



Brain Injury Center of Ventura County

HEADTALES

Improving the quality of life for people living with a brain injury and their families throughout Ventura County

Fourth Quarter 2014

P. O. Box 1477 • Camarillo, CA 93011 • 805-482-1312

www.BrainInjuryCenter.org

Brain Injury Center of Ventura County celebrates

NATIONAL

Family Caregiver MONTH

In honor of "National Family Caregiver Month," the Brain Injury Center (BIC) of Ventura County dedicates this newsletter issue to caregivers of acquired brain injury (ABI) survivors. Often the unsung heroes, caregivers and family members have both a rewarding and difficult job for the survivors they support. This month, and every month, we salute you!

"National Family Caregiver Month is a reminder to recognize those who make the most important difference in the lives of the thousands of brain injury survivors living in Ventura County," said Donna Davies, President of the BIC Board of Directors and a traumatic brain injury caregiver. "The largest percentage of the support and care does not come from the institutions and professionals we first think of when we think 'caregivers.' Most caregiving comes from the loved ones who carry on the tasks of advocate, scheduler, memory keeper, medical care deliverer, monitor, financial guide, legal representative, and the numerous other responsibilities that provide hope and support."

Being a family caregiver is not a one-size-fits-all position. The National Family Caregivers Association reports that family caregivers provide more than 80 percent of home health care services. Although there are many rewards, caring for another person with a brain injury – whether a spouse, sibling, parent or child – is stressful. Caregivers need to ensure they take care of themselves and have a strong support system. Part of BIC's mission is to provide caregivers resources through referral services, support groups, social gatherings and workshops. Camilla Seippel, one of BIC's Brain Injury Specialists, works with caregivers in the TeleREACH Program to help improve self care and assist with issues the family may face in supporting their loved ones.

"In addition to helping the caregiver understand the nature of TBI, the TeleREACH program focuses on a few specific goals tailored to the needs of the caregiver, and supports the caregiver in developing adaptive strategies for meeting those goals," said Seippel. "Sometimes the goals directly address issues related to the caregiver-survivor dynamic such as dealing with conflict in the caregiver-survivor relationship, adapting to survivor behavior changes, and adaptive communication. Other times one or more of these goals may focus solely on the caregiver needs, for example developing healthy and adaptive strategies for physical and emotional self-care. Sometimes one or more goals may be focused on long-term care planning for the survivor, or addressing the need for in-home assistance."

This issue highlights ABI caregivers and provides tips to help caregivers provide the best possible care to their loved ones while taking care of themselves.



Bernadette Lyons-Sales

Survivors make thank you cards to show their appreciation to their caregivers, family and friends that support them.



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PRESIDENT'S MESSAGE

Donna Davies, President, BIC Board of Directors



National Family Caregiver Month is a reminder to recognize those who make the most important difference in the lives of the thousands of brain injury survivors living in Ventura County. The largest percentage of the support and care does not come from the institutions and professionals we first think of when we think “caregivers.” Most caregiving comes from the loved ones who carry on the tasks of advocate, scheduler, memory keeper, medical care deliverer, monitor, financial guide, legal representative, and the numerous other responsibilities that provide hope and support wherever needed. Whatever your relationship to the survivor, you are the people who stand by them. They did not ask for or anticipate the incident that resulted in the life changing brain damage that occurred. And you, the caregivers, never imagined how your lives would change. Whether you are 24/7 caregivers, or part-time providers, you are always “on duty” in your heads and hearts. The Brain Injury Center cannot lift the burden of care each of you caregivers carries, but we do provide a shoulder, shared experience and a place to be understood through our support groups, our telephone outreach program, meetings with our peer mentors, or referrals to understanding community resource people who can assist you. During this November take some special time to care for you. We know it is not easy. We are thankful you are there for your loved one. Let us be there for you when you face difficult times or challenges. Providing you support is one of our most important functions. Hugs to each of you.

