

National Alliance
for the Mentally Ill



NEWSLINE

COOK COUNTY NORTH SUBURBAN

P.O. Box 612 Winnetka, IL 60093 **March-April 2004**

A Federal Failure in Psychiatric Research: Continuing NIMH Negligence in Funding Sufficient Research on Serious Mental Illnesses

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Report Executive Summary

The National Institute of Mental Health (NIMH) has primary responsibility for funding research on serious mental illnesses, defined as schizophrenia, bipolar disorder, autism, and severe forms of depression, panic disorder, and obsessive-compulsive disorder. This report is the third evaluation of NIMH's performance in this task. It covers the period 1997 to 2002, during which time NIMH's budget doubled from \$661 million to \$1.3 billion.

I. The Problem

- There are approximately 11.6 million adults in the United States who have a serious mental illness in a one-year period. Of these, 5.6 million have a severe and persistent form of mental illness.
- Individuals with a serious mental illness make up one-third of the homeless population and 5 to 7 percent of the jail and prison population. At any given time, there are approximately one-quarter of a million seriously mentally ill people who are homeless or incarcerated.
- Individuals with a serious mental illness account for 58 percent of total direct costs for all mental illnesses. This amount includes over 40 billion federal dollars spent under Medicaid, Medicare, Supplemental Security Income (SSI), and Social Security Disability Income (SSDI) and is a major reason for the rapid increase in costs of these programs.

II. NIMH's Response to the Problem

- In 2002, 28.5 percent of NIMH awards went to research on serious mental illnesses. These illnesses account for 58 percent of the total costs of all mental illnesses.
- Only 5.8 percent of all NIMH awards went to clinically relevant research on serious mental illnesses. "Clinically relevant" means reasonably likely to improve the treatment and quality of life for individuals presently affected.
- Between 1997 and 2002, the proportion of NIMH research awards for all aspects of serious mental illnesses decreased by 11 percent (from 32.1 to 28.5 percent). For clinically relevant aspects of serious mental illnesses, it decreased by 22 percent (from 7.4 to 5.8 percent).
- During those same years, NIMH rejected for funding many reasonable research proposals on serious mental illnesses and funded much research that had no relationship to any mental illness. For example, NIMH rejected funding for a treatment trial for schizophrenia but funded research on how people think in Papua New Guinea; rejected funding for research on bipolar disorder in children but funded research on self-esteem in college students; and rejected funding for

Continued on page 7

NAMI CCNS General Meeting
Monday, March 29 at 7:30 p.m.

**"Cognitive Behavioral Therapy:
What it is and Who Benefits"**
Presented by Dr. Karen Cassiday, Ph.D.

Rush North Shore Medical Center
9600 Gross Point Rd., Skokie
Sharfstein Auditorium (Main Entrance)
For further information phone
(847) 724-1460

Dr. Karen Cassiday is a clinical psychologist who specializes in cognitive behavioral therapy and the treatment of anxiety disorders. She is a founding fellow of the Academy of Cognitive Therapy and the chair of the Scientific Advisory Board of the Obsessive Compulsive Foundation of Metropolitan Chicago. She maintains an active teaching career and is on the clinical faculty at the Chicago Medical School and Rush Medical School and trains graduate students in cognitive behavioral therapy. She has published research studies and case studies in the area of anxiety disorders.

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President's Letter

Dear Members,

On January 26th, the annual meeting of NAMI – Cook County North Suburban was held at Rush North Shore Hospital, followed by an outstanding presentation by Dr. John Zajecka on the topic of Methods of Diagnosing Mental Illness. I presented an overview of our affiliate's activities and accomplishments for the year 2003 achieved through the collective efforts of the many people who volunteer to implement the four arms of NAMI's mission: Education, Support, Advocacy, and Research. I would like to publicly thank three individuals who provided invaluable support last year but will no longer continue in their roles. Maureen Sullivan, organizer of the bimonthly educational programs; Pat Witry, membership coordinator, and Charlene Floreani, board secretary. We will miss their contributions and wish them the best in their new endeavors. I also want to thank Alan Carlile who has served as the NAMI-CCNS treasurer for the past two years. He is remaining on the board and assuming other responsibilities. Finally, I want to thank Wilpower for providing the meeting space for our monthly board meetings and Thresholds for providing the refreshments prepared by their clients and served at our bimonthly educational meetings.

At the annual meeting, the slate of board candidates was unanimously voted into office. Our board now is comprised of 19 members, representing individuals, family members, and professionals whose lives are affected by mental illness. Our first board meeting of this year was held on February 9th at which time the officers and committee chairs were appointed.

The year 2004 promises to allow more impact by NAMI-CCNS in our geographical area to address the issues and needs of peoples impacted by mental illness. In December, the board members decided to focus on the following goals for this calendar year:

- **Linkages:** Develop relationships between NAMI-CCNS and local mental health and other local service organizations to help improve programs and services for people affected by mental illness.
- **Public Awareness:** Increase public awareness of mental illness in order to reduce stigma and increase access to services.
- **Information Dissemination:** Develop the NAMI-CCNS website to optimize information sharing.
- **Services:** Create comprehensive and coordinated services and programs that meet membership needs.

