

# CAPVI News

The Newsletter of the California Association for Parents of Children with Visual Impairments

Issue no. 3

Winter, 2004

## OUR 24 POUND DAREDEVIL

By Grace Tiscareño-Sato



She isn't even walking fully independently yet, but my 2 year-old daughter Milagro, ("miracle" in Spanish) is already skateboarding in the driveway and becoming a "whale rider".

How did she become such a little 24 pound

daredevil? With a lot of terrific services, a lot of love, and two parents who have strongly resisted overprotecting her despite her very, very fragile beginnings.

My pregnancy experience was terrifying and nearly ended in a late term miscarriage. Instead, we celebrated the live birth of an eighteen ounce baby at 25 weeks gestation, endured five months and six surgeries in the NICU, mostly attempts to save her retina from the ravages of ROP.

After all that, my husband and I are truly enjoying her gregarious personality and her daring style of play. It's the best reward for our little family.

My purpose in writing this article is three-fold: to share stories of wonderful moments with my daughter; to give parents of visually impaired and blind toddlers activity ideas for playing with their children; and to encourage parents of little VI kids to allow

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## CAPVI RECEIVES GRANT FROM THE HILTON-PERKINS PROGRAM FOR THE SECOND YEAR

CAPVI has once again been given a \$2,000 grant from the Hilton-Perkins Program. Thanks to the Program, CAPVI will be able to fund the printing and mailing of our next two newsletters. We will also be able to print brochures describing CAPVI, soliciting memberships and donations. We plan to place these brochures in doctors' offices, at Family Resource Centers, in clinics, and other places where families with children who are visually impaired will see and use them. Some of the money will be used to hold regional meetings for parents around the state. We will have informational tables at conventions and conferences concerning the visually impaired.

Thank you, Hilton-Perkins Program! All of these activities will be even more effective with membership dues matching the grant. Please remember to send in your dues (see page 7), so that we can publish four quarterly newsletters this year, rather than just two of them and continue to expand the services we can offer parents.

Spread the news, contact any parents of children with visual impairments known to you. Spread the news about CAPVI and NAPVI! Together, our experiences with our children will help other parents.

**IMPORTANT NOTICE:** CAPVI is entirely dependent on grants, donations, and membership dues in order to continue and expand the work we do. Although we have not asked in the past, we are now asking members for dues. Please see Page 7 for the form. *No family will be turned away for lack of funds.* CAPVI is a registered nonprofit corporation; Tax ID #: T.I.N. 33-0298284. Our CA Corporation (non-profit) Number is C 1607838.

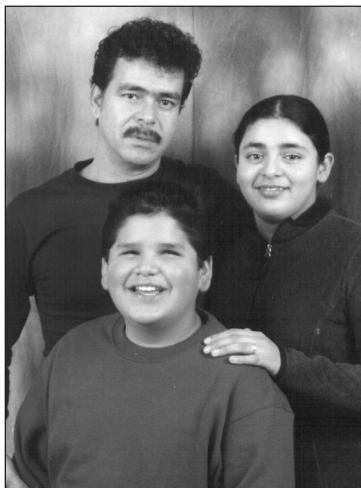
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**NAPVI Anuncia su Website Bilingüe: Inglés / Español: [www.napvi.com](http://www.napvi.com)**

# MEMBER SPOTLIGHT!

In each newsletter, we will highlight some of our members. If you would like to participate, please email [suzi@slmcreative.com](mailto:suzi@slmcreative.com)



*Carlos with his children*

## Carlos Martinez

Allow me to introduce myself: My name is Carlos Martinez. My partner and I raised two children, Carlos (11 years old) and Priscilla (10 years old). Priscilla has no disability, while Carlos enjoyed normal vision at birth, then received

a diagnosis of Bilateral Retinoblastoma when he was one year old. After intensive treatments such as radiation, and laser and chemotherapy his eyes were removed. This is where my journey began.

We live in the city of Los Angeles where Carlos has attended preschool through Junior High. Since the beginning he showed great independence, self confidence, and academic abilities. Because of these gifts, we took the risk of enrolling him in a regular classroom with resource services. We did this with great fear and trepidation about leaving him in a new and strange surrounding.