This final quarter of year the Board of Directors is evaluating what we have accomplished and setting the direction for 2015. The nearly \$80,000 raised at the 2014 Evening of Magical Memories is the funding that will kick-start the coming year’s work. The support groups will continue with renewed enthusiasm and focus, not only in West County where four groups currently meet regularly, but additionally in East County. Chrissy Riley and Camilla Seippel, our Brain Injury Specialists, continue to work with consultant rehabilitation specialist Celeste Racicot to enhance the many services available through BIC that support survivors in reaching new levels of self direction and life satisfaction. Our Professional Advisory Council is working with Executive Director Jeanette Villanueva in planning for additional program components and getting ready for our annual Ventura County Brain Injury Conference. Keep up to date by watching our Facebook page and our website. We on the Board know none of this would be possible without the many hours of support and leadership provided to BIC by the family-caregivers who started BIC and continue to give, give, and give to keep us strong and effective. 🐾

The Gift of Giving



Support BIC with a generous donation

The Brain Injury Center of Ventura County is grateful for your support. Because we are not government funded, we rely on the community’s generosity to enable us to fulfill our mission of helping people with brain injuries and their families. Especially as we head into the holidays, please consider giving a gift that makes a difference in the lives of those affected by brain injury. If you can, please complete the attached envelope with your contribution and drop it in the mail.



Thank you!

FROM THE EXECUTIVE DIRECTOR

Jeanette Marie Villanueva, MPPA

It has been an eventful time for the Brain Injury Center. My first six months on the job have flown by!

We have been busy with several priorities, including working with the Neuroscience Center of Ventura County and the Camarillo Health Care District on a joint venture called the Collaborative B.R.A.I.N. Pilot Project. It stands for Bicultural Rehabilitation Access Integration and Needs Assessment, and would fill a much-needed gap in Ventura County healthcare by providing a continuity of care for ABI survivors. Although we are still in the development phase, I am proud of our commitment to work together as a community to benefit ABI survivors. I will keep you posted on our progress.

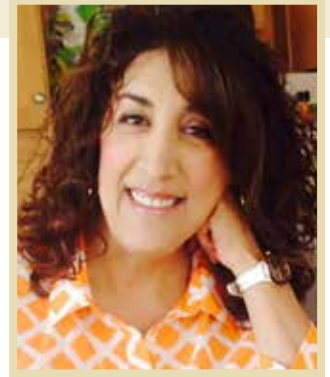
As you will see from the coverage in this issue, "An Evening of Magical Memories" was a thorough success. It not only raised nearly \$80,000, which we depend on to provide programs and services, but was filled with so much love and support for brain injury survivors. Congratulations to Jenna Prewitt and the Van Gundy's – you inspired us. To Dotti Oliver and the Fundraising Committee – thank you for your hard work. It was magical!

This issue of Head Tales is dedicated to our ABI caregivers in honor of National Family Caregiver Month. I have had the opportunity to spend time with our survivors in program classes, support groups and socials, and I recognize the difference caregivers make in the

lives of their brain injured loved ones. Parents, spouses, children, friends and neighbors who give of themselves to support survivors – juggling multiple responsibilities and giving their heart to their ABI loved ones. So you know you are not alone, we have profiled a few caregivers who have courageously shared their joys and challenges.

Caregivers, family and friends, the Brain Injury Center is here for you too. We can help with referrals, support and even provide a sense of community. We also offer the TeleREACH Program, one-to-one support over the phone with a Certified Brain Injury Specialist focused solely on the caregiver's needs. Like all our services, Tele-REACH is offered free of charge.

As we head into the holidays and 2015, I am thankful for the many people that help provide direction and support to the Brain Injury Center of Ventura County. Our Board of Directors made tough decisions to keep us moving forward and well positioned for the future, the Professional Advisory Council provided insight into the needs of our survivors, and the countless volunteers make our accomplishments possible. Because of all of you our future is bright!