These goals are based on the needs we have heard from our members and others in the communities served by NAMI-CCNS. These goals are achievable only with the help of the many volunteers who contribute their time and energy to this organization. There is always room for more volunteers; please call or send an email if you have an interest in helping NAMI-CCNS achieve its goals for 2004.

As I bring this letter to a close, I want to share some of the activities that have already taken place in this new year. In January, a new consumer social group, "Sundays at

One," held its first, very successful meeting. This program has been organized by Alan Carlile and Nate Maier and will be held monthly. (*see Calendar*)

Earlier this month, I had the pleasure of serving on a panel at the annual Turning Point Town Hall Meeting in Skokie where the focus was current issues and needs of the mentally ill and their families. Legislative, medical, state government agency, and consumer representatives were also on the panel. The program was taped and will be airing on the local cable station in Skokie.

Board meetings are open to all members. We encourage you to attend. This is a good way to learn about what NAMI-CCNS is doing. The meetings are held at 7:30 p.m. at Wilpower, 444 N. Frontage Road, Northfield. In the spring, board meetings will be held on March 10 and April 14. If you would like to contact me directly, please do so by email: CHughesNamiCCNS@aol.com or call the NAMI-CCNS telephone number: 847-724-1460.

Sincerely,

Candice Hughes

NAMI-CCNS 2004 Board

Candice Hughes, President

James Brodnicki

Alan Carlile

Chris Dee

Maun Dee

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Peter Kelly*

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Todd Logan

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Sally Mann

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Tina Nelson

Ellen Roth*

Julie Savastio

Deborah Walsh*

James Walsh*

*New members, elected to two-year terms



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Editor: Linda Logan, Ph.D.

Questions, comments?

Please e-mail: ldatl@comcast.net

Visit our web site www.namiccns.org

Web site maintained by Beth Kordick

A Guide to... **Noncompliance**

By
Linda Logan

What is noncompliance?

Noncompliance is characterized by a fundamental nonadherence to the therapeutic directives a doctor recommends for the patient. The five most common forms of noncompliance are:

- Not having prescription filled
- Taking incorrect amount
- Taking medication at the wrong time
- Forgetting or skipping doses
- Stopping medication

What are some of the reasons a person may be noncompliance?

- Unpleasant side effects

Many psychiatric medicines come with an array of side effects, ranging from the mildly troublesome to the severely problematic. *The side effect most often associated with noncompliance is weight gain.* At a recent APA meeting, doctors reported 90% of noncompliance issue were due to weight gain; 80% of the patients interviewed felt that weight gain adversely affected their overall life (duh).

Today's medications most closely associated with weight gains are the second-generation antipsychotics (SGAs). While each medication's side effects risk profiles varies, on the whole olanzapine (Zyprexa) and clozapine (Clozaril) are the worst offenders. The FDA recommends careful screening and monitoring of people on these medications for signs of rapid weight gain. Doctors are advised to monitor patients' cholesterol, triglyceride and blood sugar levels.

Other side effects that can become bothersome to the point the patient discontinues his medications are:

- Sexual side effects, such as lowered libido, impaired sexual performance, and anorgasmia (failure to achieve orgasm)
- Feeling of being drugged out:
Sometimes a person just starting a medication may feel like a zombie, dragging himself around, with a brain full of mud. Many times, this can be rectified with a change in dosage; other times, the side effects receded as time goes on.
- Anti-cholinergic effects such as: constipation, ringing in ears; dry mouth (and nasal passages); problems with bladder control; difficulty with urination

Why *don't* people with severe mental illnesses take their medications?

- They don't think they're sick, so they don't need medication

Researchers studying noncompliance believe that impaired awareness, or agnosia, (from the Greek words, nosos=disease; gnosis=knowledge; a=not;=literally means "to not know a

disease), is the main reason some patients don't take their meds. According to The Treatment advocacy Center, agnosia is "the single largest reason why individuals with schizophrenia do not take their medications." Other studies show 50% of schizophrenic patients and 40% of people with bipolar disorder

Agnosia is not denial, which is a psychological defense mechanism; researchers believe impaired awareness has a biological basis (specifically the frontal lobe and portions of the parietal lobe in the right hemisphere).

- They don't "believe" in medication

Many people reject the notion that mental disorders have underlying biological or chemical bases that are mediated by psychiatric medication.

- They think the medication doesn't work or, conversely,

the medication has worked so well, they no longer need it

- They just don't like what it "stands for"

Sometimes people with severe mental disorders need to take their medication for life. While nobody relishes this thought, it is helpful to remind the person that there are many medical conditions, such as diabetes or hypertension that also require daily medication for life. While I can't say I'm delighted to gulp down a handful of medications every morning, I prefer to look at them as a lifesaver rather than an albatross.