I've closely followed everything he does and built the best possible relationship with my son. With our support Carlos has taken significant risks and challenges. He enjoys participating in a wide variety of programs offered by Braille Institute, the Foundation for the Junior Blind, and mainstream programs in our community. He's an excellent pianist, plays base in a Junior Mariachi band, sings in the Braille Institute choir, received first prize in the National Braille Challenge (an academic contest), and participated in a summer program for Technology Training through the California School for the Blind in Fremont.

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# CORTICALLY VISUALLY IMPAIRED CHILDREN: A NEED FOR MORE STUDY

*Excerpt with permission from British Journal of Ophthalmology  
editorial by Creig S. Hoyt, M.D. and Douglas R. Fredrick, M.D.*

In the developed world the face of childhood blindness has changed dramatically in the past two to three decades. Improved medical and ophthalmological care since the late 1950s can be credited with the decrease in the prevalence of congenital and acquired ocular blindness.

For example, the prevalence of congenital cataracts has been reduced dramatically as the result of rubella immunisation programmes. Moreover, a thorough understanding of the importance of early surgery coupled with significant improvements in surgical techniques has resulted in vastly improved visual outcomes in children with congenital and developmental cataracts. Regrettably, the reduction in ocular blindness has been more than offset by an increasing rate of neurological visual impairment.

This change can be attributed to the improvement in rates of survival of very premature infants and critically ill children. For those who provide care for visually impaired children this epidemic of neurological visual impairment has brought with it a myriad of new diagnostic and rehabilitation problems. These children are usually multidisabled visually impaired whose needs are not limited to visual rehabilitation and assistance. In addition, quite often, their multiple disabilities compound the problems of clinical visual assessment as well as rehabilitation strategies.

The term cortical blindness refers to the loss of vision, secondary to injuries or maldevelopment involving the geniculostriate pathways. Clinically, it is manifested as the absence of vision and optokinetic nystagmus in the presence of a normal ocular examination and intact pupillary light responses. It most commonly occurs in children following hypoxic insults, but may also arise as a sequela of meningitis, encephalitis, head trauma, hydrocephalus, or metabolic derangements. While

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# UPCOMING EVENTS

## Leber's Congenital Amaurosis (LCA) National Conference April 2-5, 2004 in Los Angeles

*The NAPVI and FFCVI (Florida Families of Children with Visual Impairments) conference will be hosted by AER in conjunction with its biannual conference at the Disney World Resort Hilton. There is an Early Bird Special for lower conference registration fees which is valid until May 1, 2004.*

**For more information: NAPVI at (800) 562-6265 or [APVI@perkins.org](mailto:APVI@perkins.org). Or you can contact Judith Lesner, Region 6 NAPVI representative at (510) 652-0432.**

## 3rd Annual Beeper Egg Hunt Benefiting the Blind Babies Foundation on April 10, 2004, 11am-2pm Midtown Terrace Playground, San Francisco

*The Beeper Egg Hunt is a signature event of the Blind Babies Foundation and is the largest event in Northern California for children who are blind or visually impaired. Bring your children to participate in the beeper egg hunt, face painting, exploring tactile bunny land, enjoy live music, barbeque and visit with the Easter Bunny! For more information, call (415) 586-6140 or email [bbfinfo@blindbabies.org](mailto:bbfinfo@blindbabies.org)*

## Beeper Egg Hunt in Fresno Benefiting The Blind Babies Foundation on April 10, 2004 at Oso De Oro Park, Fresno

**For more information, call (559) 353-6420 or email [bbfinfo@blindbabies.org](mailto:bbfinfo@blindbabies.org)**

## Active Learning Conference, Co-Sponsored By The James William Peabody Foundation & Palm Springs Elks Lodge #1905 on March 21, 2004

*This conference will take place from 8am-3:30pm at the Palm Springs Elks Lodge, Cathedral City, California. Join presenter, Patty Obrzut as she provides participants with a fresh and innovative approach for creating an "Active Learning" environment. Learn how to promote skills attainment and independence in children of all developmental ages. "Active Learning" is a concept developed by Dr. Lilli Nielsen. "Active Learning" promotes the use of simple adaptations in the environment, and the use of equipment to encourage a child's independent activity. To register or for more information, contact Lorana Enroth at (760) 862-9982 or email [miraclebaby99@aol.com](mailto:miraclebaby99@aol.com). For more information about "Active Learning" check out [www.lilliworks.com](http://www.lilliworks.com)*

