Proxy Parent Foundation newsletter

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ISSUE 7

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PROXY PARENT FOUNDATION

Proxy Parent Foundation offers two services.

We administer 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.

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What's going on...

by Gary M. Chang*

In April, two of our Board Members, Carla Jacobs and Tom Stevens, appeared on the syndicated Ventura radio show, "Grey Matters", hosted by Cherie Kurman, Esq. to talk about our organization and services. Please log on to our website at www. proxyparentfoundation.org to have a listen and send any questions or comments on the show and/ or suggestions for topics you would like us to discuss in future presentations or articles to info@ proxyparentfoundation.org.

In the next few months, the Proxy Parent Foundation Roadshow will be hitting the highways for the following events. On May 10 we will be appearing at the Orange County Mental Health Association's 17th Annual "Meeting of the Minds" Conference; on May 22 we'll be at the NAMI Westside Los Angeles Annual "Pathway to Wellness" Conference; and on May 26 you can find us at the NAMI Santa Barbara monthly meeting. Additionally, we will be hosting a table and are planning on presenting a workshop at the Annual NAMI California Conference to be held this year in Sacramento from August 18-20.

We would love to see you, so if you would like to drop by to reacquaint ourselves with each other or meet in person for the first time, or if you would like us to make a presentation to a group that you think might be interested in our services, please call 714.977.3310 or e-mail us at info@ proxyparentfoundation.org and we will provide you locations and times of the events listed above, or make arrangements to schedule an appearance.

*Gary M. Chang, Esq. is Director of Legal Affairs for Proxy Parent Foundation.

The All-Time Courage Team

by Baron L. Miller*

Spring is back, along with its literal and symbolic messages of regeneration and hope, and with it the game of baseball. This wondrous mode of entertainment is mentioned not only as a distinctive mark of our vernal season, but because some majorleaguers are furthering a core mission of PLAN — fighting the stigma of mental illness. Unbeknownst to these players, they are trying out for a brilliant new team.

Some baseball fans delight in devising imaginary squads of players. We create categories, and make selections to fill out our teams. In addition to groupings like best hitter and fielder at each position, I have a personal enjoyment is in creating atypical combinations, contrivances like All-Time Switch Hitting Team, All-Time Sons of Former Major Leaguers Team, and All-Time Polish Surname Team.

Now I am beginning an All-Time Courage baseball team. This might sound peculiar, for, depending on one's point of view, either all ballplayers are courageous for repeatedly putting themselves at risk of injury and failure, or they are devoid of what is perhaps a more important form of courage: that displayed by those who lead a life without glamour and fame while engaged in activities seemingly more difficult and significant than playing a child's game.

I think it fair to say that the type of courage commonly displayed by a ballplayer pales in comparison to what is exhibited by one who suffers from a mental illness so severe as to turn each day into a grueling installment of a punishing life. With all due respect to an infielder who confronts the possibility of a bad hop bouncing into his face, he is in a different league than the teenager who spends her summer adjusting to new medications in a locked psychiatric unit before valorously marching alone through a wall of strange faces on



the first day of class at her new school. Playing ball requires toughness and guts; living with mental illness requires that and much more – let's call it extraordinary bravery.

Neither does a ballplayer's ordinary courage measure up to that of one who dedicates her life to providing care and assistance and advocacy for victims of mental illness. A batter taking a chance on some chin music simply does not belong in the same lineup as the parent or parent by proxy who ceaselessly and gallantly supports the fragile emotions and physical vulnerabilities of her disabled charge. Standing up for those shunned by society, and caring for those with a limited ability to help themselves, demands exceptional courage not available on a ball field.

Yet there is now a breed of ballplayer who manifests a previously unseen courage, a player for whom my new team has been created. We who advocate for the mentally ill can take some credit for this new player, for it is we who have effected a profound change in the way our world views mental illness. This has produced a new phenomenon in the community of baseball machismo: ballplayers who are coming out publicly with their own mental illnesses.

Take slugging first baseman Joey Votto, winner of the 2010 National League Most Valuable Player award. He tells us right out loud that in 2009, due to depression and panic attacks, he was hospitalized - twice. And Zack Greinke, winner of the 2009 American League Cy Young award, who says he suffers from a social anxiety disorder which causes him to experience a disabling fear of scrutiny in performance situations, a scrutiny he as a pitcher is subjected to around 100 times a game, the number of times he throws a pitch. The courageous Greinke openly credits psychotherapy and anti-depressant medications for making him able to so magnificently overcome his dread.

Smooth fielding shortstop Khalil Greene boldly says he too suffers from a social anxiety disorder, and discloses that he has endured it since childhood. Two-time All Star pitcher Justin Duchsherer and veteran lefty Scott Schoenweis offer not a hint of apology when they refer to their illnesses as clinical depression. Outfielder Milton Bradley and pitcher Ian Snell admit to having contemplated suicide, and future Hall of Famer Ken Griffey, Jr. divulged that at age 18 he was so angry and depressed that he didn't want to live any more, which was the reason why on one very bad day he swallowed hundreds of aspirins.

Some wise person defined courage not as an absence of fear, but instead as doing something despite the fear. These ballplayers face not only serious personal obstacles in doing their jobs due to impaired neural, chemical, and cognitive functions, but by talking about their illnesses they risk ridicule from their teammates, opponents, and fans. As a sports announcer might put it, that's some kind of courage.