What the patient can do to help improve compliance?

- Get plugged in

Don't let your illness isolate you. You will only feel worse. Join a support group for people with mental disorders.

- Educate yourself

Learn everything you can about your condition, including treatment protocols and psychopharmacology algorithms.

• Join a patient support or psychosocial rehab group
Again, check NAMI CCNS and other area mental health organizations, such as Wilpower, Inc. and Josselyn.

- Ask for assistance

If you feel you cannot manage your medication regimen or pursue leads for support programs, ask friends or family for help. People don't have ESP, if you don't ask, it may never get done.

What can family members do?

- Be the manager

Family members may feel that once a person has been diagnosed and put on proper medications, the rest of follow-up care should be easy. How hard is it to pop a couple of pills a day and keep a weekly appointment? The point is, many people with serious mental disorders are either too demoralized or lack the energy and motivation to properly handle their treatment and medication plan. While you may feel resentful about having to micromanage your relative's medical condition and treatment, consider the upside: the more the family can help a person with severe mental disorder, the less chance there is for potentially devastating outcomes such as: relapse, re-hospitalization homelessness,

prison and/or jail, violence or suicide.

Some ways to help manage your relative's care are:

- Oversee his schedule (keep track of his appointments and make sure he gets there)
- Keep prescriptions filled
- Buy a pill organizer and fill it up for the week (or day, whichever works better)
- Have the person take his medications in front of you

"Most medications...must be taken in sufficient quantity, on a regular schedule, for a specific period of time to be effective. Self-administration of medications often leads to nonadherence [noncompliance]." The World Health Organization saw dramatic improvements in compliance rates of people with tuberculosis when "direct-observed therapy" (DOT) was implemented. Sending people home with a bottle of pills is not enough to ensure compliance. DOT was originally designed for tuberculosis, but it is being used in another areas of medicine equally well (e.g., methadone and substance abuse).

- Educate yourself about your relative's disorders and medications

Learn about what side effects may be anticipated and keep an eye out for them. Join one of NAMI CCNS' excellent psychoeducation programs, "Family to Family" and "Visions for Tomorrow." (*See Calendar*)

- Help the person keep a notebook, marking the meds taken and a summary of the day's activities and his thoughts and feelings. This helps not only you and him to track his progress (or lack of), but is an invaluable aide for the doctor, as well.
- Be understanding and constructive

Assure him, for instance, that it is completely normal to be troubled by some side effects. Tell him you and he can discuss these with the doctor at the next appointment and see what can be done (if they are serious, call you doctor immediately).

- Remain supportive and hopeful

Remain optimistic without sounding like a Pollyanna. There is nothing worse than a family "cheerleader" who dismisses the patient's negative comments and promises great things for the future (e.g., "You'll be back at your law office in no time!"). This only makes the person feel you don't understand --- perhaps you *can't* understand ---and increases his feelings of isolation and alienation.

What kinds of things may help improve compliance?

- Therapeutic alliance

The treatment plan begins and ends with the doctor. If the patient feels the doctor is unresponsive to his needs, doesn't listen, doesn't care, or just feels there is "bad chemistry" with the doctor, the outcomes for improvement are diminished.

- New ways of taking medication

Some drug manufacturers have come out with antipsychotics that can be injected, called "depot medication," (e.g., risperidone, fluphenazine). These drugs last a long time, obviating the need for daily administration.

Some unorthodox strategies to improve compliance for family members

Disclaimer: The following ideas have not been scientifically tested. They are the result of brainstorming with other people in discussions of noncompliance. Some readers may feel uncomfortable about condoning "forced medication," an issue that will not be addressed here. I do feel, however, that medication being unwittingly (or reluctantly) given to someone by a loving family member is quite different from forced medication issued at an institution. Readers are obviously free to reject these ideas altogether.

Make a videotape of the person at his most symptomatic. A schizophrenic person who refuses to believe he is sick (or will become sick again) may reconsider if he sees a tape of himself at his worst.

- Medicate the person without his awareness

I know a woman whose mother, a woman with severe depression, refused all medication. The woman decided she would visit her mother every morning "for coffee." While she made a fresh pot, she would drop the tablet and let it dissolve in her mother's cup. This worked for years.

- Use medications as incentives for "rewards"

For instance, if your brother refuses to take his meds, claiming they don't work, try re-framing the issue. Say, "I know they don't work, but if you take it, we can go to the movies tonight." By de-emphasizing the medication's therapeutic role, it can be used as a bargaining chip for the patient to earn or be rewarded for things or activities he wants.

What can mental health professional do to improve compliance rates?

See Dr. David Osser's excellent treatment algorithm from Harvard Medical School on page 6.

