



# Newsletter for the Earle Baum Center

Serving People With Sight Loss

(707) 523-3222 [ebc@earlebaum.org](mailto:ebc@earlebaum.org)

November 2010 Volume 10 Issue 4

## She just wants to be a regular mom



Pam McConky is a relatively new client of the EBC. She lives in Petaluma with her husband Dave, 3 year old son Eric and 5 day old daughter Hannah. Showing no signs of having just given birth a few days earlier, Pam exhibited her youthful energy as she bounced down

the hallway to welcome me. We quickly settled around the all familiar kitchen table to discuss her life and what it is to be a modern day mother with Retinitis Pigmentosa or "RP". Typical of many people with RP, it is not obvious that Pam is visually impaired.

Pam shared how "shocked and confused" she was when told at age 18 that she could be blind by age 30. Soon after her initial diagnosis, she became an active volunteer with Foundation Fighting Blindness, an organization that raises money and funds retinal research. Regardless of the uncertainty of her future, she continued with school and work eventually became a special education teacher to students with autism.

About 6 years ago, Pam met her future hus-

band Dave, a career US Coast Guardsman now stationed at Fort Point at the Golden Gate Bridge in San Francisco. While they both openly share that Pam's eye disease was discussed before marriage, I sensed that this was still a sensitive issue. Pam will also tell you that her eye issues were a difficult topic with her family and friends. "Very guarded" was the term that she says describes those hard times.

Dave and Pam have been married 5 years and are both from the East Coast. Pam was an Army Brat and was actually born in Japan, spending her early childhood years in Texas and Hawaii before her family settled in Virginia. Dave is a native of New Hampshire. No longer located near the support system of family & friends since being transferred to the Bay Area, they quickly realized how much they needed to rely on each other. Both will tell you that moving to California has made their relationship stronger than ever.

Pam quietly lowered her voice when she told of the dreaded day that she had to give up driving. "We knew it was coming, but not so soon." This huge turning point was clearly difficult and emotional for Pam and made even harder when she told Dave of her decision after nearly hitting a pedestrian. She was keeping the changes of her sight to herself, "trying to shield Dave from my fears."

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## **Regular Mom, continued from page 1**

Dave was unaware of the progression of her sight loss and believed everything was stable. Pam is quick to tell you that "Dave has always been part of the process but I did not want to burden him." This realization took Dave by surprise and recognized the dramatic changes that would impact their lives. Later, Dave shared that "Pam not being able to drive was very difficult for both of us" and went on to say that even going out for a quart of milk became a major effort. The frustration of "not being able to pack up and just go" was echoed by both Pam and Dave made more challenging by their expanded family. "A simple task that so many of us take for granted is no longer simple". However, Pam will tell you without hesitation that they see themselves as a family like any other young family but with a few "different" needs. They feel fortunate living in Petaluma with its reasonable proximity and walking distance to schools and stores yet doing normal activities poses greater obstacles than before.

Pam's face lit up when she shared that "moving to California was a challenge but a blessing in disguise due to EBC." Pausing to collect her thoughts, she refers to EBC as a "one stop, one shop for help!"

When asked to elaborate on her experience with the EBC, she quickly replied "thanks to EBC, I am looking forward with hope." She attended the Introduction to Vision Loss class where she found instructor Denise Vancil to be "very amazing and inspiring". Pam went on to say that Susan Hirshfield was also high on her list when it came to her EBC experience. It gave Pam an outlet "to share – guilt free". With a positive tone to her voice she told how Susan's classes were "very therapeutic" and she "looked forward to going each week." It was apparent

that Pam was a bit sad when the classes ended. With a big smile Pam said that "taking these classes has taught me now to be unafraid." She hopes that a new parent's group will be established at the EBC in the future.

On a personal note, it was an emotional moment for me when Pam explained that in order to see her son's entire face, she has to hold him and look into a mirror.

Sadly she can only see a small part of him when they are close together. Also equally touching was how Pam plays ball with her older son Eric, but can only do it inside the house with a large ball that she can track. Yet, Pam continues to do all the things that any good parent will do and does whatever it takes to take care of the needs of her family and her life.

Pam expressed that the EBC is providing the tools, hope and inspiration to its clients. She is excited about her future and will tell you that "it is easy to be in denial, but easier to cling to the brighter side of life.

Losing sight can be very scary, but I can't let it get in the way."