## HELPFUL RESOURCES

NAPVI (NATIONAL ASSOCIATION FOR PARENTS  
OF CHILDREN WITH VISUAL IMPAIRMENT)  
**(800) 562-6265 • [www.napvi.org](http://www.napvi.org)**

Information & resources for parents with children who are visually impaired or blind, incl. those with additional disabilities

FREE BRAILLE BOOKS PROGRAM FROM THE AMERICAN  
ACTION FUND FOR BLIND CHILDREN & ADULTS (AAF)  
**(410) 659-9314 X 361 • [brailleaction@nfb.org](mailto:brailleaction@nfb.org)**  
**[www.actionfund.org](http://www.actionfund.org)**

AAF started this program in 1997 to provide blind children with a free Braille book every month from a popular children's reading series. Over the past six years, over 126 titles have been distributed to thousands of blind children.

BLIND BABIES FOUNDATION  
**(415) 586-6140 • [www.blindbabies.org](http://www.blindbabies.org)**

Programs that enable and empower families, to meet the unique needs of infant and preschool children who are blind, or visually impaired, or multihandicapped & visually impaired.

AMERICANS WITH DISABILITIES ACT HOME PAGE  
**[www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm)**

AMERICAN ASSOCIATION FOR PEDIATRIC  
OPHTHALMOLOGY & STRABISMUS (AAPOS)  
**<http://med-aapos.bu.edu>**

Information & support; post questions for a doctor

SUPPORT FOR FAMILIES OF CHILDREN WITH DISABILITIES  
**(415) 282-7494 • [www.supportforfamilies](http://www.supportforfamilies.org)**

A parent-run San Francisco-based nonprofit organization founded in 1982 to support families of children with any kind of disability or special health care need as they face challenges.

COUNCIL OF PARENT ATTORNEYS & ADVOCATES (COPAA)  
**(202) 544-2210 • e-mail [copaa@copaa.net](mailto:copaa@copaa.net)**  
**[www.copaa.net](http://www.copaa.net)**

An independent, nonprofit, tax-exempt organization of attorneys, advocates and parents established to improve the quality and quantity of legal assistance for parents of children with disabilities.

LEGAL RIGHTS OF PERSONS WITH DISABILITIES (4TH ED.)  
BY BILL LOCKYER (CA ATTORNEY GENERAL)  
**<http://ag.ca.gov/consumers/pdf/disabled.pdf>**  
Publication in downloadable pdf format

CAPVI does not guarantee the accuracy of the information posted on these sites, with the exception of our parent organization, NAPVI



their children to do the crazy things they will come up with, resisting the natural urge to smother them with overprotective instincts

### **HAMMOCK FUN IN THE FAMILY ROOM**

When Milagro was 6 corrected months old, our OT suggested we hang a hammock in our living room so Milagro could experience moving through space. First we gently swung her and she slowly learned to hold her head up while swinging. Next we placed the resonance board my husband built under her as she swung. This let her find various objects as she moved through space, getting tactile and auditory feedback rewards for her movement. Soon she was moving rapidly across the board, pushing with her hands, pushing off with her feet while learning how to explore, returning to favorite objects, and kicking her feet vigorously to make more noise.

### **RESONANCE BOARD AS RAMP**

The 4' x4' resonance board my husband built became a ramp in our family room just before she turned two years old. We place one end on the futon, the other on the floor, and my daughter has a slide/ramp to practice her climbing, sliding, entering and exiting skills. She attempts to go up the ramp in her socks, slips down, then removes her socks and flings them away from her body — an obvious hindrance to climbing. We motivate her to go under it by setting her favorite disco light on one side.

We also use the ramp-resonance board to create different rhythms with various objects (hands, maracas, drumsticks, Japanese pestle sticks, etc). Milagro either sets the rhythm that we echo, or repeats the rhythms we initiate. She will also do this half way up the ramp, demonstrating that she can climb while hearing and repeating different rhythms that are resonating under her feet. She has mastered the confidence to go down the slide any way you can imagine: head first, feet first, on her back, on her stomach, with and without socks. She has started to use the futon pillows as sliding aids to accelerate the trip—a very good use of available tools.