Sources: "Medication Adherence" *Medscape Mental Health* 9 (1), 2004; Weiden, P. "How to help someone who stops taking their medicines."

www.schizophrenia.com/family/compliance1.html; Bardon, L. "Joint panel urges increased surveillance for adverse effects of antipsychotic drugs" *Medscape Medical News*. Available at: www.medscape.com/viewarticle/467951; "Briefing Paper, Impaired Awareness of Illness" The Treatment Advocacy Center. Available at: www.psychlaws.org/BriefingPapers/BP14.htm; "MMT as a platform for treating Infectious Disease," *Addiction*

Spaces still Available

Family to Family psychoeducation program

12 week course for family members, partners and friends of individuals with Major Depression, Bipolar Disorder (Manic Depression), Schizophrenia, Borderline personality Disorder, Panic Disorder, Obsessive Compulsive Disorder, or Co-occurring Brain Disorders with Addictive Disorders

Classes are structured to help caregivers understand and support individuals with serious mental illness while maintaining their own well being. There is no cost to participate in the NAMI Family-to-Family Education

Strategies for Patients Who Have Been Noncompliant

For the Mental Health Professional

By Davis Osser, MD

Reprinted with permission by Dr. Osser

Harvard Algorithm Project

For more information www.mhc.com/Algorithms

Overcoming Barriers to Good Outcome: Non-Compliance

What follows is an algorithm for addressing a variety of non-pharmacologic barriers to good response in the pharmacologic treatment of psychotic disorders. Recognition and management of non-compliance is one factor which receives extended consideration. Non-compliance is also an issue in maintenance treatment and this section may be helpful for that, as well.

Question: Is the patient taking the medication as prescribed?

No: non-compliance is strongly suspected

Yes: compliance is assured (or, choose this answer if you have addressed compliance problems and are looking for additional barriers that could be contributing)

Help:

Suspect non-compliance or partial compliance if any of the following apply:

1. Patient is missing appointments
2. Patient is actively abusing/dependent on alcohol or other substances
3. Patient reports no side effects at all
4. Patient reports huge amount of side effects which clearly outweigh the benefits occurring or expected, yet denies non-compliance
5. Patient is not refilling medication when prescriptions are scheduled to require refill [Ask the patient to bring their medication containers to appointments in order to review dosing instructions. This can be helpful to detect forgetfulness as a cause of non-compliance, but if patient is actively and secretly resisting following instructions, there will be resistance to bringing in the containers! It may become clear that the patient never even had the prescription filled.]
6. Patient indicates inability to afford the cost of the medication
7. Patient does not accept/lacks insight into their diagnosis, denies need for treatment, or has not expressed clear desire to improve
8. Patient has secondary gain from staying ill (e.g. - compensation issue)
9. Patient resisted idea of medication when first proposed, and sees use of medication as stigmatizing

Question: Has sufficient time been spent with the patient to assess subjective response to the medication, and address concerns about side effects?

Comment: The education process must be ongoing and ideally should involve the family. Lessons learned from treating depression are probably applicable to patients with schizophrenia.

There, use of a multidisciplinary team approach results in the best compliance, with oral and written information given by nurses, pharmacists, and psychotherapists supplementing and reinforcing the information provided by the physician. When the prescriber is a primary care physician working in a general medical practice, the above is much less likely to occur. Physicians may spend even less time with patients who are in pre-paid insurance plans vs. fee-for-service plans.

Recommendations: Consider some of the following factors which may contribute to poor outcome:

1. Review diagnosis. Is it DSM-4 criteria based? Remember that it must be, in order to use this algorithm.
2. Have medical conditions been ruled out as cause of the psychosis?
3. Is there a severe, acute precipitant?
Be sure that there is no ongoing active alcohol abuse or dependence. This is associated with poor response.
4. Is the patient currently receiving adequate concomitant psychotherapy to address psychosocial and stress factors contributing to the patient's stability? Or, is the patient receiving brief "medication visits" only?
5. If the patient is receiving psychotherapy, does the patient have a positive alliance with the therapist? Could there be a "negative therapeutic reaction" wherein the patient is angry or upset with the psychotherapist and this is undermining medication treatment outcome?
6. "Split therapy:" Is it a problem in this case? Or -- is it needed?

Question: What is the patient's understanding of the causes of their illness?

- Patient attributes disorder to a simple explanation like "not getting enough sleep," or to stress, e.g. - "working too hard." This irrational or misinformed explanation might support non-compliance with the prescribed medication regimen.
- Patient has good understanding of illness and accepts diagnosis.

Comment: Lack of insight is very common and has been established as a factor in treatment non-compliance in patients with schizophrenia. The patient's "explanatory model" of the illness is probably a significant factor in non-compliance with treatment. The clinician should elicit the patient's self-formulation and look for irrational beliefs.

Recommendation: Sufficient time should be spent to define the illness, describe target symptoms for medication, suggest expected time course of response, review side effects of medication, sequence of doses and what to do if problems arise, and encourage the patient to ask questions. Patients should be given a patient information sheet about the medication to take with them. Review all the side effects listed on the sheet during the session and refer back to it in subsequent meetings if necessary. An appointment in one week is recommended after starting medication, to check for possible deterioration, early side effects, or other reasons for early non-compliance.