## **2011 Large Print & Braille Calendars**

2011 Calendars for the visually impaired are now for sale at the Visitor's Center. Your choice of two styles – one style is in Braille and Large Print – and feature work by blind artists.

The other style is a large print wall calendar with space to write. Both styles sell for \$12.00 and are available at the Visitor's Center with proceeds going to the Redwood Empire Council of the Blind.

Cash or check please. Make checks payable to RECB.

## Nothing is getting in his way...



Kyle Slobodnik is a young man of 24 years who is moving forward in life with zest and passion – regardless of his impaired vision. Kyle is another new client to The Earle Baum Center who is a true inspiration to those

who have the pleasure of meeting him.

Born in Denver, Colorado, and raised in Santa Rosa since age one, Kyle lives with his parents Mike and Julie Slobodnik along with his sister Kristine. Kyle graduated from Santa Rosa Junior College's Culinary Program and The California Culinary Academy in San Francisco specializing in baking and pastry. His interest and career in baking started with Cavalleri's Bakery in Santa Rosa and in October of 2008 he starting working at Oliver's grocery store on Stony Point Road in Santa Rosa.

Having worn glasses since grammar school, he had his routine eye exams on a regular basis. In February of 2009 right after getting new glasses, his parents noticed that he was having difficulty reading things that had never been an issue. After extensive testing by specialists, it was verified that Kyle's vision was quickly deteriorating. Fluid was building up behind his eyes.

Kyle openly shares how "emotional this has been for my family." His father Mike echoed these same feelings and shares how difficult it is as a parent watching his son lose sight. It was "devastating and shocking."

There is no concrete diagnosis of the cause of Kyle's sight loss. Recently, Kyle and his parents were referred to the National Eye Institute in Maryland to be part of a special

case study that will include genetic testing of both he and his parents with the hope of determining the cause of Kyle's sight loss. Kyle is quick to point out that "This may not help me, but I am doing this to help someone else."

When asked what he felt upon learning that his vision was failing which could result in total blindness, his response was "frustrated and angry". "This all came on rapidly... with white spots and having difficulty reading recipes." Kyle is losing his central vision. One of the hardest parts for Kyle has also been "losing my driver's license and having to rely on other people." With the help of Regina Perez, Orientation and Mobility Specialist at Earle Baum Center, he is quickly learning how to get around safely as well as use public transportation.

When asked of the challenges in using public transportation, Kyle shared the frustrations of having no control when an early or late bus throws off his schedule 10 to 40 minutes. Kyle is prepared for the unplanned delays by keeping his IPod with a good audio book in his backpack.

Kyle is quick to share how important his family is to him, including his 10 year old nephew Gabe. "We are like brothers and enjoy computer games and the Xbox." "My family has been willing to do anything to help me", including driving him to and from work. He wakes up at 4AM each morning and is at work by 5.

Kyle has also had great support from his employer, Oliver's. "They scale out the ingredients I need each morning in order to bake and have grouped the food elements in the same place as well as leave me big notes." He has a great team of co-workers who have all pitched in and have all worked together to support him.

***Continued on Page 4***

## ***Nothing can get in his way... continued from page 3***

His immediate manager Tracy Collingworth shared “Kyle is an upbeat guy and just powers on”. She arranged to have his parents come in to collaboratively map out a plan of action to help Kyle in the workplace. Store director Eric Meuse called Kyle “an amazing young man” who has adjusted quickly to his disability and “just puts a smile on his face and keeps going...shrugs off any issues.”

Not only is Kyle busy with his work at Oliver’s, he is a busy volunteer at New Vintage Church. Each Sunday you can find him working at the espresso cart. He is quick to share that he enjoys the contemporary services at church. His faith is strongly validated when he says “God is going to take care of me.” Kyle learned of the EBC by a family member who works with instructor Denise Vancil’s husband, Ben. He and his family live near EBC and had driven by the center many times and never really understood what was happening “in those little yellow houses”. When asked how the Earle Baum Center has helped him the response is very quick “they have helped me realize that I am not the only one facing these issues... they have been very supportive.”

