

Proxy Parent Foundation newsletter

SPRING 2016 ISSUE 14

INSIDE THIS ISSUE

- 1 Who Will Care When We're Not There?
- 2 After Years of Psychiatric Problems, I Finally had a PLAN
- 3 Book Review
Tales from Both Sides of the Brain

PROXY PARENT FOUNDATION

Proxy Parent Foundation offers two services.

We are Trustee of the PLAN of California Master Pooled Trust, which is open as a trust vehicle for any disabled person in California.

We provide Personal Support Services for beneficiaries of our Special Needs Trusts who have a mental illness or brain disorder.

Just like a loving family, we coordinate public and private social services and medical care while providing family-like attention to help the person improve his or her quality of life.

Proxy Parent Foundation is a dba of Planned Lifetime Assistance Network (PLAN) of California, a 501(c)(3) nonprofit corporation.

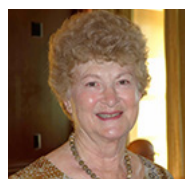
Proxy Parent Foundation
17602 Seventeenth St., #102-240
Tustin, CA 92780
714.997.3310
toll free 888.574.1258
www.proxyparentfoundation.org

In This Issue

With the already heated political rhetoric intensifying, and murmurs that the Mental Health Reform Act of 2015 that seemed a shoe-in for passage may now end up a victim of political game playing, perhaps it's time to take a deep breath and revisit the basics. For this issue that consists of articles by three Proxy Parent Foundation Board Members – Elizabeth Galton, who reintroduces what Proxy Parent Foundation is and what we stand for; John Buck, who with the help of a relative of a past recipient of personal support services, describes from an intimate perspective what those services can encompass and the effect it can have on both clients and their families; and finally a review by our Board President, Joe DeCarlo, of a book by Dr. Michael S. Gazzaniga, who has spent 50 years studying cognitive neuroscience and the interactions of the two sides of the brain.

Who Will Care When We're Not There?

By Elizabeth Galton, MD*



Proxy Parent Foundation, a dba of PLAN of California, is a 501(c)(3) California nonprofit started by family members of people with mental illness. As parents, they knew personally the question, "Who will care when I'm not there?"

Proxy Parent Foundation was formed to answer that difficult question. As trustee of the PLAN of California Master Pooled Trust,

Proxy Parent Foundation knowledgeably manages inheritances a family leaves to their loved one in a professional and economic manner. Moreover, Proxy Parent Foundation's Personal Support Specialists work directly with their loved ones as loyal, trustworthy and experienced professionals to help assure their quality of life.

The PLAN of California Master Pooled Trust is a Special Needs Trust and protects the beneficiary's qualifications for government benefits such as SSI and Medicaid. Family members may join through their living trust or will. Individuals of any disability type may also join with assets received from settlements, awards or unexpected inheritances, which if they accepted directly would disqualify them from government benefits.

Proxy Parent Foundation works with the family, beneficiary or beneficiary's appointed adviser to acquire detailed knowledge regarding the person's particular special needs. As trustee, disbursements are adjusted periodically, as developments occur in the life span of the disabled person. Proxy Parent Foundation selects and oversees professional trust accounting and investment management through its Trust Oversight Committee.

As chair of the Quality Assurance Committee, I work closely with our Director of Social Services who oversees the Personal Support Specialists assigned to the individual beneficiaries. Our Personal Support Specialists are carefully vetted and work directly with the beneficiary to help him or her find housing, access medical treatment, social services and navigate medical or personal crises. We are their friend in the community and ombudsman for whatever government services they need to gain or maintain a smooth and positive quality of life.



The Board of Directors meets four times a year. I have the pleasure of working with this Board, which has attorneys, mental health directors, financial experts and a County Supervisor all serving as volunteers. We are very active and engaged in finding the best solutions for sometimes very difficult lives.

**Dr. Galton serves on the Proxy Parent Foundation Board of Directors and chairs the Quality Assurance Committee. Dr. Galton is a psychiatrist and in her private practice performs psychoanalytic (dynamic) psychotherapy and psychoanalysis. Inspired by Board Member Carla Jacobs, with whom she co-chaired the LPS Reform Task Force that originated Laura's Law she became involved in activism for Mental Illness.*

After Years of Psychiatric Problems, I Finally had a PLAN

By John Buck* and Steve (anonymous)



Depressed. Overwhelmed. Internal voices blocking the outside world. Brian found it difficult to perform the most basic tasks. In 1994, at age 41, he had been in and out of acute psychiatric hospitals and non-supportive care homes. Brian was in Stockton, but his brother, Steve, was in Georgia and felt helpless. The long distance calls with depressing news knotted Steve's stomach and created many anxious moments.