### **YOGA BALL BALANCING ACT**

I bought a 15" diameter plastic ball one day, because it was a cool metallic purple color that really reflected light well. For \$1.99, I figured it might be a ball that Milagro could see well enough to find, roll and throw. How right I was! But she came up with better ideas than I did. One day, she rolled on top of the ball with her stomach, reaching her hands on the other side to roll and catch the floor. The ball is perfectly sized so that she can touch the floor with her hands on one side of the ball,

while nearly maintaining contact with the floor with her feet. She maintained this perfect balance on the ball, while rolling forwards and backwards, hands to feet, feet to hands.

Then, much to our surprise, she rolled herself all the way forward, gripped the ball between her thighs, and sat up on top of the ball! Then she began to bounce on top of the ball. It was an amazing sight. I

showed a video tape to her occupational therapist who simply couldn't believe her eyes. I asked her if she didn't think it odd that Milagro doesn't lose her balance and fall sideways off the ball. And why could she maintain her balance so perfectly on the ball, yet not want to take more than three or four steps walking before sitting down?

The OT explained to me that she sees that Milagro has high "standards of perfection" and that she doesn't try a new gross motor skill until she feels certain that she will do it correctly. That explains what happened next.

### **MY LITTLE WHALE SURFER**

Probably the most daring thing she does, which scares me every time, is her whale riding tricks. We have a Little Tikes whale teeter-totter that can be used by one or two toddlers. Within a few weeks of getting this toy, she was riding in the center seat, holding on to the handles, and then standing in the seat while holding on to the handles! What made her do that? What made her then let go of one handle and continue to rock the whale while holding on with just one hand? I don't know but I watched with dropped jaw. The amazing thing is that she did it right the first time, without falling off. She's done this a few times and has never fallen off.



*Acrobatics on Milagro's whale*

children with these types of injuries seldom regain normal vision, sufficient vision often returns to allow them to navigate independently and to receive a partially sighted education. While the recovery of vision may be rapid and complete, much more often it is protracted and partial. Because these children usually regain some vision, it has been proposed that their visual loss be referred to as cortical visual impairment (CVI) rather than cortical blindness.

Assessment of the residual visual function in these neurologically impaired children is difficult. Standard clinical, electrophysiological, and neuroimaging techniques are usually disappointing in their inability to define precisely the nature and extent of residual visual function in these children. Clinicians examining children with CVI must depend primarily on behavioural assessments in their attempt to define the nature of the visual insult and attempt to establish a prognosis.

One problem that now bedevils even the discussion of CVI is that the term CVI has been broadened increasingly in its definition so that it is no longer restricted to the patient with injury to the geniculostriate pathways. It is regrettable that the term CVI now seems to be applied to any child with a neurological insult and apparent non-ocular visual dysfunction. As a result patients with saccadic paralysis, ocular motor apraxia, visual inattention, visual perceptual disorders, autism, and even seizure disorders are often given the diagnosis of CVI even in the absence of injury to the geniculostriate pathways. This is a heterogeneous group of disorders that undoubtedly have uniquely different neurovisual pathologies and each requires a uniquely different adaptation to the underlying neurological deficits.

Obviously, all of the different neurological insults resulting in visual impairment require careful investigation. However, it is imperative that clinical studies be undertaken on a well defined homogeneous group of patients. Even within the group of patients with injury to the geniculostriate pathways there are distinct subgroups. For

example, patients with posterior periventricular leucomalacia are distinctly different from patients with infarction of the visual cortex. A consistent terminology for patients with different types of neurological insults and visual dysfunction needs to be established and widely accepted.