Kyle got a comprehensive overview of vision rehabilitation when he attended the Introduction to Vision Loss class taught by Denise Vancil. It was followed by Susan Hirshfield’s Living With Vision Loss class which was “very helpful and very supportive.” He then shared that “meeting with Jacques (Law) each week at EBC is the best thing”. Thanks to Zoom Text and

Jacques adaptive computer training, Kyle is quickly gaining new computer skills that will keep him in the loop of life. When asked what he would say to someone newly experiencing sight loss, he replied “let them know about EBC and reassure them that they are going to be okay. I don’t know what I would do without EBC”.

Kyle is truly an inspiration to anyone who has the pleasure to meet him. He is a confident young man who is moving forward in life and appreciates and understands the meaning of family, life and community.

**Nothing is getting in his way.**

**Flu season is here.**

**Have you gotten your flu shot yet?**

## **Tech Club News**

Formed in 2007, the EBC Tech Club currently meets the first Monday of each month from 9:30 AM to 11:00 AM. Beginning in 2011 the meeting times move to 11:00 am to 12:30 PM. The first meeting of 2011 will be on Monday, February 7<sup>th</sup>.

Tech Club discusses hardware and software solutions as well as services as it relates to persons with visual impairments. Topics include cell phones, digital recorders, EBook resources & players, video magnifiers and software applications.

An Email group has been established where member receive announcements of upcoming Tech Club meetings. In addition members can email questions to the group. It is not required to attend the monthly meetings to be a member of the Email group. Membership to this group is by subscription only, so please contact the EBC Tech Dept at 707-532-3222 if you are interested or have further questions.

## New Face at VIST/ VA

The Department of Veterans Affairs (VA) recently announced the appointment of Lila Jaffray as the new VIST coordinator for our area. VIST stands for Visual Impaired Services Team. In her new role as coordinator, Lila will be coordinating services for veterans with vision impairment.



Jaffray has over 16 years experience in working with the blind and vision impaired. She began her career with the VA at the **Western Regional Blind Center** in Palo Alto. Currently she is based at the San Francisco VA office. Her geographic area includes San Francisco, Ukiah, Martinez, and Santa Rosa.

Jaffray was excited to be working with the Northbay area veterans. She also works with a VA team of social workers and program coordinators to better serve the needs of the veterans. She shared that she will be working on a new and improved outreach program for local vets and will be once again partnering with Earle Baum Center. 2011 plans call for starting a new VIST Support Group for our area. This support group is scheduled to have its first meeting in early 2011. Final details are still in the planning stages at press time. Jaffray also will be looking at a future recreation program for disabled vets and shared that "the goal is to get our vets involved in more recreation activities as part of a general rehab program." She went on to say "I am looking forward to working with the vets."

Lila Jaffray can be contacted at 415-221-4810 Ext #2813

## Thanks to our Volunteers

A hearty Earle Baum Center thank you to Don Voss. Don just completed his sixth year as barbecue chef for our summer TGIF barbeques. Gina Milton and Leslie Leal took on the task of shopping, food preparation, serving and cleaning up. Thanks for doing such a great job. Thank you's also go out to the other barbecue volunteers including Nancy Shaw, Joe Reidl, Paul Mousakis, Grace Garcia, Gladys Gerber, Shane Shaw, Claudette Hunter, Yadira Esparaza, Jeanette Stewart, Christina Damrow, John Jones, and Linda Picton. And a special thanks to the Soroptimists for once again managing the final barbecue of the season.

*Interested in Volunteering at EBC? Please call 707-523-3222*

## Get Connected! Get Answers!

*"When life throws you a curve ball and you don't know where to turn, call 2-1-1"* Sonoma County's 2-1-1 program provides a wide range of information on local community services and programs and is especially helpful for seniors and persons with disabilities. Through 2-1-1 you can get information on home health care, adult day care, home-delivered meals, and transportation.

When you call 2-1-1 you will be immediately connected with a trained specialist who will listen and connect you with the services and people that can help you. 2-1-1 is available 24 hours a day. It is fast, free and confidential.

This local community program is sponsored by Sonoma County Community Foundation, The Sonoma County Volunteer Center and United Way of the Wine Country.

**THANK YOU!**  
**FOR THE BIGGEST EARLEFEST YET!**  
**Special Thanks to Our 2010 Sponsors**

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**All of Our Many Volunteers!**



## From the Center



Every year at this time, I look back with disbelief that the year has passed so quickly. Sometimes, it feels like nothing was accomplished and the mountain before me has barely been touched.

