



NAMI Ohio's

NEWS BRIEFS

Vol. 29
No. 1
Winter 2007

Ohio's Voice on Mental Illness

*Happy Holidays from
our Family to Yours.*



The Mauro's



The Snider's

In this issue:

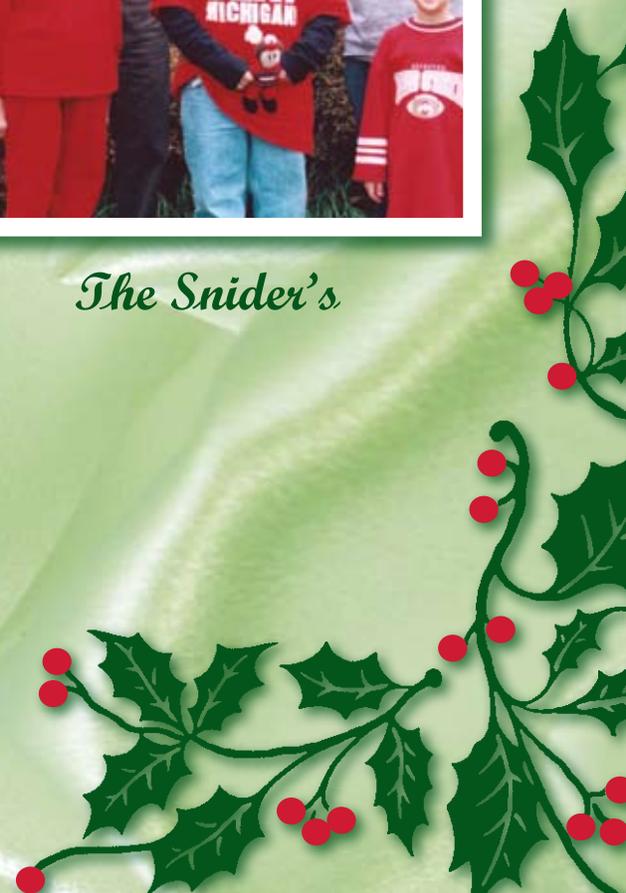
Safe Living Conditions

System Reform: Time to Act

Honoring Herb Reisenfeld

Can Four Minutes Make a Difference?

Campus Security and CIT



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NAMI Ohio Photo Album

The holidays are a wonderful time to celebrate family and to express our gratitude for all of our blessings throughout the year. In this final month of our 25th Anniversary, we are celebrating by putting together a Faces of NAMI Ohio Photo Album. As a member of our family, we invite you to participate, by sending us a photo of your family to be included in our photo album. The album will be placed on display at our statewide conference May 9th – 10th at the Hyatt Regency in Columbus. Send your photo along with your generous annual donation to us at:

NAMI Ohio
747 E. Broad Street
Columbus, Ohio 43205

Remember, if you mail your donation before the end of the year, you can write it off your 2007 taxes.

NEWS BRIEFS is changing its name and we need your help

Please help us come up with a new name for NEWSBRIEFS. We want something fresh that speaks to NAMI Ohio's mission of support, education & advocacy. Please send suggestions to us at amiohio@amiohio.org along with your contact information. The person who comes up with the winning name will be acknowledged in our next issue.



NAMI News Briefs Contents



Ohio's Voice on Mental Illness with more than 55 affiliates statewide

Articles

NAMI Ohio Cosponsors Medicaid Managed Care Public Forums	4
Herb Reisenfeld Father of NAMI Ohio 1926-2007	5
Can Four Minutes Make a Difference?	6
Campus Security Encourage to Attend CIT Training	7
Focus on Affiliates	10
Death by Smoke	11
Brother's Love	12

Features

Safe Living Conditions for Ohio's Mentally Ill	2
Time to Act	3
Ask the Doctor	8
Ask the Child Psychiatrist	9
Wall of Honor	13

On the cover...



