

# Proxy Parent Foundation newsletter

SUMMER 2017 ISSUE 16

## INSIDE THIS ISSUE

- 1 Welcome
- 2 My Two Children
- 3 Anticipating the Future
- 3 Book Review  
*Mental Illness: A Handbook for Carers*

### 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](http://www.proxyparentfoundation.org)

## Welcome

I write while still stewing over President Trump's proposed budget that would gut Medicaid and other public benefits such as SSI, SSDI and Food Stamps. Let's pray that the common sense and decency inherent in this county will prevail and his efforts to eliminate these programs will be rebuffed by Congress. However, regardless of outcome, self-sufficiency is always key and I believe that you will find the articles in this newsletter very timely in the way that they address: (1) the very personal ways that we as family members deal with the emotional weight and conflicts we feel while caring for and about our loved ones, and (2) how Proxy Parent Foundation can, independently of the public systems, provide personal assistance and support to many of our trust or Pay-As-You-Go beneficiaries, while also doing our best to connect them to and engage them with the existing public agencies that were created to provide the various types of aid to which they are entitled.

The first article is by Board Member, Baron Miller, who has written several times in past newsletters on special needs planning and trust issues. Here he takes a step back and gives us his deeply personal perspective on dealing with the reality of his daughter's mental illness. It is a very moving piece which will resound with all like family members.

Over the years, our Director of Social Services, Bruce Lewitt has spoken to many of you and has worked with you for your loved ones. Nancy Nigrosh, Bruce's wife, has written an

article describing how Proxy Parent Foundation's personal support services, have recently been able to help one of our newer beneficiaries take the first steps from a situation in which he had long been trapped by his illness.

The latest book review by Joe DeCarlo, Board President, is on a volume from across the pond, "Mental Illness: A Handbook for Carers", which is not only very informative on the nature and different types of mental illness itself, but also a practical guide for both supportive family members and those interested in becoming a mental health professional as to a wide range of practical issues.

Last but not least, I'm proud to announce that Proxy Parent Foundation Board of Trustee's 1st Vice President, Tom Stevens, Chairman of Los Angeles Capital Management, was just named 2017 Recipient of the Rafer Johnson Humanitarian Award by Special Olympics Southern California (see photo below), a very special honor exemplifying his years of active service to the developmentally disabled community. We are very honored that he serves on our Board with equal generosity and commitment.

*Gary M. Chang*  
Director of Legal Affairs



Tom Stevens and the legendary Rafer Johnson



## My Two Children

By Baron Miller\*

My 42-year-old child has schizophrenia. Behavior problems began at age 12, and a full-blown psychotic break occurred at age 15. She has been sick most of her life, and she isn't getting better.

Some years ago I decided that in practicality I have had 2 children, one of whom figuratively died at age 15, and the other who was then figuratively born. Of the earlier child there are fond memories, for she was cheerful and bright and witty and charming. The current child presents an unending series of challenges.

I tend to dwell on the current child, since her needs are immense and require equivalent attention. She is necessarily a focus for me, no matter how frequently and how much I would prefer otherwise. I'm not complaining – all lives have trials – and just like other parents of chronically ill children I am able to take some pride in my efforts to assist her, no matter how inadequate that assistance proves to be.

My child voices no complaints either. She resides in her unique world, and seems resigned to it. She lives it her way, which is often what I consider a less than optimal way, but she never seems to dwell on what might have been.

I have tended to avoid the fond memories, to ignore them. They are bittersweet, of course, and seemed to interrupt the

energy I need to deal with the series of problems that now frequently arise. I realized recently the mistake of my snubbing the past.

I was cleaning out a storage room, knowing I would come upon a number of boxes containing my daughter's childhood memorabilia, and dreading it. I knew that many of the mementos I came across would be pre-psychosis, and some would be early post-psychosis when there was still hope she would be able to deal effectively with her illness.

I knew I would succumb to broken-heartedness. What a great loss she had suffered, and I had suffered. What promise she had, all destroyed. How sad, how cruel, how inexorably depressing.

But as I went through photos and report cards and awards and handwritten notes and souvenirs, and dutifully dusted and preserved them because the loss of them is unimaginable, something clicked in my brain, and I understood that yes, a bad thing had happened to my precious child that had effectively killed her as a budding teen, but it didn't mean I could no longer enjoy what was her short and beautiful life. I was realizing there is more than one way to view that life.

One is with regret, emphasizing what she lost, and what I lost, and its sorrow. The other is with pleasure, the same way I would look back at her early years if she had never gotten sick. It is not that I can simply overlook her illness having robbed

her of her previous life. That is always a distressing reality, but that does not preclude me from lovingly enjoying the memory of that life.

I am sure there is nothing quite like being the parent of a chronically ill child. It requires knowledge most of us never prepared to gain, skills none of us have fully developed. It paradoxically begs for stoicism, a stoicism impossible for any but the most detached. It insists on forgetting that which is too painful to recall, while ensuring that fond memories are among the most important things of all.

We must deal with contemporary realities, which of course include planning for impending realities. Yet we need not give up our tender memories, need not allow them to be tainted because our child's future was thwarted. I think as we get older, we realize more and more how much and how frequently a wonderful memory can be relived, and the utter loveliness of being able to relive it. The good memories, like those boxes of mementoes that prompt them, are sacred, and it is, I recognize, our good fortune to have them to cherish.