Then, I think about the previous years' anniversary in October, our holiday party and returning to work in January after our break and begin reviewing all that went on.

At the beginning of 2010, having passed the 10 year milestone since we opened our doors, the economic conditions were very bad for many people we serve and the country faced challenges that still continue. We all hoped that recovery would be faster than predicted but unfortunately, we were not so fortunate. Along with the Federal financial crisis, the State of California faced its' own crisis creating a domino effect that impacted the most of us. As a result, the EBC faced greater challenges than in most years. So, what did we do about it? The opposite of what you might think. I will just touch on a couple of highlights.

In March, the EBC opened a Low Vision Clinic, a medical component to our vision rehabilitation model. The service combines two major components that begin with extensive evaluations by our Optometrist to fully understand the remaining functional vision of our patients. That is followed by more evaluations by our Low Vision Therapist working with a range of vision aids and tools to help patients best utilize remaining sight. To many, the result is dramatic when they can once again do things that they thought were lost. The Low Vision Clinic

added a completely new dimension to the EBC and supports the rest of the our services. We feel very fortunate to be able to offer Low Vision Examinations.

Since the beginning of 2010, our staff has grown and transitioned as the complexity of the organization has increased. We have been fortunate to have received many donations and significant grants to make the growth possible.

This year, we decided to ratchet up EarleFest, our Americana music festival, to have a bigger impact. EarleFest was an incredible collaboration of many talented people. Putting on a large event is a major undertaking and our base of skilled volunteers and staff proved invaluable. On September 25, we held our third annual event. We were prepared for a much larger crowd than in the past and everything was in place. However, prepared or not, when a rush of cars and large crowds lined up before the doors opened, the reality of a much larger event set in. Everyone stepped up and the quality of those committed to overseeing their share of the effort became even clearer. Overall, the event appeared to be seamless with only a few growing pains that are to be expected. Even the glitches were handled well and everyone stepped up with such grace that the impact was non-existent.

EarleFest attracted between 1200 to 1300 attendees to enjoy stellar music, great food and beverage and contribute generously to the EBC. The event was amazing! The feedback was positive and we made a lot of new friends at the EBC. Our venue is magnificent for a music festival and all I will say is "wait until next year". It will be even better.

So, looking back over 2010 and reaching our 11<sup>th</sup> anniversary, even though the

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## ***From the Center, continued from page 8***

mountain of needs still seems to tower over us, our vantage has improved and the EBC continued to make a greater difference with the help of so many.

We are grateful to all our supporters over the years and hope the base of support grows. If you are able to contribute to the Earle Baum Center, your generosity will be greatly appreciated. Together, we will strive to reach the highest peaks so we can look back and cherish our accomplishments.

Here's to 2011. May it bring all of us peace, good health and prosperity.

Allan Brenner, President/CEO

## **Express Your Creativity**

*Are you interested in poetry? Would you like to learn more about poetry?*

The Bennett Valley Senior Center is now offering a weekly Poetry Class every Tuesday morning from 9 AM to 11 AM now through December. These weekly drop-in classes are taught by Tom J. Mariani, Poet Laureate/ UUCSR. There is a \$2.00 drop-in use fee per session. These weekly classes will cover the history of poetry and styles. Attendees will also enjoy prompts and suggestions as well as a better understanding and appreciation of poetry. The Bennett Valley Senior Center is located at 704 Bennett Valley Road – Santa Rosa. For further information please call 545-8608.

The Sonoma County Library is now featuring Poetry Slams on the 3<sup>rd</sup> Friday of each month at 7:00 PM through June of 2011. These poetry slams are open to the public and free of charge and are non – competitive. Friday evening poetry slams are held at various Sonoma County Library Locations. There are three rounds for each po-

etry slam with each contestant limited to 1 poem per round, with a limit of 3 minutes.

Contestants are encouraged to bring 3 poems. Judges are randomly selected out of the audience. All contestants compete for 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> places with gift cards as prizes. For official Poetry Slam rules go to <http://poetryslam.com/>. The Sonoma County Library is located at 211 E Street – Downtown Santa Rosa. For further information and slam locations please call 537-0162 Ext. # 5

If you are interested in writing a 50,000 word novel check out “The Write-In’s”, a special class being held at the Unitarian Universalist Congregation Church in Santa Rosa. Classes are free and open to the public every Monday in November from 6:00 PM to 8:00 PM. For further information call 568-5381.