The Mauro's
Catie, Jim and Aaron



The Snider's
Jeff Snider, Harvey Snider, Cheryl Bravo & Eric Bravo
Lois Snider, Andrew Bravo and Jordan Bravo



Safe Living Conditions for Ohio's Mentally Ill

By Harvey Snider, President

In October, the Cleveland Plain Dealer printed an article entitled, "Nursing homes warehouse homeless, mentally ill." According to the article, "Some Cuyahoga County nursing homes have become warehouses for the homeless and mentally ill, using millions of taxpayer dollars to house patients who often don't qualify for the care. Medicaid pays nursing homes to take in hundreds of Cuyahoga patients discharged every year from hospital psychiatric wards. The mentally ill are eligible for admission to nursing homes only if they need 24-hour supervision or hands-on assistance. But 60 percent of the psychiatric patients admitted into Cuyahoga nursing homes, most on Medicaid's dime, don't need the care, the state found."

Of course, all Ohioans, particularly public officials, should be concerned with the misuse of public dollars. However, beyond the condemnation of such acts, we need to be concerned with the underlying problem of mental health service delivery.

These situations all too often represent a case of the "tail" wagging the "dog." While we should never condone nor overlook the violation of Medicaid rules, we should always demand that these rules governing the system of care be reasonable and workable and that they have as their only objective the provision

of quality services to those who need them. What "qualification" for care is more compelling than a serious, chronic illness? What difference should it make whether an individual with serious mental illness has another physical ailment if he or she needs a place for treatment and there is no other alternative to a nursing home? If the choice is made to provide someone with life-saving care at the expense of a rule that puts that person at risk, God bless the person who made the decision.

We at NAMI Ohio are tired of the same old argument that Ohio has a separate system of care for the mentally ill. While it is the case that there is a defined structure for such services, it is, quite simply, broken. There are alternative settings, but they are wholly inadequate. The fundamental reason that the 1300 mentally ill individuals referred to in the article are in nursing homes is because they are not being served elsewhere. If they were to be removed from nursing homes, local communities in Ohio would not be able to absorb them into safe living conditions with adequate supports.

There is no question that the mentally ill are better served in community based residential care settings with adequate supports. The simple fact is there is not enough such community based care

available. Group homes do cost less. But don't be fooled by this apparent good news. It costs the system less because that is all the system will pay. It is not a reflection of the real costs of supplying housing, food and otherwise providing a home. While the nursing home may get \$148.00 per day, Adult Care Facilities, for example, receive as little as \$18.00 per day. There are additional supplements for some individuals, but they are inadequate to serve the current need and they are shrinking.

We need to accept the facts that mentally ill individuals may require differing living and care environments; that we have created a system of care that is complicated, fragmented, fraught with bureaucracy and unable to respond to the need. There will always be a need for structure in delivering care. However, that structure must be a reflection of what is needed to deliver services that meet the needs of those served. Services should not be designed to accommodate the structure within which they are delivered. The bottom line is that Ohio's system of health care has always viewed mental health as somehow different from other health needs. Far too often that difference results in a discriminatory view of mental illness that leads to less than adequate care. We implore Ohio's leaders to fix the root problems.



SYSTEM REFORM: Time to Act

By Jim Mauro, Executive Director

Efforts are said to be underway in the Strickland Administration to reform the behavioral health system. NAMI Ohio is committed to playing a role in this important process, and while we appreciate the Administration's desire to seek input and build consensus, we believe the time for talk is over and the time to act is now. What we really need is bold leadership, and a willingness to make difficult and oftentimes unpopular decisions that will lead to better outcomes for families and consumers. Consumers and families are hurting and they cannot wait any longer for relief. To this end, I would like to offer the following advice:

Trust Doctors to Know Best

- Doctors go to school for years to learn how to properly prescribe medication. So long as a doctor is current on information regarding prescribing best practices, Medicaid and Medicaid Managed Care should not be allowed to restrict the doctor's ability to practice medicine by imposing cost containment strategies such as prior authorization, and fail first. These strategies do not save the state money. The best health outcomes result from experienced, educated physicians and patients working together. Peer driven drug utilization review programs and physician and patient education are more effective in reducing costs and in improving the quality of care. NAMI Ohio believes that medication therapy

is the single most important element of recovery for those we represent.

Improve Oversight of Medicaid

- Either provide local boards with the tools they need (utilization review) to manage the behavioral health Medicaid system or place the Medicaid oversight responsibility entirely at the state level. The current system is not working.