To his credit, former pitcher Steve Blass, who went from 2nd place in the 1972 Cy
Young award voting to inexplicable wildness and an exorbitantly inflated ERA in 1973, now says he suffered from performance anxiety during his horrific season. He says he didn't feel he could say anything about it then due to stigma. Well, Zack Greinke has shattered that, as attested to by his former teammate, Mike Sweeney. "[Greinke] is like Jackie Robinson," Sweeney said. "[H]e's the guy who really paved the way for the modern player to come out about these types of issues."

These particular players may not be immobilized by the often overwhelming illnesses of schizophrenia and bipolar disorder, but they are suffering from very real and debilitating mental illnesses, and they must overcome them to succeed at their vocation. To their everlasting credit they acknowledge a need for help to survive as they do, and because of their visibility they are on the front lines of the fight against stigma.

This Spring each pitch they throw and each swing they take won't be just for these players or their teams, it will be for all of us.

And as each of them openly confronts his personal terror, he will be demonstrating his qualifications as a charter member of the All-Time Courage Team.



*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, and 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.

Health Reform and Public Mental Health: The First Wave

by Marvin Southard*

Health Reform, in whatever final form it takes, will have a profound impact on the public mental health system in California. Especially important will be the effect of parity. Parity means that no limitations on care can be placed by an insurer-- public or private-- for mental health and substance abuse treatment that does not apply in exactly the same way to physical health care treatment. Coupled with a vastly expanded number of persons who will have public coverage, it has become evident that costcontainment within this structure cannot happen without a well-conceived delivery of mental health, substance abuse and physical health care services.



1115 Medicaid Waiver—A Bridge Towards Health Care Reform

In Nov. 2010, the federal government approved California's five-year, \$10 billion Section 1115 Medicaid Waiver. Known as the "Bridge to Reform" this waiver is the mechanism by which each state implements the federal Medicaid program within its borders. The "Bridge to Reform" will expand the number of individuals who are eligible for federally reimbursed mental health services and help support counties' currently uncompensated care costs. Hopefully, it will also improve the physical and mental health care of vulnerable populations.

The waiver is complicated with many different parts, but for this article I will highlight what is called the Low Income Health Plan (LIPH). People between the ages of 19 and 64 who are not currently eligible for Medicaid (known in California as Medi-cal) may be eligible for services under the LIPH if they have incomes less than 133% of the federal poverty level.

Currently many of these individuals are receiving what is known as "indigent" care in California: care that is paid for by the counties, the cost of which is not "matched" by federal dollars. Some counties in California currently provide more service for indigents than others do. Los Angeles County, for example, provides over \$120 million unmatched dollars for the mental health care of its indigents. For those counties that do provide a significant level of indigent care, the LIPH will provide opportunity to expand services through the influx of the new federal match.

Increased Populations to be Served

In the case of Los Angeles, for example, that means more services can be provided to the indigent population with severe mental illness we are already serving. It also means the number of indigents with severe mental illness can be expanded to address the unmet need. Additionally, their access to physical health care can be increased. The LIPH also means that individuals who have lower mental health

needs and the primary care practitioners who care for them will have increased access to Los Angeles County Department of Mental Health funded psychiatric consultation. Overall, the LIPH will require considerable coordination and integration between the public mental health and physical health care systems.

These waves of health care reform are occurring now. Counties in California have until July 1, 2011 to prepare their systems to embrace the challenges and opportunities inherent in the LIHP. Everyone is working really hard to make sure that its implementation is not experienced as a tsunami.

*Marvin Southard is the Director of County of Los Angeles — Department of Mental Health. He leads the largest public mental health system in the country, serving over 200,000 clients annually in one of the most ethnically diverse counties in the nation with a budget of over \$1 billion. Prior to this, he served in a similar capacity in Kern County for five years. Mr. Southard is a Member at Large for the Proxy Parent Foundation Board of Directors.

Book Review

by Joseph DeCarlo*

The Cleveland Clinic Guide to Epilepsy by Elaine Wyllie, M.D.



Over 3 million Americans suffer from Epilepsy and I am a parent of a son who has Epilepsy and is

Autistic. I have read many books and articles on this subject only to find this to be the best source I have read. This book explains the definition, causes, treatment options including medication and surgery. The author also explains the myths as well as the facts of

Epilepsy. The author, Dr. Elaine Wyllie is a world renowned Neurologist and specialist in Epilepsy at the Cleveland Clinic.

This was a very easy read and is divided into four parts. Part one looks at the history and myths of Epilepsy such as, is Epilepsy contagious (NO), should you put a spoon in the mouth of someone who is having a seizure (NO), is Epilepsy a mental illness (NO), it is a brain disorder. Famous people who had Epilepsy include Socrates, Alexander the Great, Julius Cesar and Vincent Van Gogh to name just a few. There are many types of seizures with Grand Mal (tonic-clonic) being the most severe to Petite Mal being smallest type. Part One also covers finding a cause of seizures and the use of an EEG, MRI or PET Scans to detect causes.

In Part Two, the author covers treatment of Epilepsy including medications and surgery. Different kinds of medications are identified and dosages are discussed. The Vagus Nerve Stimulator (VNS) is also covered. The different types of surgery and their complications and success ratios are analyzed. Part Three deals with chapters of Epilepsy in children, seniors and women. Part Four covers living with Epilepsy, case studies help illustrate how people cope with Epilepsy in their work and daily lives. Depression and anxiety are also addressed which may result from seizure medication side effects.

The bottom line is that medical knowledge and treatment of Epilepsy have come a long way however, there still is no silver bullet for a cure. The human genome has been mapped, it may be possible in the future to do a total "genetic scan" to help understand a persons' DNA and assist in determining which treatments would work best for a person suffering from Epilepsy.

*Joseph DeCarlo is the father of a 34 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@jdproperty.com.

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