After flying to Stockton, Steve was able to assist his brother and effectively communicate while with him, but once Steve flew back home to Georgia, Brian's situation quickly deteriorated. After years of mayhem, there finally was a PLAN!

Planned Lifetime Assistance Network, PLAN, also referred to as Proxy Parent Foundation, provides local support of a loved one when the family members cannot be physically present. The PLAN representative can perform a myriad of tasks ranging from transporting a disabled family member to doctor's appointments, advocating for the disabled member or just talking and providing support. The "pay as you go" plan allows for support when required, especially during a crisis period when the support is so critical.

In Brian's case, his mother had passed away in 1984 and his father moved away to Montana in 1993 and was not active in Brian's life. This meant that Brian's only sibling, Steve, in Georgia, had to look out for his older brother. Brian had schizophrenia and obsessive compulsive disorder (OCD). In 1994 Steve had been married for several years with two small children, so it was not practical to move to California.

Although Steve was active in his brother's life and called Brian weekly and saw him at least annually, Steve wanted to be more involved to help and protect his brother, but 2,500 miles separated them. After gaining conservatorship of Brian in 1993, a relative told Steve about the Proxy Parent/PLAN organization. John Buck was the CEO of Turning Point Community Programs, the regional provider that was selected to provide services in Sacramento and San Joaquin counties. John took Brian

under his wing and was instrumental in turning Brian's life around. John researched and visited potential care homes for Brian, advised Steve of Brian's legal rights, talked to Brian's psychiatrist, recommended certain goals in Brian's program to enhance Brian's quality of life, intervened with the Regional Center when necessary and most importantly, was the caring friend who would occasionally visit Brian. These visits were especially important when Brian was enduring acute psychiatric episodes.

John tells that one time it took Brian 30 minutes to open the door and get into the car because he was bothered by voices that haunted him and caused his jerky and violent arm and hand movements. Fortunately, with the help of new medicine, a wonderful care home and day program, John's support and the assistance of many other people, Brian did not have any major setbacks between 2000 and 2015. This was the longest period of sustained performance without any setbacks during Brian's entire life, and it all started with a PLAN! Unfortunately in 2015, at age 63, Brian passed away of pneumonia and sepsis after falling and breaking his kneecap.

As Brian's brother Steve can attest, John Buck from Turning Point was so much more than a member of Brian's care team. He was like an extended family member who took a genuine interest in Brian's well being. John was the trusted friend that was with Brian during the bad times and the good times. During a crisis, John's presence brought stability to Brian and peace of mind to Steve. During the good times, John took Brian fishing in the San Joaquin Delta region in John's boat. One time John allowed Brian to drive the boat and Brian had the biggest grin on his face



as he controlled the boat and said, “This is the most fun I have had in my entire life!”

Brian frequently asked Steve, “When am I going to see John again because I really like talking to him?” John also took Brian out for dinner during the Thanksgiving holiday when Steve could not visit Brian. John had a great way of joking with Brian to get him to relax while also getting him motivated to perform a required task. As the success of Turning Point grew from a 23 person organization to over 500 staff, with John serving as CEO, John still made time for Brian and never forgot that people are helped one person at a time.

John’s Personal Observations and Perspectives

It is an immense responsibility to be trusted to guide and support another person’s loved one. Steve’s brother Brian was my first person to provide services to under the Proxy Parent umbrella. Brian was a man with tremendous challenges making my own path appear to be a cakewalk. Despite his numerous disabilities, which were both psychiatric and developmental, his sense of humor and appreciation of those surrounding him always showed through. There were difficult times when he needed to be protected from himself and there were times he enjoyed it to the maximum.

When providing Proxy Parent services I always felt I had two “clients” – my buddies and their families. I often relate to my buddies like a big brother. I help with advice, problem solving and encourage hope and happiness. Brian always wanted to drive a motor vehicle but would never have been able to handle the complexities of traffic and traffic laws. But I taught him over the years to drive my 1981 Sea

Ray ski boat. This allowed him to drive but not have to worry about making split second decisions and you should have seen that smile! We also fished and at age 49 he caught his first fish, which he ate for dinner later that night. He was so proud!