Prioritize the Severely Mentally Disabled (SMD) Population

- Resources are finite. Local boards must prioritize core services for those in greatest need. Funds should never be diverted away from these core services to meet Medicaid match. If need be, create a separate line item in the budget to cover these costs and prohibit alternative uses.

Create More Housing Options

- People with serious mental illness cannot be expected to recover when they do not have a roof over their heads. Create and adequately fund at least 2,000 new housing options for individuals with mental illness throughout Ohio. These housing options should be for those SMD clients whose only income is SSI. We are being told that over 400 referrals are being turned down by the adult care facility operators because they cannot provide adequate care on the \$18 a day that the client can pay.

Stop Suing Each Other

- Millions of dollars that should go to provide services have been consumed in lawsuits. Stop it.

Increase Consumer and Family Representation on Boards

- We claim we want a consumer-driven system, yet under current law, only one of the eighteen members of the local board must be a consumer or family member. We need to seek out qualified consumer and family members to serve on local boards and then gradually increase the number of representatives to at least nine.

Make More Effective Use of the Pink Slip Process

- Contrary to popular belief, the Ohio Revised Code does not limit the use of pink slips to only those incidents in which a person presents an imminent danger to themselves or others. There are two other conditions including: "violating the rights of others," and the "inability to care for oneself." Getting someone help before they completely come apart is an act of compassion, not a violation of civil liberties. We must prioritize caring for those who are too ill to care for themselves.

Ensure an Adequate Supply of Hospital Beds

- The number of available hospital beds must meet the actual need. We must expand the number of beds available throughout the state of Ohio, particularly those for children. Although we support outpatient community based care, it is no substitute for hospitalization for those who need it. The lack of enough hospital beds has created pain for too many of our citizens.

Eliminate the Need for Families to Have to Give Up Custody of Children to Receive Treatment

- In pockets around the state, families are still told to give up rights to their child if they want to get that child needed treatment. How is it that some counties

have figured out how to avoid this practice, while others still operate in the dark ages? This should NEVER happen!

Coordinate the System of Care for All Children

- A child's diagnosis should have no bearing on whether that child receives treatment. Clarify in law, once and for all, which system is responsible for serving children with Autism and Asperger's Syndrome and fund those services appropriately.

Consumers and families cannot afford further delay in making the changes to our mental health care delivery system that will result in better health outcomes. Studies show that some individuals with serious mental illness die 30 years sooner than the rest of the population. If this is not a health crisis, I have no

idea what is. We must be much more effective and efficient in our use of limited resources. This may require significant change to the way we do business in this state. Existing system prejudice and allegiance to "it's the way we have always done it" thinking must end. We need imaginative and selfless leadership from all those in positions to make a difference. Most particularly we need that from the Governor and the Ohio General Assembly.

Suspend Rather than Terminate Medicaid for those in Jails and Prisons. Requiring individuals with Serious Mental Illness to reapply for Medicaid after they are released from prison and then having to wait months to be approved is just asking for trouble.

NAMI Ohio Cosponsors Medicaid Managed Care Public Forums

Over 250 people participated in six forums co-sponsored by NAMI Ohio which were held around the state this fall. The purpose of the forums was to provide individuals with mental health and substance abuse disorders and their families the opportunity to learn about the transition to Medicaid Managed Care and to understand how this change impacts their healthcare. Attendees also had the opportunity to express concerns about

the new system and receive answers to questions about their benefits. A final report of the forums will be prepared and sent to the Ohio Department of Job and Family Services. Look for a link to the report on NAMI Ohio's website soon. www.namiohio.org.



▲ Jeff Corzine, Senior Program Administrator with the Ohio Department of Job and Family Services, speaks to members of the public at the Medicaid Managed Care Forum in Cleveland, Ohio.

Herb Reisenfeld

Father of NAMI Ohio

1926 - 2007

Note: Former NAMI Ohio Executive Director, Terry Russell, delivered the eulogy for Herb Reisenfeld. The following is Russell's comments:

I am so fortunate that Herb Reisenfeld entered my life and was such a positive influence. I am honored that his daughter, Sally, invited me to give this Eulogy today because I can say with all my heart that I loved Herb Reisenfeld.

