


## REGISTRY GROWS!

In the past year we have made a dedicated effort to increase enrollment into the Stanley Center Registry--the nation's **only** bipolar registry--so we are able to gather enough information to insure statistically sound data. **As a result of these efforts, Registry membership has more than doubled in the last 7 months!** There are currently 1,800 people enrolled in the Stanley Center Registry compared to 800 in March 1998. To meet our goal of enrolling 5,000 participants by October 1999, we have added two clinical interviewers and two additional staff to help us inform providers about the Stanley Center and encourage them to refer patients to us.


You can play a vital part in helping us by continuing to tell your friends, family, members of your support group, and others with bipolar disorder who live within a 150 mile radius of Pittsburgh about the Stanley Center and encouraging them to call us at 1-800-424-7657. 

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## THIRD INTERNATIONAL CONFERENCE ON BIPOLAR DISORDER

June 17 - 19, 1999 are the confirmed dates for **The Third International Conference on Bipolar Disorder**. Sponsored by the Department of Psychiatry and the University of Pittsburgh Medical Center, the conference will be held again in Pittsburgh, with June 19 tailored especially to consumers. We expect this conference to be as educational and beneficial as the previous two. You will receive a brochure detailing presenters and lecture topics within the month.

Abstracts, slides, and audio recordings of presentations from the June 1997 conference are available at our new web address--<http://www.wpic.pitt.edu/stanley>. 

## NEW SUPPORT GROUP ANNOUNCEMENT

### *New Beaver County Support Group!*

The Beaver County Manic Depressive Support Group meets the 2nd Thursday of the month at 7:30 p.m. at 341 Jefferson Street in the Rochester Methodist Church in Rochester, PA. For more information about this support group, contact the Beaver County Mental Health Association at 724-775-4165. 

# "THROUGH MY EYES"

by  
Linda Schmitmeyer

"I know Daddy is sick because when I feed the fish and ask him what day it is so I can mark it off, he doesn't know anymore." This was my 6-year old daughter's answer when I asked her if she understood that, despite no obvious signs of an illness, her father was sick.

My husband had been diagnosed several months earlier as manic depressive, an illness that manifests itself in extreme and unpredictable mood swings. He suffered from depression for two years before having a manic episode that left him hospitalized for a month. His illness and the drugs he takes to level his mood swings have left this once sharp-witted engineer unable to perform his routine work and, to my daughter's observant eye, unsure of even what day it was.

Remembering Elly's response to my question reminded me of the hopelessness I often felt as I watched the fabric of our comfortable, middle-class lives unravel. For months on end the phrase, "How will we ever get through this?" echoed through my brain.

As we celebrated Thanksgiving Day this year, my fear of dealing with this often misunderstood illness had subsided, and even though my husband has yet to return to work and our financial future remains uncertain, we have patched together a working budget that allows us to pay our bills. But it is the people — family, neighbors and friends who helped us along the way — to whom I am forever grateful.

In long, late-night phone calls to my sister, I would rant against the seemingly endless downward spiral of our lives. I cried; she listened — patient, supportive, always encouraging.


These cathartic conversations offered temporary relief from my chaos, allowing me to sleep better and face the next day.

When Steve was hospitalized several hundred miles from our home, one neighbor watched our children while another drove me to the state psychiatric hospital. And when he was transferred to a private facility, the knowledgeable advice of a psychiatric nurse helped fortify me against the stigma associated with mental illness. "People will say it is his character. It is not," she warned. "It is a brain disorder. Your understanding this will help him get better."

Her words set me on a path toward knowledge, which, in the long run, has helped all our family endure the slow pace of recovery from a manic episode in a society accustomed to quick-fixes. But it is my husband — the once gregarious, self-confident man whose sense of self has been shaken to the core by years of not knowing why he could no longer concentrate and think clearly — to whom I am most grateful.

Manic depression is a life-long illness, and Steve will continue through the peaks and valleys of the sickness for the rest of his life. Yet he doesn't give up or become mired in the hopelessness that often drags down the mentally ill. The feeling of despair that haunted me for years has been replaced by a deep-felt gratitude. Steve and I, cradled by family and friends in our hours of need, have been strengthened both as a couple and as a family.

This Thanksgiving, as we bowed our heads in thanks, we better understood what it means to be blessed.

*Linda's husband, Steve, is a Stanley Center Registry participant who recently appeared with his family on a KDKA news segment featuring the Stanley Center.* 

# SOCIAL STIGMA OF PSYCHIATRIC DISORDER

by  
Joan Mallinger, Ph.D.