Once the behaviours of the various types of neurological insults affecting vision have been catalogued the real problem begins. Understanding why these children behave as they do is of fundamental importance if better strategies of rehabilitation and education are to be designed. Yet our knowledge is wanting in this area and in most cases the best we can do is speculate. For example, it is well known that children with CVI often prefer to turn their head and eyes away from the target of fixation. Why do they do this? The study of Porro and Br J Ophthalmol 1998;82:1225-1227 suggested they may be using intact peripheral field when the central field is damaged. An extremely eccentric position of fixation might even suggest they are using the temporal crescent as the authors suggest. However, equally plausible is the notion that they may be using their extrageniculostriate system as a replacement for the injured geniculostriate system. This might even come about as the result of rewiring of neural pathways not ordinarily intended to have visual function. Yet, much more simple explanations may prove to be correct. For example, it may be that this "aversion" to the target is simply a way to reduce the amount of visual information to be processed. We need new tools to explore these theses in order to understand this important group of visually impaired children. In the meantime, careful, well designed clinical studies of the recovery patterns of these children provide fundamental information about the problems of neurologically damaged visually impaired. It is hoped that the study of Porro and co-workers is the first of many that will address the needs of this large group of understudied and poorly served visually impaired children.

## **MEMBER SPOTLIGHT, Continued from page 2**

When my son was enrolled in preschool, I participated in ongoing parent groups. I gained insight about my experience and learned that I was not alone; that other families who had a child with a disability were not only surviving, but thriving. I gathered information about my son's disability and grew to accept the help of professionals and other parents. I learned how important it was to get support from people who understood my pain. Because of these experiences I became a firm believer in the importance of parents connecting with other parents.

Four years ago I was hired as a Parent Mentor at the Blind Childrens Center to work with families with young children who are blind or visually impaired. I serve as a role model and help normalize their experiences. My job is to help families learn that children with a disability are children first. When I first entered this realm, I envisioned blindness as being everything in our lives. I now see blindness as simply one aspect of our intricate lives. I can see my son as a complete person and love him unconditionally. Because of this, I now can provide other families with skills and training that strengthen abilities; I serve as a guide to facilitate the journey of others.

As a parent-professional I too have taken significant risks and challenges. I co-founded RAICES, a program emphasizing the needs of Latino immigrants and parents of children with disabilities. I facilitate weekly parent-to-parent support groups, attend IFSP and IEP meetings, speak publicly, provide advocacy training and support to families, assist staff in gaining awareness of the needs of families, attend community meetings, and serve on the board of several organizations including the Southern California Network and CAPVI. It gives me great pleasure to serve alongside Ann Ward as the co-chair of CAPVI. I'm hoping our group emerges as a stable force and becomes a vital organization that represents the voice of parents in California. Your collaboration is important to me. I invite you to attend our meetings and share with us what our organization can do to facilitate your participation.

## **MY 24 POUND DAREDEVIL, Continued from page 4**

### **SKATEBOARDING IN THE SLOPING DRIVEWAY**

Amazingly, I have seen Milagro do daring things that sighted kids don't even want to attempt. Example, a two year old girl was visiting our home with her parents and was watching Milagro "skateboard" down the driveway. I offered the wagon to my little visitor. Her daddy convinced her to go to the wagon, but she wouldn't even think about setting foot in the wagon.

Milagro will not only ride the wagon downhill, but she'll vigorously "pump" the handle to make the wagon go faster! She even tries to pull off her helmet while rolling. We've had to really insist that she keep her hands on the handle and leave the helmet on. She's just fearless — having only light and shadow perception for vision isn't slowing her down!

My Blind Babies Foundation home counselor, Elizabeth Bates, heard my need to have hope for my daughter's future early on in our relationship. She gave me many books and resources. One of them, "Small Victories", contains essays written by blind and disabled adults. A particularly excellent passage by Robert Jones (born prematurely in 1957) I took to heart early on. It reads, "Let your kids fall flat on their faces. Let them decide their own limitations. Don't say 'you can't do that because of your disability.'" Tough advice for any parent; much more so if your child has only light perception.

Another author, Venetia Hayden, shared how she learned not to overprotect and allowed her blind daughter, Maureen, to ice skate with her brother's hockey team. She believed the best way to protect her daughter was to encourage her to "go out and learn how to move her body in space and be balanced and gain all that kinetic awareness."