NAMI Ohio celebrates its 25th Anniversary this year and the Father of the NAMI Movement in this state was Herb. He was active in supporting mental health causes in Cincinnati and helped finance one of Ohio's first group homes. He traveled to Columbus 25 years ago and met with some other family members (mostly Mothers) and created the Alliance for the Mentally Ill of Ohio. A few years later, he was elected to the NAMI National Board of Directors. During his candidate's speech he pulled off his coat to reveal a "Superman" costume, stating he would "knock down walls to help the mentally ill." After he was elected, he would often fly to Washington and be at the National Office before the doors were unlocked in the morning, and was later elected President of that body.

In 1952, Herb started the first drywall business in Cincinnati. That business expanded to other states and became the largest drywall business in the

region. Like everything that Herb did, he was extremely successful, but always felt that it was important for him to give back and help others.

In 1998, NAMI Ohio was going through some very tough financial times. Herb recruited me to come in and try to turn the agency around. Early on, I realized



that it might have been an impossible task had Herb not come to me and quietly donated enough funds to cover all expenses during the summer of that year.

I would often travel to Washington or around the state and Herb loved to go with me and it was his tenaciousness that motivated me: he would not give up!

But NAMI was not his only interest. Herb was a devoted Father: his four children were his focus. They would

travel the world with him and he gave each of them the opportunity to succeed in their lives. This is best shown by his commitment to his son, Gregory. During Greg's adolescence, he was diagnosed with a major mental illness. Herb sought out the best treatment available throughout the country for Greg. During his work with NAMI National he met a psychiatrist and he sent Greg to New Mexico to be treated by this doctor. When the doctor moved to Wyoming, Herb even moved his son there and he would often visit him to make sure that his life was as comfortable as possible.

Everyone around Herb knew that he could be "difficult", but he was difficult for the right reasons. Herb could not hear very well and I always sat him next to me at Board meetings so he could hear better, but more importantly, so I could "control" his "enthusiasm". Herb loved to be with people and all those who got to know him respected and cared for him.

Herb loved the Cincinnati Bengals, the Reds and Cincinnati University, where he once was the head fencing coach.

During my last visit with Herb at the Village I was extremely sad that his illness (Alzheimer's) had taken its toll on him. But as I left, Herb hugged me and said that he loved me. I will always remember that hug and I will miss this very special person in my life.



Can Four Minutes Make a Difference?

By C.A. MacConnell

I'm all wound up this evening. I testified today in front of the General Assembly's Joint Committee on Healthcare Access and Affordability today in Cincinnati. The legislators have been traveling around Ohio all summer soliciting public input on the state of our health care system. I was asked to testify by NAMI Ohio, and to communicate in my own words the need to ensure that individuals on Medicaid and Medicaid Managed Care have access to the mental health medications they need. Unfortunately, Governor Strickland just vetoed language in the budget bill which would have helped ensure this access.

Anyway, the Convention Center Room 109 looked big & scary...a long, creepy aisle, a microphone, fronted by the thrones where the Reps and Senators sit, and a bunch of rows of identical chairs filled in with suits and skirts - mostly doctors, health organization heads, and government officials. I didn't wear a suit, but I did wear a long, black skirt, and if you know me, you know that is very, very strange indeed. Sitting there in that skirt, I felt like ripping it off and putting on some torn up boy shorts. But alas, I didn't. I also took all of my earrings out but two. I only let one tattoo show. I didn't have any appropriate shoes, so I just opted for my Doc Martin sandals. Gotta do what you gotta do. Let's just say that among the crowd, I felt like a pencil in the land of laser pens. Ever feel that way? I do all the time.

Anyway, I got there at like 5 p.m., and when I went to sign a witness slip, the lady told me that she already had thirty people signed up, and that I really shouldn't bother, because they wouldn't get to me. I filled out the slip

"Sitting there in that skirt, I felt like ripping it off and putting on some torn up boy shorts. But alas, I didn't."

anyhow and asked her to slip me in on the list. I tried to be sneaky, but she was a tough cookie. She said no, I wouldn't get to speak. So I gave her my written testimony and sat down, waiting for my turn, which she said wasn't going to happen. I was a tougher cookie than she, I'm afraid.