It is widely accepted that a negative attitude toward those with psychiatric disorders exists; in fact, this is often a reason cited for the delay or avoidance of treatment. One need only look in the TV Guide and note descriptions of nightly police dramas about efforts to nab the “mental patient” turned murderer to reinforce the notion of a negative view of psychiatric disorders. However, references to “mental patients” in neutral or heroic roles are nonexistent. We generally refer to this negative attitude as stigma. I’ve long wondered about the less dramatic, everyday expressions of stigma. How and when is it expressed or experienced? Why is it a problem for some but not others, even when they suffer from the same illness? Also, do different psychiatric disorders produce different experiences with stigma? My doctoral thesis was an attempt to explore some of these issues. To that end, I spoke with 31 participants in various Stanley Center studies of bipolar disorder, and 29 participants in a study on recurrent unipolar depression.

Stigma is defined in the dictionary as a physical mark. In its original use, stigma was a positive reference to the physical marks of war. Soldiers who were marked with scars and battle wounds were considered distinguished soldiers who had fought with courage and valor. Later on, however, physical marks were inflicted on criminals and slaves to insure identification and ownership. As it evolved, the term stigma retained this negative connotation after the practice of physical marking was abandoned.

As the term is used today, stigma is not a physical mark, but a metaphorical one, referring to a blemish or flaw of character. Individuals

whose behavior is not understood are often thought of as flawed and are thus socially, rather than physically, marked or stigmatized. One who is stigmatized because of mental illness may be viewed as less worthy and less socially desirable. One of the reasons that the process is so dehumanizing is that the stigmatized person comes to be identified solely by the undesirable trait and all other components of his or her personality, in essence, vanish.

Social devaluation and distancing as a result of the stigma of a psychiatric disorder can only be said to occur if other people actually know of the disorder. After all, there is no physical mark to distinguish the stigmatized person. So the questions I asked of patients were “Who have you told?” and “Who expressed concern about the symptoms of illness?” Surprisingly, neither unipolar nor bipolar patients confided very much in others of the symptoms that plagued them. Also, patients reported that very few members of their social networks ever asked whether something was wrong, even during the most symptomatic phase of their episode. I also asked patients about their own experiences of social distancing—both social withdrawal as well as perceptions of rejection.

But that was a problem right off the bat. If, according to the study participants, very few people knew of their illness, how could any social distancing be attributable to stigma from the illness in the first place? The answer may be as others have suggested: distancing may come from the fear of stigmatization. I asked study participants questions about their own fears of stigmatization. The findings in my dissertation suggested that the fear of stigmatization was sometimes associated with perceptions of social rejection. Overall social distancing, however, declined sharply over the four month time span that participants remained with the study.


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Fear of stigmatization is a pertinent issue. An article in the *Psychiatric News* reported the legal struggle of a psychiatrist to retain his license to practice after disclosing to his licensing board that he had been treated for bipolar disorder. The licensing board wanted to revoke his license, and their action reflects the process of stigmatization: this doctor's identity as a psychiatric patient became paramount to the licensing board, nullifying his prior roles and skills. Anyone would fear such an outcome from exposure. Or would they?

There are people who in recent years have publicly divulged their battles with bipolar and unipolar disorder and have not suffered the identity-robbing consequences of stigma. Some articles I came upon in my research suggest that if a person is well known to others, the additional knowledge of a psychiatric disorder can more likely be integrated into another's understanding of him or her. The less well known an individual is, the more likely the revealed psychiatric label

will dominate perceptions of his identity and make other characteristics more difficult to see. However, many studies I have read suggest that this is not usually a permanent condition and that, after time, a more realistic view of the individual evolves.


Education has been a major tool used toward the destigmatization of psychiatric illness. But studies suggest that education alone can not limit the power of stigma and the fear that patients have of stigma. In a study of the difficulty of opening group homes in residential neighborhoods, for example, frustrated advocates ultimately found that social rejection was lessened after skeptical neighborhood residents actually met the real people who wanted to be their neighbors. It was much more difficult for homeowners to reject real, complex human beings, as opposed to stigmatized one-dimensional "mental patients," even after educational programs had been provided.

Returning to the question I asked study participants—"Who have you told about your illness?"—I think it might be useful to explore someday what happens when people do tell, and under what circumstances. Television and movies continue to portray the "mental patient" as monster, and there are accounts of the negative outcome of divulging psychiatric treatment. There is mounting evidence, however, that the fear of stigma may be another monster to be reckoned with. 



## STIGMA BUSTERS NETWORK

There is now a "Stigma Busters Network" on the NAMI web site. Stigma Busters invites the public to keep NAMI informed, through e-mail, about information in any media (print, radio, TV, movies) that is offensive to people diagnosed with a mental illness. To register with stigma busters e-mail alert, go to the NAMI web site at [www.nami.org](http://www.nami.org) and click on campaign and then click on stigma.



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### Stanley Center *INNOVATIONS*

The Stanley Center Innovations for Participants is published by the Stanley Center for the Innovative Treatment of Bipolar Disorder staff.  
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## STANLEY CENTER RESEARCH STUDIES

If you are interested in any of the following Stanley Center research studies, are able to give informed and competent consent, and live within driving distance of **Pittsburgh** or **UPMC-Beaver Valley Mental Health Services in Rochester, PA**, please call Joan Battenfield, BSN, Senior Program Coordinator, or Steve Verfaillie, MSW, Program Coordinator at (412) 624-2211 or 1(800) 424-7657. We will consider each person's situation individually and will work closely with your provider to maximize continuity of care.