Parents: let your visually impaired kids' experiments fueled by curiosity happen. If they fall, they fall and you can comfort them, but they must experience the movement, the motion, the balance and imbalance of moving through space. Squelching their experiments with the natural instinct to protect, giving in to your fear that they'll bump their little heads or cut their little lips will not help them develop into the curious, independent exploring children we need them to become. It hasn't always been easy for us, but watching our fragile premature baby become a confident, daring little girl is worth everything.

*Read Milagro's story and see her in action at her web page: [www.babymilagro.org](http://www.babymilagro.org)*



# GREAT TURNOUT FOR THE 8TH ANNUAL LOWENFELD- AKESON SYMPOSIUM

Over sixty parents and professionals gathered for the 8th annual Lowenfeld-Akeson Early Years Symposium at the California School for the Blind in Fremont on Saturday, February 7, 2004. People were welcomed by Stuart Wittenstein and Steven Goodman of the California School for the Blind, as well as by Julie Bernas-Pierce from the Blind Babies Foundation, and Sharon Sacks of CSU Los Angeles. The very interesting morning speaker was Dr. William Takeshita, O.D., of the Center for the Partially Sighted. The topic for the Symposium was Cortical Visual Impairment. Dr. Takeshita spoke of the study conducted by the Center, on children with neurological vision impairment seen at the Center from 1990-2002. He spoke of the different types of neurological vision impairment, and of some of the implications for the patients and their families. After lunch, attendees broke up into three groups for "CVI Parent-Professional Perspectives: 'The How To's':" Birth to Three, led by Stephanie Spaid and Jenny Dorwin; Three to Five, led by Deborah Faryniarz and Outi Talvala; and Five to Eight, led by Judith Lesner and Pat Leader. The day concluded with an informal CAPVI meeting.

## Do you homeschool your visually impaired child?

The NAPVI office has had some recent requests for more information on home schooling for children with visual impairments. If you are currently home-schooling your child, or plan to do so in the future, and would like to be part of a national parent support group for home-schooling, please contact the NAPVI office at (800) 562-6265 or email [napvi@perkins.org](mailto:napvi@perkins.org).



**IMPORTANT: Most of our ongoing correspondence is being done by email. To receive email updates regarding CAPVI, events and Joint Action Committee news, please email [pierce@sonnet.com](mailto:pierce@sonnet.com)**

Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
City: \_\_\_\_\_ State \_\_\_\_\_ Zip: \_\_\_\_\_ Phone: \_\_\_\_\_  
Email: \_\_\_\_\_  
How do you prefer to be contacted? \_\_\_\_\_  
Child's diagnosis (*Optional*) \_\_\_\_\_  
I am interested in learning more about: \_\_\_\_\_

- ☐ \$10 — Annual Student Membership  
☐ \$25 — Annual Family Membership  
☐ \$50 — Annual Professional Membership  
☐ \$15 — Newsletter Subscription for non-member

- ☐ \$500 & up — Corporate Sponsor\*  
☐ I would like to lend additional support to CAPVI with my tax-deductible donation of \$ \_\_\_\_\_



All CAPVI members receive our quarterly newsletter and invitations to upcoming meetings and events. We do not share our mailing list with anyone. All information provided will be kept in strictest confidence. CAPVI is a registered nonprofit corporation; Tax ID #: T.I.N. 33-0298284. Our CA Corporation (non-profit) Number is C 1607838. **No family will be turned away for lack of funds. Please send your written request to the address below for membership at no charge due to financial hardship.**

\*Corporate sponsorship includes mention/logo included in all CAPVI publications/events. For more information about sponsorship opportunities, please email [suzi@slmcreative.com](mailto:suzi@slmcreative.com).

Please make your check payable to "CAPVI" and mail to: CAPVI, 22478 Longeway Road, Sonoma, CA 95370

# CAPVI

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Sonora, California 95370

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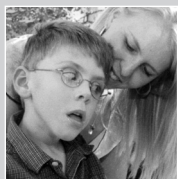
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The California Association for Parents of Children with Visual Impairments (CAPVI) is a non-profit organization of, by, and for parents committed to providing support to the parents of children who have visual impairments.

If you would like to submit articles or information for consideration for use in future newsletters, please email [suzi@slmcreative.com](mailto:suzi@slmcreative.com) or call 415-945-9345. CAPVI reserves the right to edit all submissions for content and available space.

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