Sexual side effects seem to be underemphasized by clinicians. They occur in as high as 75% of patients taking SSRI antidepressants, such as fluoxetine (Prozac), sertraline (Zoloft), and paroxetine (Paxil), and have been described as the "Achilles Heel" of these medications. This occurs often with risperidone, and older generation neuroleptics with prolactin elevation. Patients are often not clearly informed about them, and even if they are informed, they may be reluctant to bring them up with their physician. They must contribute to non-compliance more than has been generally appreciated.

Recommendation: The patient may need more counseling and negotiation to resolve the differing formulations of the problem. The clinician should offer a more comprehensive model of the factors (biological and psychosocial) that are contributing to the psychotic disorder and how different treatments address the different factors. This should be tailored to the patients experience by incorporating some aspect of the patient's explanation if possible. For example, if the patient believes that insomnia is the cause of everything, the patient should be told that inability to sleep is, in fact, an important symptom of the potential relapse, and improvement in sleep would be a good indicator of when the patient is more stable. Then, sleep would be monitored closely.

Question: Does the patient have a complicated medication treatment regimen that could be simplified?

Comment: Even if the patient is only on one, relatively uncomplicated pharmacotherapeutic agent, he/she may be on other non-psychiatric medications which make the overall task of keeping them organized rather difficult. This is especially common in the elderly, where non-compliance rates have been reported to be as high as 75%. Patients with comorbid organicity, attention-deficit disorder, or demanding daily activity schedules often forget or confuse their medication schedules. Actually, it is probably the exceptional patient who is compulsively reliable with oral medication compliance.

Recommendation: To help patients with complicated medication regimens, the following might be tried:

1. Give written instructions.
2. Use pill boxes organized weekly or, better, monthly, with clear instructions about what to do if a dose is missed.
3. Reduce the number of pills/capsules per day by giving larger size pills. Keep in mind that certain medications have a maximum dose that may be given at any one time: eg - bupropion SR(Wellbutrin) 200 mg, clozapine (Clozaril and others) 450 mg. Consult the Physician's Desk Reference or package insert.
4. Reduce the number of times per day that the medication must be taken. Some medications are often given several times a day when this is unnecessary because the half-life of the drug is 24 hours or more. Recent studies suggest risperidone can be given qd, and some experts recommend giving quetiapine qd. .
5. Organize medication ingestion around daily routines, such as meals. Ziprasidone must be taken with food.
6. Some complicated, but suboptimally effective pharmacotherapy regimens evolve from well-motivated efforts,

but simpler approaches might have been passed over which may work better.

Question: Does the patient have significant others who are not supportive of the pharmacotherapy? (e.g. - spouse, parents, AA sponsor)

Comment: "Not supportive" could mean overt opposition ("There's nothing wrong with you, you don't need that crutch.") However, it could also mean excessive (albeit well-motivated) reminders ("nagging") that stimulates oppositional behavior. Sometimes pill-pushing by significant others is motivated in part by their own resistance to accepting any responsibility for contributing to the stress in the patient's life that is fueling the motivation to become non-compliant. The patient may feel that taking the medication is equivalent to admitting that the problem is all theirs and that the significant others (spouse, parents, housemates are not exhibiting any problematic behavior. **Recommendation:** Consider having a family compliance counseling session. Explore what the significant other's understanding of the illness is, and what they think the patient's needs are. Psychoeducational work may be helpful. Sometimes, more complicated and multidetermined undermining of the treatment plan may be going on, which may require a series of meetings to address.

Question: Does the patient have certain personality traits that might call for a particular individualized approach to improving compliance?

- Dependent
- Compulsive/paranoid
- Passive-aggressive/hostile-dependent

Suggestion: For dependent patients: These patients are generally compliant but if they are not, they may hide this fact so as to not displease the clinician, family members, or significant others. Supportively explore possible reasons for non-compliance: explanatory model, cost, side effects, etc.

Suggestion: For the compulsive/paranoid patient: These patients require more extensive discussion and reassurance than others. They particularly appreciate being offered different treatment choices or alternatives so they can actively make choices and feel in control. Allow more options and go over contingencies in advance when presenting the titration schedule.

Suggestion: Passive-aggressive/hostile-dependent patients: These patients are particularly prone to poor compliance. They require detailed explanations of the medication, indications, target symptoms, side effects, etc., and yet they may still refuse to try it on a minor point. The best approach is to be very clear about the limitations of drug therapy. Avoid excessive claims for benefits and undue reassurance about side effects. These patients report more side effects than other patients, and this should be responded to with sober professionalism. Sometimes a "counterprojective approach" of slightly exaggerating the problems with medication and anticipating their negative appraisal of the medication may allow them to feel more comfortable with going ahead with an adequate trial.