PROGRAM UPDATE

Chrissy Riley, Brain Injury Specialist

We are currently in the midst of a skill-building class for brain injury survivors called "Building Better Relationships." Attendees are learning new techniques for developing and strengthening relationships with friends, family members, coworkers, and significant others. We are looking forward to offering more skill building and social skills training courses in the future.

Our support groups for brain injury survivors and family members continue to be held on a bi-weekly basis in three locations throughout the county, including a Spanish speaking group in Oxnard. We are working to strengthen our groups by implementing a more formal structure and including an educational component that addresses many of the issues that individuals face after a brain injury such as isolation, depression, stress, communication, attention, and fatigue.

Bernadette Lyons-Sales and Jenna Prewitt are currently interning with the Brain Injury Center to gain work experience and hone

their vocational skills so that they can pursue their employment goals in the community. Both Bernadette and Jenna continue to be very helpful in the office, and we hope to support them and other individuals with brain injury in their endeavors to gain employment and/or volunteer opportunities.

In recognition of National Family Caregivers Month, I would like to personally thank each of our family members who have taken on the role of caregiving for a loved one. The countless hours that each of you dedicate to providing care to your spouses, siblings, parents, children, and other relatives is extremely important and doesn't go unnoticed. At the Brain Injury Center, we support family caregivers through support groups, individualized assessment and goal setting, and TeleREACH.



TBI CAREGIVER TIPS

By Dennis Wood, BIC Board Member/Brain Injury Survivor and Camilla Seippel, BIC Brain Injury Specialist

Family caregivers play an important role in helping their loved ones recover from a traumatic brain injury. However, caring for a TBI survivor can be a long-term commitment. Since many caregivers typically put themselves last on their list, we have compiled a few tips.

- Your family member or friend suffering from TBI often cannot control their behaviors or emotions. Outbursts and uncharacteristic remarks should be expected; try not to take it personal.
- Be sure to get plenty of sleep. Get at least eight hours of sleep and take naps. Rest every time you have an opportunity.
- Exercise and keep active. It helps relieve stress, improves sleep, reduces depression and increases your energy level. It will also improve your mood and benefit your overall health.
- Reward yourself periodically with short breaks. Designate time away from the survivor to help reduce stress. Schedule time for relaxation activities like reading, walking and listening to music.
- Spend time with others to ensure you don't feel isolated. It's important to spend time with friends and take part in social activities. Attend BIC's monthly socials for survivors and caregivers.
- Educate yourself about TBI so you understand what your survivor may be experiencing.
- Take advantage of the resources available to you, such as family and friends who are willing to help and the Brain Injury Center of Ventura County's Tele-REACH program for caregivers.

Dennis Wood, Vice President of BIC's Board of Directors, is the CEO of Senior Helpers. He has lived with traumatic brain injury for many years and offers a valuable perspective as a survivor. Wood is also a graduate of the University of Southern California.

Camilla Seippel received her undergraduate degree from the University of Tampa and her Master's degree in Psychology from Antioch University, and is completing requirements toward her Psy.D. in Clinical Psychology. Earlier this year she received her Brain Injury Certification from the BIAA.

"The support survivors require often interferes with the independence they crave."

Linda Prewitt, Caregiver / Mother

What is the greatest challenge of being a caregiver?

Most adults desire freedom and independence. This includes adults with traumatic brain injuries. Most young adults learn from the mistakes and poor decisions they make, but brain injured individuals can be seriously hurt by poor choices. The support that brain injury survivors require often interferes with the independence they crave. Caregivers need to figure out how to help survivors make choices and decisions that will not harm them. When their choices are not wise, the caregivers must step in to protect them, though this might interfere with what they perceive as their freedom of choice.

What would you like your survivor to know?

I would like my daughter to know that I love her unconditionally. I will love her when she disagrees with my decisions. I will love her when she calls me names. I will love her even when she tells me that she hates me and never wants to see me again—because I understand that it's not me she hates, but her condition. I want Jenna to know that I will be there for her as long as I am alive.



