Serving Families of Children with Special Needs • Sirviendo Familias con Necesidades Especiales

# Welcome/Bienvenidos

Letter from the Director/Carta Enviada por el Director



By Cece Pinheiro

**Dear Friends**— We are so grateful for Caroline's nonprofit thrift store in Aptos. Caroline's is the life blood of SPIN and a life line to our SPIN families. Thanks to Caroline's and Christy Licker SPIN is able to help so many more families in need again this year!

QUIZ NITE 2017! SPIN celebrated our 17th year with Quiz Nite 2017! Many non-profits do numerous fund raisers every year, we do only one, Quiz Nite, it is the one time a year those who support SPIN can come out and help us honor a family with a special needs child. A great time was had by all and this year's theme was "Tropical Fantasy" and Lex VandenBerghe our MC was spectacular in his grass skirt. This year's honored family was the Potts family, mom and dad Tricia and Bob and kids Lauren, Evelyn and Oliver, congrats!

I'm keeping my comments brief this time because I want you to take the time to read the article below titled "The Suitcase" by my friend Bob Mclalan, who has a sister with down syndrome. The article is a chapter from his upcoming book about the sibling experience with his sister.

# The Suitcase

By Bob McLalan

POR CECE PINHEIRO

**Queridos Amigos**— Estamos muy agradecidos por la tienda de segunda mano sin fines de lucro de Caroline's en Aptos. Caroline's es la sangre vital de SPIN y una línea de vida para nuestras familias de SPIN. Gracias a Caroline's SPIN pudo ayudar a mucho más familias necesitadas este año

QUIZ NITE 2017! SPIN celebro sus 17 años con Quiz Nite 2017! Muchas organizaciones sin fines de lucro hacen numerosos eventos para recaudar fondos cada año, nosotros sólo hacemos uno, Quiz Nite, es una de las pocas veces al año donde las personas que apoyan a SPIN pueden salir y ayudarnos a honorar a una familia con hijos con necesidades especiales. Todos pasaron un gran momento. El tema de este año fue "Fantasía Tropical" y Lex VandenBerghe nuestro MC estuvo espectacular en su falda de Hula Hawaiana. Este año la familia honorada fue la familia Potts, Tricia, Bob y sus hijos Lauren, Evelyn y Oliver, felicidades!

Estoy manteniendo mis comentarios breves esta vez porque quiero que usted tome el tiempo para leer el siguiente artículo titulado "La maleta" por mi amigo Bob Mclalan, quien tiene una hermana con síndrome de Down. El artículo es un capítulo de su próximo libro sobre su experiencia de tener una hermana con necesidades especiales. Lamentablemente los artículos de Bob aún no están disponibles en Español.

...Nurturing Special Kids' Potential



...Nutriendo el Potencial de Niños Especiales

y phone rang one night after midnight and once I picked up the receiver, I heard a hysterical woman apologizing and trying to tell me something about the police and news cameras.

Once I got her to calm down, I realized she was the owner of the board and care facility where my sister lived. She told me that the police and the State of California were closing the facility and transferring my sister to somewhere else. I tried to get more information but other than telling me that she had no idea of where Toni went: she hung up.

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# Special Parents Information Network

SPIN is a nonprofit organization dedicated to providing support, information and training to the families and guardians of children with special needs.

Red de informacion para Padres Especiales SPIN es una organización sin fin de lucro dedicada a proveer apoyo, informacion y entrenamiento para las familias y tutores de ninos con necesidades especiales.

# BOARD OF DIRECTORS MESA DIRECTIVA

Greg Horne Ken Kulpa Brenda Miller Dee Teutschel Tami Woods

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Sonia Plageman, Parent Support Training Coordinator

#### **San Benito County:**

Ricardo Cornejo, Parent Support & Training Coordinator

# The Suitcase—continued from page 2

BY BOB McLalan

I had no idea of who to call. Offices were closed at the regional center. I waited expectantly for a call from her case manager but none arrived. She disappeared into the night in a vehicle of a State of California. I never learned what happened at the house. No explanations were provided.

Early the next morning, I received a call from a residential center in Fremont. The woman I spoke to explained that Toni had been brought there on an emergency placement. No details were provided about what happened. She gave me the address and I drove across the bay to see her.

Driving up a palm tree lined lane I entered a circle around which were various dorms and houses that contained about 125 residents. The large house in the back was where they kept Toni.