[Sources: Cramer JA, Rosenheck R. Compliance with medication regimens for mental and physical disorders. *Psychiatric Services* 1998;49:196-201.
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The New Goals of Treatment: Remission and Recovery: A Summary of Dr. Zajecka's January Presentation

By Tom Maier

Dr. John Zajecka, noted psychiatrist and researcher, addressed over 50 NAMI CCNS members at Rush North Shore Medical Center the evening of January 26. He spoke for an hour and a half on a wide range of topics, then fielded questions for another 45 minutes, before hospital staff had to push us out the door. In addressing the future of treatment, he identified three major trends in psychiatric research and practice. First, the profession is moving from the concept of a single illness with specific criteria, toward a multi-dimensional approach that recognizes overlapping symptoms and illnesses. As an example, he noted the overlap of symptoms between bipolar disorder and schizophrenia. Whatever the diagnosis, the goal of treatment has now become remission and recovery, in contrast with the old goal of merely keeping symptoms under control. Second, more resources are now focused on early identification methods in order to move toward prevention. Third, there is increasing recognition that certain metabolic disorders, for example, diabetes, may well be related to mental illness.

Dr. Zajecka stated that current best-practice diagnostic methods rely on clinical data from the patient, as well as significant others. Gathering this data requires sitting down in conversation with the individuals involved. Responding to a question, *Dr. Zajecka confirmed that family members might tell a physician anything they want--contrary to what some physicians, citing HIPAA regulations, tell us.*

So far, blood tests, brain scans and similar tests are not yet validated as effective diagnostic markers, but research continues to be devoted to identifying biological markers. One hot new area, according to Dr. Zajecka, is "Brain Derived Neurotrophic Factor" (or BDNF). BDNF is responsible for growth of nerve cells, which may explain why environmental factors, in conjunction with genetic factors, can lead to mental illness. BDNF levels can be diminished by both environment and genetics. He noted that anti-depressant medications actually turn the gene for producing BDNF back on.

Genetic studies, although already producing breakthroughs,

have just scratched the surface. The goal is to identify vulnerability in individuals, while there is still a need to identify environmental factors. Dr. Zajecka noted that genetics is a rapidly growing area of research.* In summing up, Dr. Zajecka emphasized the future is bright regarding diagnosis and for effective and safe treatment. He repeated that there is growing emphasis on prevention, identifying vulnerability and early intervention and reiterated the expectation is no less than full remission and recovery.

* *Science* magazine named research on the genetics of mental illness the #2 scientific breakthrough of 2003, second only to "newfound insights into the nature of the cosmos."

Continued from page 1

research on the causes of postpartum depression but funded research on the hearing mechanism of crickets, as detailed in Appendix A.

- NIMH's failure to fund sufficient research on serious mental illnesses is the main reason why research on these illnesses is so grossly underfunded compared to other diseases. For example, per person affected, for every \$1 NIMH spent in 1999 for research on bipolar disorder, NIH spent over \$12 for research on cervical cancer. For every \$1 NIMH spent for research on depression, NIH spent almost \$15 for research on multiple sclerosis. For every \$1 NIMH spent for research on schizophrenia, NIH spent \$30 on research for HIV/AIDS.
- Research on serious mental disorders is not an important part of the NIMH research portfolio.
- During the five-year period of doubling of the NIMH budget, a period that could have been used by NIMH to correct its traditional neglect of research on serious mental illnesses, the proportion of NIMH research awards allocated to serious mental illnesses actually decreased, rather than staying the same or increasing.

III. The Solution

- Congress should hold hearings to establish a minimum percentage of the NIMH budget that must be spent for research on serious mental illnesses.
- NIMH should be required to report to Congress annually how much it is spending on each serious mental illness.
- The Government Accounting Office should evaluate the NIMH research portfolio vis-à-vis the discrepancy between the allocation of NIMH resources and the public's needs.
- Behavioral research on diseases is important, and all NIH institutes are supposed to fund behavioral research on diseases for which they have primary responsibility. NIMH should therefore support behavioral research for psychiatric disorders but not for other diseases.
- Basic neuroscience research is also important. However, allocation of responsibility for such research needs to be better coordinated between the National Science Foundation (NSF) and various NIH institutes, including NIMH.

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<http://www.citizen.org/publications/release.cfm?ID=7702>

Calendar

March 8 Mary Anne Ehlert and Brian Rubin present "Heart to Heart: An educational seminar for special needs families." Mary Anne Ehlert (CFP of Ehlert Financial Group, Inc.) and Brian Rubin (Brian Rubin and Associates) discuss special needs planning, estate planning, special needs trusts, guardianship proceedings, etc. Wilpower, Inc. 444 N. Frontage Road, Northfield. 6:45 p.m. – 8:30 p.m.