Linda Prewitt
with her daughter, Jenna



Donna Davies with her son, Jon

"This journey of living with brain injury is not a crisis...it is life."

Donna Davies, Jon's mother

What advice would you give a new family caregiver?

First, do not take the behavior or verbal barbs personally. It is the brain injury lashing out, it is not you the survivor hates. It is coming from a place you are both going to need to learn to understand. The brain that is struggling to cope.

Second, the gift you provide as your loved one's family caregiver is the last thing to be released from Pandora's Box: HOPE. You will be with them as all the doubts, fears and other negatives fly at them. You will be the HOPE that keeps them going.

Third, you will need to keep reminding yourself that this journey of living with brain injury is not a crisis...it is life. It is a marathon, the long race. Take care of yourself, be patient with yourself and find people who will support you in your new role.

Fourth, I would give them a hug – a long, warm, sincere hug.

What are the greatest joys and challenges of being a caregiver?

The joys come when you actually see progress, which sometimes take weeks or even months. The challenges can easily become totally overwhelming – emotionally, physically, spiritually, socially. Joy returns when you learn, ever so slowly, how to overcome the challenges.

What do most people not know or understand about the role of a caregiver?

For me, the strangest part of being a caregiver was my discovery that I was back in the role of full-time mom after my son's car accident in 1995. Paul was 16 then, and quite independent. But the car accident left him in a coma for several months, and then slowly he needed to learn how to do everything all over again. He was a newborn child all over again. I was the record-keeper, the therapy coordinator, the insurance negotiator, the loving mom and at times – the disciplinarian. And it took another 16 years to get him close to where he was before the accident, yet with multiple disabilities that will take new methods and technology to help him overcome. Caregiving becomes a life-long job and you have to learn how to find others to help you so you get time off in order to survive and be any where close to successful.

How do you manage the stress?

Stress has been a problem for me my entire life. So I was very thankful that I had a great support system already in place – my family, my church, my doctors, and a wonderful counselor had been already working with me for three years before Paul's TBI. And we found the support groups at the hospitals and then in Ventura to be absolutely necessary for me, and eventually for Paul as well.

"I had a great support system already in place."

*Beverly Aggen,
Caregiver / Paul's mother*



Beverly Aggen with her son, Paul

What is the greatest challenge of being a caregiver?

The greatest challenge I face as a "loved one" is to try, in some small way, to understand what Tina is going through. It is also a challenge to see her in pain, to see her experience depression or loneliness, to worry about her all the time, to sometimes feel at a loss as to how to help her, and to just keep hoping that she will get better. It is a challenge to see progress only to see setbacks as well. It is a challenge to balance the time I want to spend with her along with the time to work, to keep our household running, to give our children attention.

What do most people not understand about the role of a caregiver?

Caregivers of brain injury survivors fall into many categories. Some are spouses, some are parents, and some are children of the survivors. Some are paid and some are unpaid. Caregivers deal with different situations and different challenges, depending on the nature of the brain injury, the symptoms that accompany the injury, the limitations of the survivors, and the age of the survivors. In addition, caregivers need support too.

What would you like your survivor to know?

I want Tina to know that I love her and always will, no matter what challenges our lives may bring. She is a beautiful, wonderful, generous, caring woman who still has so much to give, not just to me as her husband but to our children, our extended families, our friends, and the world.



George and Tina Meade

"Caregivers deal with different situations and challenges."

George Meade, Caregiver / Husband

Support Groups

BIC offers these programs at no charge. Please contact the office before attending for the first time.