The grounds were very nicely kept and the residents seemed to be able to enjoy the property at their leisure. They were safely far off from the road below and the staff was ample enough to keep an eye on everyone.

The grass was well kept and in the center of the circle was statue of the Virgin Mary. Being a catholic, I saw the statue as a good sign.

Toni escorted me around the house with a staff member who explained the daily programs and activities. We entered into a small bedroom and there on the bed was a solitary suitcase. All of Toni's possessions were contained in it. She had pictures of her brothers, Michael Jackson, Elvis Presley, her watch and some clothes. At 40 years of age these were all her possessions. So many of the gifts and clothes that she had received over the years were either lost, or stolen. I learned long ago that anything I gave her had a short life span. This suitcase showed me the difference between the world she lived in and mine.

Mine was about relationships, children, family, possessions and permanence. It was about work and

disappointment too but I traveled freely and had independence in my choices. I made my own decisions. My life was the foundation upon which I could build a career or pursue some dreams out in the future. My life was such a contrast to hers and I tried to bring some of mine to her.

Toni spent her life living in institutions, with no family around, and spent her holidays and birthdays on the ward with the other souls left behind. She wore clothes that didn't fit her let alone be fashionable. Her hair was never styled. Just cut. Her meals were communal and no one asked "how would you like your eggs done?" That suitcase still comes to my mind now and then and my reaction to the memory is the same now as it was when I saw it lying on a bed that was not hers, within a house that was not her home. It made me sad.

Serving in the Marines, I was familiar with the way institutions can coerce and force compliance from the men. In that environment, I could understand why regimentation, discipline and cold order were so important but for someone like, Toni who was born with Down Syndrome, it must have difficult and confusing to understand the rationale of what was happening in her world.

Most importantly, I was not a helpless individual trapped inside a vast state hospital complex without rights or advocates. Unlike Toni I knew the date when my enlistment ended. When the day arrived, I would gather my things and drive off the base to return to my home and family.

Toni's life was very much like living in the military. She would be required to move out on a moment's notice. Travel and live in many places. All her possessions could be packed in a Sea bag or footlocker. She had the cold comforts of living is a in large ward with no privacy, medical care, communal dining with a hundred of her closest friends, heat and people telling her what to do all day.

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### WEBSITE ANNOUNCEMENT

Please remember to check out the SPIN website: *iRecuerde visitar el sitio Web de SPIN:* 

# www.spinsc.org

for the latest on activities, events, support groups, and more! para lo último en actividades, talleres, grupos de apoyo, y más!

# announcements/ anuncios

# Welcome new Board Members/ *Bienvenidos Miembros nuevos de la Mesa Directiva*

Dr. Greg Horne was born and educated in England, and moved to the USA in 1978. Now retired, he spent his career in Management Consulting, working with HIgh-Tech, Aerospace, and Life Sciences companies. He lives in Aptos with his wife Kathy and their two children, Molly (18) and Christian (19), both of whom are on the Autism spectrum.

Dr. Greg Horne nació y se educó en Inglaterra, y se trasladó a los Estados Unidos en 1978. Ya jubilado, durante su carrera él trabajó como Consultor de Gerencia con empresas de alta tecnología, la industria aeroespacial y ciencias orgánicas. Él vive en Aptos con su esposa Kathy y sus dos hijos, Molly (18) y Christian (19), ambos de los cuales están en el espectro del autismo.



My name is Brenda Miller and I am new to the SPIN board of directors. I live in Scotts Valley with my husband Russ and we have three children ages 27, 24, 19. Our middle child is Melissa and she has Down Syndrome. I am so excited to help SPIN as a board member!

Mi nombre es Brenda Miller y soy un miembro Nuevo a la Mesa Directiva de SPIN. Vivo en Scotts Valley junto con mi esposo Russ y nuestros tres hijos. Sus edades son 27, 24 y 19. Nuestra hija mediana es Melissa y ella tiene síndrome de Down. Estoy, muy emocionada de formar parte de la mesa directiva y poder ayudar!



**NEW Groups!** If you would like help to start a new parent support group for a specific disability, call (831) 423-7713 to discuss how SPIN can help you get a group going.

**Nuevos grupos!** Si usted quisiera ayudar a iniciar un nuevo grupo de apoyo de padres para una discapacidad específica, póngase en contacto con Elizabeth Chavez al 722-2800 o echavez@spinsc.org para discutir cómo SPIN puede ayudarle a empezar un grupo.