## **Automatic Way to Support EBC**

Thanks to Oliver’s Markets, EBC is excited to announce that we are now a partner with eScrip. eScrip is a hassle free way for the community to support local non-profits through everyday purchases made at local eScrip merchants. The list of merchants is available on the eScrip website.

eScrip has created a system that rewards customer loyalty by contributing a percentage of purchases to your chosen local non-profit. You shop the way you like for groceries, clothing, travel and entertainment.

The program is very simple in design and convenient to use. All you need to do is go to [www.escrip.com](http://www.escrip.com) and sign up. Register your local grocery club cards and debit/credit cards, then designate the Earle Baum Center to receive contributions. Our group number is 500024246. Then just start shopping as usual.

## **Introduction to Vision Loss Presentation Coming to Ukiah**

On Wednesday, December 8<sup>th</sup>, Patricia Jefferson, EBC Vision Rehabilitation Assistant, will conduct a free, informational presentation on “Introduction to Vision Loss” at the Ukiah Senior Center from 3:00 pm to 4:30 pm. The Ukiah Senior Center is located at 499 Leslie Street in Ukiah.

Jefferson will present an in-depth presentation on the services, classes and assorted programs that EBC provides to those with vision loss. Key topics will include mobility aids, record keeping, organizing & labeling, local services, in home safety and assistive technologies.

Persons with low vision impairment, as well as family members and friends, are encouraged to attend this free 1.5 hour presentation. There will be a question and answer period following the presentation.

Please call EBC at 707-523-3222 or the Ukiah Senior Center at 707-462-4343 for further information and to RSVP

## **How Would He Play Games?**

*“The holidays were upon us, and our relatives & friends were soon to arrive. It would soon be time for all of us to play our favorite board games. The games of Monopoly, Scrabble, Checkers & Tic Tac Toe were sitting by the fireplace waiting to be played. But we knew that our visually impaired brother couldn’t see, so how was he going to play? ” This is an all too familiar scenario and question that comes up every holiday season with many families who have a family member who is visually impaired.*

Fortunately many of today’s classic board games have been adapted so that visually impaired and blind individuals can enjoy playing them along with their sighted counterparts. With large print, high contrast, Braille & tactile markings the games become playable for all.

Monopoly, which is historically one of the most popular games. Thanks to special Braille features on the boards, cards, dice, and instructions making them easier to read. The cards and board are also displayed in large print to accommodate individuals who are low vision. The game has an overlay sitting on top of the board that allows players to easily recognize the spaces and designated areas for properties.

Other examples of accessible games include the following: Checkers Set - A plastic board with alternating raised and recessed 1" squares sets the stage for this game of checkers. Wooden checker pieces are shaped as circles and squares.

Scrabble comes designed with the low vision user in mind. This high-contrast version of Scrabble features 5/8" square tiles that are white with black letters, and a rotating board with large black letters against a white background. Squares of the board also have been raised to prevent tiles from sliding around. There is also a Braille version. Contact the following companies for more information:

**Light House 415-431-1481**

**Independent Living Aids  
800-537-2118**

**Maxi Aids 800-522-6294**



## **We thank our recent donors for their generosity**

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Our apologies if we've omitted your name. If you should have been listed and were not, please contact the Earle Baum Center at 523-3222.



EARLE BAUM CENTER  
4539 Occidental Road  
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### **MISSION STATEMENT**

To provide opportunities for people who are blind or visually impaired to improve and enrich their personal, social and economic lives.

Contact us: email: [ebc@earlebaum.org](mailto:ebc@earlebaum.org) Telephone: (707) 523-3222  
Fax: (707) 636-2768 [www.earlebaum.org](http://www.earlebaum.org)

### **Holiday Schedule**

**EBC Holiday Party**  
**Thursday**  
**December 16, 2010**



The Earle Baum Center will be  
**CLOSED**  
**NOVEMBER 22 TO 26**  
**DECEMBER 20 TO 31**  
**No Classes or Services**

### **New Meeting Times**

#### **Exercise Class**

Beginning In January – 2011  
The Exercise Class will Meet  
On Tuesdays & Thursdays from  
9:45 AM to 10:45 AM

#### **Tech Club**

Beginning In February – 2011  
The Tech Club will Meet  
On Mondays from  
11:00 AM to 12:30 PM