CAMARILLO

1st and 3rd Wednesday of every month
4:00-5:30pm

AlmaVia of Camarillo

2500 N. Ponderosa Drive, Camarillo

Survivor and loved one's group held concurrently

Facilitator:

Chrissy Riley, CBIS*

OXNARD

1st and 3rd Wednesday of every month
2:00-3:30 pm

St. John's Regional Medical Center

1600 N. Rose Ave., Oxnard

Survivor and loved one's group held concurrently

Enter through main/front entrance

Facilitator:

Camilla Seippel, Psy.D Candidate/CBIS*

OXNARD

GRUPO DE APOYO EN ESPAÑOL

Segundo y Cuarto miércoles de cada mes
14:00-15:30

En la Sain John's Hospital de Oxnard

1600 N. Rose Ave., Oxnard

Los sobrevivientes, la familia y los cuidadores están invitados a participar en este grupo de apoyo gratuito.

Entrar por entrada principal

Facilitadora:

Camilla Seippel, Psy.D Candidate/CBIS*

VENTURA

2nd and 4th Wednesday of every month
4:00-5:30pm

Bible Fellowship Church

6950 Ralston, Bldg. #300, Ventura

Facilitator:

Camilla Seippel, Psy.D Candidate/CBIS*

*Certified Brain Injury Specialist

INDIVIDUAL SUPPORTIVE SERVICES

One hour sessions are available for either brain injury survivors and/or family members. Referrals, and support to promote physical and emotional health and well-being are offered.

Appointments are required.

Please contact the office for more information.

SOCIAL GATHERING FOR BRAIN INJURY SURVIVORS AND LOVED ONES

Activities are offered each month – an opportunity to have some fun.

Call (805) 482-1312 or email

info@BrainInjuryCenter.org

to express your interest.



Estate Planning For Special Needs People

By David Edsall and Katherine Edsall Wells

Many families wish to provide for their special needs child but are concerned that any inheritance received by the child could cause a discontinuation of needed benefits for that child or worse, be used to reimburse the State or federal government for benefits that the child may have already received.

If a family member wishes to leave money or property to a loved one with a disability, it can be done, but must be planned carefully. The "Special Needs Trust" is one option that addresses many of these concerns and establishes a legal framework for ensuring that the gift is used as intended. By setting up a Special Needs Trust within your own trust or will, you can set aside assets for the special needs individual in a way that would avoid these concerns.

A "Special Needs Trust" ensures that the assets will be allocated for the benefit of the special needs individual without affecting eligibility for SSI, Medical, or other benefits -- because instead of leaving assets directly to your loved one, you leave it to the Trustee of the Special Needs Trust, whom you select.

The Special Needs Trust works wonderfully in practice, but the Trustee must be well advised on the rules of spending in order to protect the benefits the special needs individual is receiving. For example, the Trustee cannot distribute the money directly to the special needs beneficiary without affecting eligibility. However, the Trustee can spend the Trust assets on a wide variety of goods and services for the special needs beneficiary, from basic necessities to activities and entertainment. The funds in the Special Needs Trust are commonly used to pay for personal care attendants, home furnishings, computers, out-of-pocket dental and medical expenses, education, recreation, vehicles, and physical re-

habilitation. The Trustee must pay the vendors directly and cannot give money to the special needs person to pay without jeopardizing those precious benefits.

In addition, the Special Needs Trust acts as a legal safeguard to ensure that the person you've appointed in charge of the assets -- in this case, the Trustee -- will use the trust assets solely for the benefit of the special needs individual. By law, the Trustee has a fiduciary duty to carry out the terms of the Trust for the benefit of the beneficiary, so the Trustee is legally bound to follow the terms of the Trust as you have directed in your estate planning documents. This ensures that your loved one will be protected even after you are gone.