# announcements/ anuncios



Alone we can
do so little.
Together we can
do so much.

Helen Keller

Solos podemos hacer poco. Juntos podemos hacer mucho.

Helen Keller

The Suitcase— continued from page 2
By Bob McLalan

She had the infrastructure to support and sustain her but there was little warmth and no comfort. She was not an individual: just a patient. You could put her individuality on her dog tags. Like all military personal you are your name, rank, service number, religion and blood type.

Living in any hierarchical institution the power at the top has to have some coercive methods to get cooperation from an unruly or out of control patient, Marine or prisoner. My method was simply reminding her that if she became uncooperative or unruly the state could find it necessary to send her back to Agnew. I would try to make her understand that if she presented a danger to herself or to someone else, I would have no power to refuse the state.

The word Agnew brought that cooperation. It was a word that she clearly understood its meaning and would quickly adjust herself and be more cooperative. She could not tell you what she ate for breakfast but she remembered Agnew. It was clearly a name and place that was deep in her memory.



She seemed physically fine when I entered into her life. I never saw any scars and she seemed well adjusted. I thought it better to not spend time searching back into her past for gothic horror stories of abuse. I had no evidence of any so I thought it was better to put the rumors of inhumane care at the hospitals behind me.

We weren't living in a movie about asylums and I felt that even if I was able to get all the reports to verify my greatest fears, that my time and energy would be wasted on events in the past and not on her. As her brother, I had only so much time and energy to devote to her. In spite of the bitterness of my knowledge of the history of mental healthcare, my decision to write off the past and move forward has served the both of us well over the years. Since all the reports were written by staff and doctors and witnesses were not capable of providing contrary perspectives I would never really know what happened. Sometimes, I would wonder what her life was like over the 15 years since I last saw her saw but I concluded that I needed to be prepared for the fights ahead and leave the past behind.

For the two of us the starting point was the day January 1969 when I walked into Agnew State Hospital and took her out for lunch. Almost everything else was behind her and all that mattered to her today was that her "brudder" was coming to take her to McDonalds.

To red more articles, see chapters from his upcoming book or to read more about Bob go to www.bobmclalanstories.com

 L-R The Forest Family handing out food on Martin Luther King Day of service

# announcements/ anuncios

# **Summer Fun**

Summer is approaching. Looking for recreational activities? Here are a couple places to start your search: Se acerca el verano. Busca actividades recreativas? Aquí hay un par de lugares para comenzar su búsqueda:

## **Camp Krem- Camping Unlimited**

Camping Unlimited is a non-profit organization providing children and adults with Special Needs a full program of recreation, education, fun and adventure.

www.campingunlimited.org

#### **Dancenter**

Dance classes for teens and adults with Special Needs

Phone: (831) 475-5032 www.dancenter.com

### **Easter Seals Camp Harmon**

Camp Harmon is a residential camp for children and adults with disabilities, ages 8-65. Campers attend 6 or 8 day sessions and participate in nature, farm and garden, arts and crafts, swimming, and many other activities.

Phone: (831) 338-3383 www.campharmon.org

### **Shared Adventures**

Recreational activities in the community for children and adults with special needs

Phone: (831) 459, 7210

Phone: (831) 459-7210 www.sharedadventures.com

### **Monterey Bay Horsemanship & Therapeutic Center**

Located oceanside in beautiful La Selva Beach, California, our fabulous Equestrian Center offers a year round program for all ages and ability levels, including those with special needs.

(831) 761-1142 www.gombhtc.org

## **Lichen Oaks Adaptive Riding Center**

Phone: (831) 335-2347 www.lichenoaksarc.org

### **Adaptive Yoga Project**

(831) 423-9642

AdaptiveYogaProject.com

For additional Summer/Recreational activities visit www.spinsc.org under local Resources/Recreation. Para información sobre actividades para el verano o simplemente actividades recreacionales visite la página web de SPIN http://www.spinsc.org/default.asp?page=localresources.htm

# We Want You—Now! A Call for Board Members

Would you like to give back to the community? Would you like to help families of kids with special needs & help SPIN become a stronger organization? If you want to serve on a dynamic & dedicated Board of Directors, then SPIN would like to talk to you.

Please call Cece Pinheiro at 722-2800 for more details.