March 11 "Visions for Tomorrow Support Group" This group is for parents of children, adolescents and young adults with mental disorders. Kenilworth Union Church, 211 Kenilworth Ave, Kenilworth. 7:30-9:00 p.m. Jan Fitzhugh, Ph.D., facilitator. Call 847 446-8416 for details.

March 11-12 Autism and Asperger's of Chicago will feature Dr. Temple Grandin, Dr. Lori Ernsperger, Nancy Kashman and Janet Mora. For more information, call 1-800-489-0727

March 12 Josselyn Center's "Ohadi Conference on Children and Adolescents with Bipolar Disorders." This year's theme is comorbidity and differential diagnosis. Keynote Speaker: Boris Birmaher, MD, keynote speaker. Five Seasons Country Club in Northbrook. Call Josselyn Center for information.

March 12 "Literacy for the Child with Autism" in Macomb. For more information, call 888-732-7462

March 12-14 Teacher training for "Visions for Tomorrow." This three -day intensive training course is designed to teach parents of children with mental disorders the "Visions for Tomorrow" curriculum so that they will be qualified to teach Visions to others in their communities. For information, call NAMI Illinois VFT Program Coordinator, Barb Maier at 847 446-8416. *Thanks to a generous grant from the Office of the Illinois Attorney General, hotel, meals, childcare, and VFT manual and materials are covered.*

March 19-20 "Autism and Oral Sensory Motor Deficits: Effective Interactive Language Techniques" in Glenview. For more information, go to www.eritherapyseminars.com

March 28 "Sundays at One," a new social meeting group for young adults (ages 18-35) coping with mental disorders. Run by Alan Carlile and Nathan Maier. Borders Bookstore, 49 S. Waukegan Road, Northbrook (corner of Waukegan and Lake Cook Roads). 1:00 p.m.-3:00 p.m. For information and registration, call Alan at 847 736-4587 or Nathan at 847 446-8416. (*see Support Groups, p. 10 for more info*)

March 2 NAMI CCNS General Meeting presents Dr. Karen Cassiday, "Cognitive Behavioral Therapy: What is it and who benefits" 7:30 p.m. at Rush North Shore Medical Center 9600 Gross Point Rd., Skokie in the Sharfstein Auditorium (inside Main Entrance). For further information phone (847) 724-1460 (*see front page for more information*)

March 10 NAMI CCNS Board meeting. Wilpower, Inc. 444 N. Frontage road, Northfield. 7:30 p.m. Call Candice Hughes for information 847 724-1460

April 8 "Visions for Tomorrow Support Group" (*see March 11*)

April 12 Representative Lou Lang will talk about issues around the upcoming election as well as mental health issues and a letter writing campaign at Wilpower, Inc., 444 N. Frontage Rd. 7:00-8:30 p.m.

April 14 NAMI CCNS Board meeting (*see March 10*)

April 25 "Sundays at One" (*see March 28, above*)

April 26 NAMI CCNS General Meeting "Turning Point Behavioral Health Care Center: Services and Programs," presented by Aaron Petersen, Case Manager at Turning Point. 7:30 p.m. at Rush North Shore Medical Center, 9600 Gross Point Rd., Skokie in the Sharfstein Auditorium (inside Main Entrance). For further information phone (847) 724-1460

Legislative Update

Insurance Parity for Mental Health Still Needed

By Sally S. Mann

Lack of insurance parity for mental illness remains a burning issue at both the national and state level. While some patients receive SSI benefits to cover their medications and visits to therapists; many who are working do not.

Without coverage, patients without insurance do not receive the treatment they desperately need. For those with coverage, visits to therapists are often limited. Inadequate and inequitable coverage continues to be a source of stress for people with mental illness and their families. In a survey conducted by NAMI National when the question was asked, "Does the private health insurance that you or your loved one with a mental illness have adequately cover the costs of mental health treatment?" 56% said "No" Thirty six percent had no coverage at all. This is a national disgrace!

National

At the national level, The Senator Paul Wellstone Mental Health Equitable Treatment Act of 2003 has not yet passed in the Senate and the House, although Senators Durbin and Fitzgerald are Representative Schakowsky are co-sponsors. This is an election year and anyone attending candidates' forum should ask the candidates their position on this vital issue. We need to keep reminding our legislators to keep this issue alive.

Illinois

In Illinois the current insurance parity law will expire on December 31, 2005 unless extended. , We need to start *now* to repeal the sunset provision as it takes time for lawmakers to review legislation. Please contact President Emil Jones and urge him to sponsor HB 4104, which repeals the sunset clause of the parity bill. If *not* repealed, the parity bill will no longer exist (i.e., it will sunset, on 12/31/05).

Senator Emil Jones, Jr.
(Senator 14th District and President of the Senate)
327 Capitol Building
Springfield, IL 62706
217 782-2728

Research Studies

GENETIC STUDY OF SCHIZOPHRENIA

Researchers at the Evanston Northwestern Healthcare Research Institute and Northwestern University are searching for the genes that cause schizophrenia. If we can identify

these genes, we hope we will be able to develop better treatments for this important brain disease. We are seeking individuals with schizophrenia to help us with our research. Participants are asked give a blood sample and undergo a clinical interview. Volunteers will be reimbursed for time and any expenses.