While a Special Needs Trust can be set up at any time, it is more commonly funded after the death of the donor as part of the donor's estate plan. This vehicle in practice insures that your special needs beneficiary will receive the benefits that you intend. While there are more informal methods, such as leaving the assets to another child with oral instructions to take care of the special needs individual, these methods seldom work as intended by the donor and lack the legal framework to ensure compliance in the event the assets are not used as intended. 🌱

David Edsall is a Ventura County attorney highly regarded for his achievements in estate planning, including probate and preparation of wills and trusts. His firm, Edsall Law, also specializes in business matters and civil litigation. Edsall has been a longtime supporter of the Brain Injury Center of Ventura County, has conducted workshops on estate planning for special needs people and currently volunteers his time as BIC's legal counsel and advisor.

Katherine Wells is a partner in the firm and David's daughter. She returned to Ventura after working with one of Los Angeles' most prominent law firms. Katherine graduated summa cum laude from the University of Southern California and received her Juris Doctor degree from Stanford Law School.

Brain Injury Center holds annual fundraiser

An Evening of Magical Memories



Honoree Jenna Prewitt, Brain Injury Survivor



Tom and Priscilla Van Gundy, "Above and Beyond" Distinguished Service Award



Dotti Oliver, Event Chair and BIC Board Member, with Nancy Simmons, committee member

The Brain Injury Center of Ventura County held its annual fundraiser "An Evening of Magical Memories" on Saturday, Sept. 27, 2014 at the Residence Inn by Marriott in Oxnard. The event honored Jenna Prewitt, brain injury survivor; and Tom and Priscilla Van Gundy with the "Above and Beyond" Distinguished Service Award.

Tom and Priscilla Van Gundy, second-generation owners of Van Gundy Jewelers, have gone above and beyond to give back to Ventura County. "The Van Gundy's run their family business with the highest integrity, ethics and sense of community spirit," said Dotti Oliver, Brain Injury Center (BIC) Board Member and Chair of the Fundraising Committee. "They are not only financially generous with BIC, but they also give their personal time to support our events and give hope to our brain injury survivors."

The couple says commitment to community is part of their family history. "Our community involvement goes back to when my father opened our original store in 1964," said Tom. "He always made sure we were making donations and giving back. It was just part of doing business and it is still important to us today."

Jenna Prewitt received a traumatic brain injury in a near-fatal car accident in 2002. She was 16 years old and spent three months in a coma, nearly two months in the intensive care unit at Los Robles Hospital and another three months learning how to breathe, swallow, move and speak again. After rehabilitation, she went home nine months after her accident.

"Brain injury doesn't go away, but I have come a long way," said Prewitt. "It took six years, but I graduated from Ventura College and I may only have one year left before earning my Bachelor's degree from California State University, Channel Islands." In an effort to help others and spread awareness, she gives presentations in high schools and volunteers at BIC. "With support from friends, family, and the community, I believe it's possible for me and others with brain injuries to make a positive difference in the world."

The Brain Injury Center of Ventura County is a nonprofit organization and does not receive state or federal funding. The largest fundraiser of the year, "An Evening of Magical Memories" raised more than \$80,000. 🐼

Join Brain Injury Center of Ventura County
at Yolanda's for a delicious meal with
your family and friends!



Yolanda's Mexican Café
86 E. Daily Drive, Camarillo

Tuesday, December 16 • 4-9:30pm

Questions? Call the Brain Injury Center
(805) 482-1312

Present this ad to your server
and Yolanda's will donate 20%
of your bill to BIC—dine in or
take out meals included.



A 501(c)(3) non-profit organization TIN: 77-0491413



**Brain Injury Center
of Ventura County**
P.O. Box 1477
Camarillo, CA 93011-1147
(805) 482-1312
www.BrainInjuryCenter.org

SAVE the DATE

APRIL 11 2015

BRAIN INJURY CONFERENCE

Stay Connected

The Brain Injury Center of Ventura County offers
several ways to stay engaged and informed.



Join us at our monthly social.
Check our website calendar for details!



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www.facebook.com/BrainInjuryCenter



Visit our website, www.BrainInjuryCenter.org.



Starbucks Social



Tyler Sutton and Yvonne Serros
Last month more than 25 people
joined us at Starbucks!