# thank you/ gracias

# **Donors/Donantes**

**Alfaros** 

Alison & John Burns

**Alladin Nursery** 

Amanda & Tom Owens

Ann & John Dizikes

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# thank you/ gracias

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Shear Joy Salon Sonia Plageman

Soquel Vineyards Spring Hills Golf **Spring Hill Womens** Golf Club Sunny's Catering-Sunny Stickel Tami Woods Terri St.Cloud The Allison Lee Condit Foundation The Garden Co. The Hat Company **Thomas & Anne Stickel** Thomas & Deborah Chan Thomas S. Young, D.D.S, Inc. Tim Teutschel Toadal Fitness **Verve Coffee Roasters** Village Host Wishbone Pet



▲ L-R SPIN Quiz Nite 2017 Honored Family! The Potts family, Lauren, Evelyn, & Oliver, Parents Tricia and Bob and Assemblyman Mark Stone



L-R SPIN Executive Director Cece Pinheiro and SPIN Board Chair Dee Teutschel



L-R Quiz Night 2017 fun!



# Special Parents Information Network

### Mailing address/Domicilio P.O Box 2367 Santa Cruz, CA 95063

Santa Cruz, CA 95063 Email:info@spinsc.org

### So. Santa Cruz Co Office

294 Green Valley Rd. Ste. 313 Watsonville, Ca 95076 Phone: (831)722-2800 Fax: (831)722-2580

#### No. Santa Cruz Co Office

740 Front Street, Suite 175 Santa Cruz, Ca 95060 Phone: (831) 423-7713

### San Benito Co Office

320 Hillcrest #105 Hollister, CA 95023 Phone: (831) 722-2800

# **Support Group Meetings**

**GET CONNECTED! CHECK OUT SUPPORT INFO** 

#### **SPIN All Disabilities Parent Support Group**

Join the group for special speakers and topics, as well as receive informational and emotional support from other parents. Meetings are held at different locations once a month. Call Heidi at (831) 423-7713 for info.

#### Grupo de Apoyo Para Todas las Discapacidades

Es usted padre de un hijo/a con necesidades especiales. Quiere conocer otros padres, compartir sus experinecias, saber de nuevos recursos. Quiere recibir apoyo de personas que entienden su situacion entonces venga a nuestras juntas y haga nuevas amistades. Nos estaremos reuniendo cada tercer sabado del mes. Llame a Elizabeth Chavez al (831) 722-2800 para más información

### **San Benito Parent Support Group**

If Parents are interested in The San Benito County Support Group; please contact Ricardo Cornejo at (831) 722-2800 or rcornejo@spinsc.org for more information.

#### **SPIN ONLINE SUPPORT GROUP:**

This group is open only to parents or family members in the Santa Cruz and San Benito counties of Central California. To participate, go to this webpage: http://groups.yahoo.com/group/spinsc Follow the directions to join. Be sure to tell us your first and last name; city where you reside, and child's disability. This is to protect our group and keep it local. Your information will be kept confidential by the

moderator. The more who join the more people who can give and receive support! Our group email is: spinsc@yahoogroups.com Contact Heidi Lister at 423-7713 or heidilister@att.net for more info.

#### **Autism/ Asperger Support Group**

Meets the Second Tuesday of every month. 7:00-9:00pm at Hope Services in downtown Santa Cruz.
Contact Heidi at heidilister@att.net for more info.

#### **PARENT / COMMUNITY Led Support Groups**

C.H.A.D.D Support Group for Parents of children with AD/HD. Meetings are held in Aptos. Contact Judy Brenis for more information about this informational group at 831-684-0590 or visit their website: http://www.chadd.net/436

**Grupo Renacer** Parent-led support group for all disabilities (for Spanish speaking parents). Contact Maricella Padilla at (831) 763-2620.

NAMI (National Alliance for Mental Illness) Parents Support Group for Parents of Teens & Young Adults whose children have neurobehavioral and/or mental health issues. Contact Emily Chapman at ebc73@comcast.net or (831) 476-1020 for meeting place and dates. Or go to their website: http://youth.namiscc.org for their online NAMI Yahoo Parent group.

SPIN is a member of "FEDC" - California Family Empowerment Disability Council

**Current Resident or** 



P.O Box 2367 Santa Cruz, Ca 95063 Email:info@spinsc.org Website:wwwspinsc.org