*\*Baron L. Miller is an attorney in private practice in San Francisco who specializes in estate planning for California families of the mentally ill. He is a long-time NAMI family member, an advocate for the rights and interests of families of the mentally ill, and a board member of Proxy Parent Foundation. He does not charge for telephone consultations on the propriety of making payments for the benefit of an SSI recipient. He can be reached at 415.522.0500.*



## Anticipating the Future

By Nancy Nigrosch  
Director, School of Writing for Film, Television & Digital Media, Academy of Art University

When our children are very young, we try to be aware and prepare for a number of certainties ahead. Once children are grown up, predicting the future is less certain. Yet, in the case of a beloved family member with severe or chronic mental illness, we might well ask, "Who will care when we're not there?"

As Proxy Parents, we've had long experience with how families address this inevitable question since the question itself defines the very mission of our foundation.

Most recently, a family who'd reached out to Proxy Parent Foundation a number of times over the years, contacted us about their son Hank, who'd been living in the family home. Hank had once lived briefly in a Board and Care, but it wasn't a positive experience for him, and he'd moved back in with his folks. When Hank's mom passed away, his dad's health began to deteriorate and Hank's siblings assisted their dad to put together the paperwork for a Special Needs Trust for their brother's benefit. Even though knowing that the only home Hank had ever known would have to be sold at some point, his dad was very reluctant to impose any significant changes on Hank. Yet, his dad realized it was time to prepare the whole family for the future. He joined our Master Pooled Trust and signed up for the Pay-As-You-Go program for one of our Personal Support Specialists (PSS) to start working with Hank.

Once Hank and our Personal Support Specialist met, they developed a very posi-

tive rapport. With Hank's particular needs in mind, the PSS began to look for an Assisted Living or a Board and Care arrangement. Months passed. Together Hank and his dad were able to acclimate toward accepting the reality of an impending move for Hank. They were now able to understand that this transition was in both their best interests.

The PSS introduced Hank to a promising Board and Care location. They visited the facility together a number of times, and surprisingly, Hank felt very comfortable with the prospect of having greater independence of this new arrangement and decided to move in. Even more surprisingly, Hank expressed how much he enjoyed his new housing arrangement, since it suited his needs in so many ways. His whole family paid frequent visits to Hank's new living situation while Hank's dad was also able to move into Assisted Living.

Shortly after the house was sold, Hank's dad passed away. With the support of his siblings and the PSS, Hank was able to handle the loss as a part of a caring community at the Board and Care. The proceeds from the sale of the house not only funded Hank's Special Needs Trust, but also served to fund the dad's estate plan for the whole family.

and the book are about mental health in England but most of the material applies to the United States. The book is divided into two sections: Mental Illness and Mental Health Services (includes a glossary of terms used by healthcare professionals).

The first section of chapters covers schizophrenia, bipolar, depression anxiety, compulsive and stress disorders, drinking and drug dependence, and mental illness in older people. Each chapter starts with a real case study. The book also addresses how people may have more than one of these disorders and how they are interrelated.

The second section of chapters relates to practical issues that people and their families face daily. This section discusses legal issues, mental health service, professionals, employment, housing, confidentiality, care giving, psychological treatments, violence and suicide.

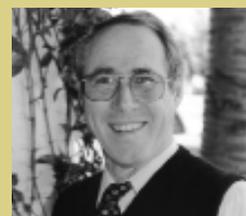
This book provides basic information on different forms of mental illness, treatment plans, emergency situations, legal issues and the role of mental health professionals and agencies. This is an easy read and a very informative book. It is a good primer for those of us who have family, friends or professionals in the mental health field.

## Book Review

By Joseph DeCarlo\*

Mental Illness: A Handbook for Carers  
by Rosalind Ramsay, Claire Gerada,  
Sara Mars and John Szmukler

This is an excellent resource for people working with and caring for family, friends or clients with mental illness. The editors



*\*Joseph DeCarlo is the father of a 41-year-old autistic son "Joey" who also suffers from epilepsy. Joey lives at home with his parents and at-*

*tends Project Independence, a Regional Center of Orange County funded program. Mr. DeCarlo is President of Proxy Parent Foundation and can be reached at joe@jdproperty.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](mailto:info@proxyparentfoundation.org)

## BOARD OF DIRECTORS

### Officers

Joe DeCarlo, *President (JD Property Management)*  
Tom Stevens, *1st Vice President*  
*(Chairman, Los Angeles Capital Mgmt.)*  
Marvin Southard, *2nd V.P. (Former Dir., LA Dept. of Mental Hlth)*  
Gary M. Chang, Esq., *Board Secretary (Attorney at Law)*  
John Buck, *Treasurer (Past CEO, Turning Point)*  
Randall Hagar, *Mbr at Large (Govt Affairs, Dir for the Calif. Psychiatric Assn.)*  
Steve Pitman, *Mbr at Large (Board President of NAMI National)*

### Board Members

Zane Alsabery, *President & CEO, Alchemy Commun. Inc.*  
Michael Antonovich, *Los Angeles Co. Supervisor*  
Elizabeth Galton, M.D.  
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*  
Ann Eldridge, *Retired Nurse*  
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](http://www.proxyparentfoundation.org)