Pablo V. Gejman, M.D.

Principal Investigator

*For more information, call toll-free 866.636.8228
Kathie Gutrich, M.Ed., B.S.N., R.N. - Coordinator*

IS YOUR TEEN DEPRESSED?

Depression is a serious illness that affects how we feel, behave and think. About 1 in 20 children and adolescents suffer from various forms of depression. Teenagers who are depressed often go untreated until a crisis occurs. If your teen is sad or angry, uninterested in usual activities, or having sleep or appetite changes, depression may be the cause. Doctors at Northwestern University are conducting a research study on the effectiveness of medication and counseling for treating depression during adolescence. If you know of a teenager who may be depressed, this research may be for them. Participants will receive a comprehensive evaluation, expert care and follow-up service at no charge. Financial compensation is offered. For more information, call the:

Treatment for Adolescents with Depression Study

312 894 TADS (8237) or e-mail
tads@northwestern.edu

NAMI CCNS Education Classes, Support Groups and Other Services

*NAMI CCNS offers two psychoeducational classes each year in the fall and winter

***Visions for Tomorrow** An 8-week course designed for primary care givers of children with mental disorders. The class covers disorders such as ADHD, bipolar disorder, schizophrenia, anxiety disorders, eating disorders, as well as brain biology treatments and medications, communication and coping skills. Class is free of charge. Call Barb Maier for information 847 446-8416

***Family to Family** A 12-week class designed for family members and close friends of individuals with brain disorders (mental illnesses). The course presents comprehensive information on schizophrenia, major depression, bipolar disorder, borderline personality disorder, panic disorder, obsessive compulsive disorder, co-occurring addictive disorders, as well as medications, coping skills and advocacy. Class is free of charge. To register, call Joyce at 847-853-6191

General Monthly Meeting is an educational program featuring speakers with expertise in mental-health related topics. (*See Calendar for details*)

Visions for Tomorrow Support Group. This group, which meets the second Thursday of each month, is for parents of children adolescents and young adults with mental disorders. Call Barb Maier, facilitator, for information. 847 446-8416 (*See Calendar for details*)

Response Team A "warm line" (*not a crisis hot line*) for anyone looking for resources, referrals (or just a chance to connect with others) about dealing with mental disorders. Call the NAMI CCNS office and leave a message, 847 724-1460 (messages are picked up three times a week by our response team members)

"Sundays at One" is a new social meeting group for young adults (ages 18-35) coping with mental disorders (such as depression, bipolar disorder, anxiety, schizophrenia, eating disorders, OCD). Run by Alan Carlile and Nathan Maier, who also struggle with chemical imbalances, the group will emphasize good mental health and offer activities for young adults who want to do things together. 1:00 p.m.-3:00 p.m. at Borders Bookstore, 49 S. Waukegan Road, Northbrook (corner of Waukegan n and Lake Cook Roads). For information and registration, call Alan at 847 736-4587 or Nathan at 847 446-8416.

Other Organizations

Anorexia Nervosa and Associated Disorders (ANAD) invites interested parties to call for referrals, information and local support groups. Call Dawn (847) 831-3438

The Depression Support Group meets the fourth Monday of every month at the Kenilworth Union Church, 211 Kenilworth Avenue, Kenilworth at 7:30 p.m. Group invites individuals and families interested in learning more about depression and manic depression (bipolar disorder) to attend. Call (847) 251-4272 for more information

The Child and Adolescent Bipolar Foundation (CABF) is a national, parent-led organization of families raising children diagnosed with (or at risk for) bipolar disorder. For information on support groups, on-line library and other activities visit www.bpkids.org or call (847) 256-8525

Depression and Bipolar Support Alliance of Metropolitan Chicago (DBSA) offers support for persons affected by depressive or manic-depressive disorders. Call (773) 275-3230

Depression and Bipolar Support Alliance (DBSA) meets the second and fourth Mondays of each month at the Devon Bank, 6445 N. Western Ave., Chicago, at 7:30 p.m. Call Chet for details (773) 465-3280

Obsessive Compulsive Disorder Support Group meets weekly Thursday evenings at Resurrection Hospital, 7435 W. Talcott, Chicago. 7:30-9:00 p.m. Call Carol Miller, facilitator, for information 773-774-3019

Obsessive-Compulsive support group Professionally-led group for adults (and their support persons) with OCD per session. Meets the first Monday of each month at Anxiety and Agoraphobia Treatment Center, Frontage Road, Northbrook . 7:30-9pm. \$25 per session. Call Alona Ramati, M.S. 847-559-0001 ext. 8 before attending first meeting for information.

NAMI CCNS
P.O. 612 Winnetka IL
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