### Research Studies for Mania

#### **Verapamil and/or Lithium for Mania**

The aim of this study is to assess the effectiveness of the medication verapamil alone or in combination with lithium for the treatment of acute mania which has not responded to the person's current medications. People who are taking lithium, Depakote or Tegretol and who are experiencing breakthrough episodes of mania or whose manic symptoms are not responding to prescribed medications may be eligible for this study. People who are not taking medications for bipolar disorder and who are experiencing a manic episode may be eligible as well. The length of the study is up to 9 weeks with an optional 24 weeks of continued medication treatment. Eligible participants must be at least 18 years of age, currently experiencing mania, have a diagnosis of bipolar disorder or schizoaffective disorder - bipolar type, and able to take lithium. Those taking multiple medications will be assessed on an individual basis.

#### **New Antipsychotic Medication and/or Lithium or Depakote for Mania**

People who are experiencing mania or symptoms of both mania and depression may be eligible for this study, which tests the effectiveness of a new antipsychotic medication added to standard mood-stabilizing medication for the treatment of mania. The study lasts up to twenty months. Eligible participants will be between the ages of 18 and 70, currently experiencing mania or symptoms of both mania and depression, have documented lithium or Depakote levels for 2 weeks prior to entering the study, and be willing to change currently prescribed medications with provider's consent (if taking medications other than lithium or Depakote).

#### **New Antipsychotic Medication for Mania**

People who are experiencing mania or symptoms of both mania and depression may be eligible for this research study. If eligible, a person can participate at one of three different study locations: Western Psychiatric Institute and Clinic (UPMC), the Special Studies Center at Mayview State Hospital, or UPMC-Beaver Valley Mental Health Services at Rochester, PA. The initial study lasts 4 weeks. Eligible participants will be between the ages of 18 and 70, be diagnosed with bipolar I disorder, and have been experiencing mania or symptoms of both mania and depression. Participants will be hospitalized at the study's expense for at least one week.



## **Research Studies for Bipolar Depression**

### **Buprenorphine for Depression**

Patients who are diagnosed with either unipolar or bipolar depression who have been unresponsive to at least 2 trials of antidepressant medication will be considered for this 8 to 24 week study. Participants must be between 18 and 65 years of age.

### **Citalopram for Bipolar Depression**

Citalopram, a selective serotonin reuptake inhibitor (SSRI), has been studied extensively in Europe and is now being investigated at the Stanley Center to assess the medication's effectiveness for the treatment of bipolar depression. People 18 years of age and older who have been diagnosed with bipolar I or bipolar II depression, who have had a major or subsyndromal episode of depression, and have been on mood stabilizer treatment for at least 4 weeks with continued depressive symptoms are eligible for participation. Patients entered into the study will receive 8 weeks of open treatment with citalopram in the acute phase of the study. Those who respond to citalopram will receive an additional 16 weeks of treatment. This is a multi-center study involving 5 sites in the United States.

### **Research Study for Rapid Cycling**

#### **Choline for Rapid-Cycling Bipolar Disorder**

The purpose of this study is to determine if choline, added to lithium carbonate, is an effective treatment for rapid-cycling bipolar disorder to improve the course and severity of mood episodes. To be considered for this study, patients must have a diagnosis of bipolar I, bipolar II, bipolar NOS with rapid-cycling or ultra-rapid cycling, be on lithium carbonate or be willing to take it at a therapeutic blood level,

willing and able to undergo a brain scan and blood tests, and be between 18 and 60 years of age. Women of child-bearing potential must agree to double-barrier contraceptive methods.

### **Research Study for Lithium Side Effects**

#### **Inositol for Lithium Induced Side Effects**

Lithium has been used in the treatment of several psychiatric disorders and remains the most effective medication in the management of bipolar disorder. However, lithium often causes a variety of side effects leading to its discontinuation and/or to a high rate of non-compliance. This study will evaluate the action of inositol on lithium-induced side effects. For this study the Stanley Center is seeking individuals who are at least 18 years of age, currently clinically stable for at least 3 months on lithium and are experiencing moderate to severe lithium side effects including but not limited to: tremor and other neuromuscular problems, edema, excessive urination and/or extreme thirst, and dermatological conditions such as acne and psoriasis. The length of the study is 11 weeks.

### **Research Study for Evaluating the Effects of Psychotherapy**

#### **Maintenance Therapies in Bipolar Disorder**

The aim of this study is to evaluate the preventive potential of a psychosocial intervention for stable patients maintained on lithium carbonate. Eligible participants will have a diagnosis of bipolar I disorder or schizoaffective disorder - manic type, be currently in a manic or depressive episode, and be 18 years or older.