying that he was "hot as a pistol."

The story of Jason was sent to me by my fellow Board Member, John Rea. John and his wife Meredith have a 17-year-old son Matthew, who has autism. To John and Meredith, like many other parents here at Harbor Regional Center, it is always about what his son can do, and what his son has accomplished, rather than what he is not able to do.

You should take a moment and take a look at the video news clip of Jason McElwain at [www.cbsnews.com](http://www.cbsnews.com), where you can search by selecting video and entering "Autistic Teen's Hoop Dreams," or by entering this title on Google. When you have had a tough day, or it is just one of those days where the world is getting you down, log on and watch the video of Jason McElwain setting an example of what can be accomplished if you are given an opportunity, and you just try your best. ■

## PREPARACIÓN EN CASO DE DESASTRES Y CONSEJOS SOBRE EL PLAN

### Para las personas con necesidades especiales

#### Persona con necesidades especiales

- Pídale a su médico un plan de atención actualizado, que incluya qué hacer en caso de una emergencia, y una lista de los medicamentos que toma actualmente.
- Tener archivados los formularios completados con la información sobre la salud de su hijo(a). (El formulario está disponible en el sitio web del centro regional Harbor Regional Center [www.harborrc.org/resourceinformation/healthhistory](http://www.harborrc.org/resourceinformation/healthhistory)).
- Tener suficientes medicamentos como para dos semanas, y también tener a mano otros suministros necesarios en relación con la discapacidad.
- Si utilizara equipo médico que requiera un suministro eléctrico, tenga un generador de electricidad de refuerzo o un plan de respaldo.
- Infórmele al equipo de la ciudad que gestione las situaciones de emergencia que usted tiene necesidades especiales, y pida instrucciones sobre qué ayuda, albergues, etc. podrían estar disponibles para las personas discapacitadas en caso de una catástrofe.
- Hable sobre plan para desastres con la escuela de su hijo(a), la guardería, el lugar donde realice actividades diarias, etc.

#### Usted y su familia

- Hable sobre cómo un desastre podría afectar a todos los miembros de la familia, y cómo abordará las necesidades especiales del miembro de su familia.
- Enseñe a los niños cómo y cuándo llamar al 9-1-1 para obtener ayuda de emergencia.
- Prepare un kit de emergencia para usted o su familia.
- Hable con su familia sobre cómo evacuar su casa. Enséñele al miembro

de su familia que tenga necesidades especiales cómo evacuar su casa, o cómo ayudarán otros miembros de su familia, si fuera necesario.

- Escoja dos lugares para encontrarse en caso de que tuvieran que separarse, como por ejemplo fuera de su casa si hubiera un incendio, o fuera de su vecindario, y cómo comunicarse entre todos.
- Pídale a un amigo que viva en otra zona que sea su “contacto familiar”. A menudo, después de un desastre es más fácil llamar a los números de larga distancia que los locales. Otros miembros de la familia deberían llamar a esta persona y decirle dónde se encuentran. Todos deben memorizar este número o deben llevarlos con ellos.
- Muéstrela a sus hijos fotos de los trabajadores de emergencia (como los trabajadores en uniformes, los uniformes de los bomberos y los artículos protectores para la cara).
- Haga planes para sus mascotas, incluso qué amigos o residencias caninas podrían atenderlos si usted no pudiera quedarse en su casa, y también tenga un refuerzo de alimento adicional para la mascota para casos de emergencia, etc.

#### Su hogar

- Revise su hogar para ver si hay materiales u objetos que podrían ser un peligro durante un desastre. (No se olvide de revisar afuera).
- Coloque cerca de los teléfonos los números de emergencia.
- Ubicar y enseñarles a los miembros de la familia cómo y cuándo cerrar los interruptores principales del agua, del gas y de la electricidad.
- Cambie las baterías de los detectores de humo y de dióxido de carbono de su hogar.
- Tenga a mano los recursos necesarios como manguera de agua, extintores de incendios, generadores, etc.
- Hable con sus vecinos para establecer cómo se ayudarán mutuamente en caso de un desastre.

*Información proporcionada por el instituto “Florida Institute for Family Involvement”* ■



**UNA LLAMADA LE COMUNICA CON  
LA ASISTENCIA DISPONIBLE EN SU COMUNIDAD**



**Llame al 2-1-1 para encontrar los servicios que necesita:**

- Dónde puede recibir ayuda con comida • Dónde obtener servicios de salud gratuitos o de bajo costo • Información sobre cuidado de niños
- Asistencia para el cuidado de padres ancianos • Recursos para encontrar empleo
- Dónde encontrar un refugio cuando esta desamparado
- Dónde obtener asistencia para problemas de alcoholismo
- Dónde trabajar como voluntario para ayudar a otros menos afortunados



**Llame al 2-1-1 si necesita Servicios Humanos y de la Salud.  
O llame 800-339-6993.  
Gratuito y Confidencial. 24 Horas al día, 7 días a la semana. Multilingüe.  
Llame al 911 para Emergencias. TTY 800-660-4026.**

**BOARD OF TRUSTEES**

- Mrs. Karen D. Kinnebrew  
*President*
- Mr. George Bird  
*Vice-President*
- Mr. W. John Rea  
*Treasurer*
- Dr. Ken Moses  
*Secretary*
- Mr. Mariano Sanz  
*Past President*
- Mr. Robert A. Irlen  
*Board Advisor*
- Ms. Rhiannon Acree
- Ms. Rebecca Barrios
- Mr. Robert Bethel
- Mr. Fu-Tien Chou
- Mr. Wesley Dale
- Mr. Gary Galosic
- Mr. Lawrence Palochik, Jr.
- Mrs. Cynthia Pellerito
- Mr. Harley Rubenstein
- Ms. Costanza Genoese Zerbi
  
- Patricia Del Monico  
*Executive Director*

**BOARD MEETINGS**

No Meeting in June  
 July 18, 2006 – 6:30 pm  
 No Meeting in August  
 September 19, 2006 – 8:00 am

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

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.

Editor .....Nancy Spiegel  
 Photography ..... Michele Broussard  
    Jennifer Lynn  
    Kristin Martin  
    Terri Nishimura  
    Audrey Sunu  
 Production Design .....Janas Communications



HARBOR DEVELOPMENTAL DISABILITIES FOUNDATION, INC.  
 21231 Hawthorne Boulevard, Torrance, California 90503  
[www.HarborRC.org](http://www.HarborRC.org)

Non-Profit Org.  
 U.S. POSTAGE  
**PAID**  
 Torrance, CA  
 Permit No. 28

**IN THIS ISSUE**

- Get Fit! Not Fat! .....1
- The Governor's Proposed Budget for 2006-2007 .....1
- UCLA Study Offers Free Behavioral Therapy  
for Children with Autism and Anxiety .....3
- UC Davis M.I.N.D. Institute Launches Largest  
Biomedical Assessment of Children with Autism .....4
- Meet our Board: Bob Bethel –  
Service “Above and Beyond” .....5
- Client Focus .....6
- Family Matters .....8
- Preparing Professionals Students Gain  
Invaluable Experience at HRC .....12
- Guest Column: Valuing What We Have .....13
- A Treehouse for All To Enjoy .....14
- Resource Center .....16