It was illuminating and fulfilling to work with Brian’s brother Steve. Because, by necessity, Steve lived so far away, in many ways, with Steve’s caring advice, I became as an extension, Brian’s “proxy family.” Over the years Brian became surrounded by a great support system that included the staff of an excellent adult residential facility and a day treatment program. He responded well to being treated with dignity and respect. With the help of an excellent trio of psychiatrists Brian gained control of his disabilities and flourished. When Brian suddenly took a turn for the worse while recovering from a knee injury I was privileged to represent his brother at his bedside. I will always miss Brian’s joy and happiness and will never forget the undying love of his brother, Steve, and his family. It was an honor to have been a “Proxy Parent” of this family.

**John Buck, is a long standing Board Member of Proxy Parent Foundation, and ex-CEO of Turning Point Services, in Sacramento, one of the leading and largest providers of support services for the mentally ill in California. Turning Point has provided personal support services to many PPF/PLAN beneficiaries over the years, and John himself has acted as personal support specialist directly with many of them as well.*

Book Review

By Joseph DeCarlo*

Tales from Both Sides of the Brain: A Life in Neuroscience by Michael S. Gazzaniga



This is a story of Dr. Gazzaniga’s life long pioneering quest to understand how the separate spheres (left

and right brain) work and interrelate with each other. Dr. Gazzaniga is the Director of SAGE Center of the Mind at University of California, Santa Barbara. He has spent over 50 years in cognitive neuroscience.

This book is actually a scientific autobiography. It is a behind-the-scene look at the operation of the brain and struggles of neuroscientists to understand and find answers about the brain. This book is an easy read for a non-scientific parent filled with humor and insights, experiments, hard work and luck involved in the challenges of understanding the brain. This book describes how the two spheres of our brain communicates, collaborates and miscommunicates the split-brain phenomenon. We all have multiple minds, each with some autonomy to create a unified mind.

Although the book deals with the past 50 years, Dr. Gazzaniga says there are big advances coming due to technology and brain mapping. Computerized ability to analyze, assimilate and correlate data into meaningful analysis will lead to new breakthroughs on the brain’s workings in the next 20 years.

**Joseph DeCarlo is the father of a 40-year old autistic son “Joey” who also has epilepsy. Joey lives at home with his parents and goes to Project Independence, a Regional Center of Orange County funded program. Mr. DeCarlo is President of the Proxy Parent Foundation and can be reached at joe@jdpproperty.com.*

Proxy Parent Foundation
17602 Seventeenth Street, #102-240
Tustin, CA 92780

ADDRESS CORRECTION REQUESTED



Please let us know if you would prefer
receiving our newsletter by email. Thank you.
info@proxyparentfoundation.org

BOARD OF DIRECTORS

Officers

Joe DeCarlo, *President (JD Property Management)*
Tom Stevens, *1st Vice President*
(Chairman, Los Angeles Capital Mgmt.)
Ann Eldridge, *2nd Vice President (Retired Nurse)*
Gary M. Chang, Esq., *Board Secretary (Attorney at Law)*
John Buck, *Treasurer (Past CEO, Turning Point)*
Steve Pitman, *Mbr at Large (Past Pres., NAMI-Orange County)*
Marvin Southard, *Mbr at Large (Dir., LA Dept. of Mental Hlth)*

Board Members

Zane Alsabery, *President & CEO, Alchemy Commun. Inc.*
Michael Antonovich, *Los Angeles Co. Supervisor*
Elizabeth Galton, M.D.
Randall Hagar, *Govt Affairs, Dir for the Calif. Psychiatric Assn.*
Steve Hawkins, *Public Relations*
Carla Jacobs, *CEO, Roy W. Smith Fndn.*
Kerry Dean Kravitz, M.D., Ph.D.
Baron Miller, Esq., *Attorney at Law*

Emeritus

Bob Brooks, *Retired Businessman*
Tom Hoeffel, *Retired Businessman*
Murray Olderman, *Sports Writer, Author*

I wish to help support Proxy Parent Foundation

a dba of Planned Lifetime Assistance Network of California

Enclosed is my Tax-deductible donation of

\$ _____

- Please use this donation to provide Proxy Parent Foundation's help to those who need it in the "here and now".
- Please use this donation as our Proxy Parent Foundation enrollment donation. (Enrollment donations must be \$1000 or more and can be made in payments.)

Name of donor: _____

Address: _____

City: _____

State: _____ Zip: _____

Phone: _____ Email: _____

Please make your check payable to:

Proxy Parent Foundation and mail to
17602 Seventeenth St. #102-240
Tustin, CA 92780



Or by credit card, go to our website at www.proxyparentfoundation.org