"I only had four minutes to tell my life story to the Representatives and Senators. Four minutes."

About five minutes in, I was already antsy. So I had to score a Diet Coke and some animal crackers, which are my favorite vending machine gourmet specialties. Then I went back to the stuffy room. Actually, it wasn't hot-stuffy. It was freezing. I'm always freezing. Unless I'm

hot, and then I'm really hot.

Damn, while I was listening I realized how lucky I am. People spoke on issues ranging from diabetes to cancer to asthma to heart conditions, and on and on. I learned that there are 1.2 million uninsured individuals in Ohio. I also learned about terms like open enrollment and conversion, and some scary truths about insurance companies. For instance, at one company, the largest one in the United States, the CEO made \$23 million last year. Hmm. Let's just say, my mouth dropped open more than once.

I started to chill out as the time went by because I figured I wasn't going to have to talk. The hearing was supposed to be over at 7:30 p.m. Turns out, several people didn't show, and at 7:29 p.m., unbelievably, they called my name. Then I started shaking. Really shaking. But I made it down the long aisle all the way to the mike, and I spoke and shook. I only had four minutes to tell my life story to the Representatives and Senators. Four minutes. I was the only one who spoke without notes. I just winged it. I guess I did okay because afterward, when I turned around, the whole room was clapping, which, weirdly, I thought was funny at first. They had been told not to clap. But they did anyhow. Then I felt a lump in my throat. An asteroid.

Then Representative Jimmy Stewart came over and shook my hand, and we

chatted a while. He was very helpful. Oddly enough, he greatly resembled my brother. While he was talking to me, I started thinking; I wonder what my bro's doing right now? Then I came back to earth and responded to Rep. Stewart, who is quite handsome, I might add.

Then a bunch of people I don't know gave me their cards. It was bizarre. There was this one man. He showed me a picture of his daughter and explained that she was too ill to speak. He thanked me for doing the speaking for her. I got

way choked up at that point.

"Then a bunch of people I don't know gave me their cards. It was bizarre. There was this one man. He showed me a picture of his daughter and explained that she was too ill to speak. He thanked me for doing the speaking for her. I got way choked up at that point."

All in all, I'm glad I did it. It felt empowering. It felt like a release, like finally, someone was hearing me, someone was listening. I'd do it again, but it made for a hard week for me. Putting myself out there can be tiring and stressful, to say the least. Let's just say, when I talk (or write!), I don't hold back. A blessing and a curse.

To read more by C.A. MacConnell, visit her website at:

www.camacconnell.com/blog

Campus Security Encouraged to Attend CIT Training

Today's young people are dealing with higher levels of stress than at any other time in our nation's history. Like it or not, colleges and universities are a hotbed for potential crises. According to a recent survey by the American College Health Association, the rate of depression among college students has doubled in the past 15 years, with over 45% of the young people surveyed stating that they have sometimes felt too depressed to function. On top of this already staggering statistic, is the fact that the average age of onset of serious mental illness, including schizophrenia and bipolar disorder is between the ages of 18 and 25.

The April 2007 Virginia Tech incident in which Seung Hui Cho killed 32 students and faculty members and then committed suicide is certainly the most tragic of such crises to occur on a campus, perhaps in our lifetime. However, it is certainly not the only one

to occur. In Ohio, we are striving to take steps to help protect against any more such tragedies. We believe a well prepared campus security force is an important part of these efforts.

It is for these reasons that NAMI Ohio, with financial assistance from the Ohio Department of Mental Health,



is reaching out to the President's on college campuses throughout the state to encourage them to send a representative to attend Crisis Intervention Team (CIT) training in their area at no cost.

CIT is an intensive 40-hour training program for law enforcement and security officers designed to provide them with the skills they need to respond to calls involving individuals experiencing a mental health crisis. These skills include recognizing the signs of mental illness, de-escalation techniques, and a good understanding of the local mental health system so they know where to take an individual in crisis to receive appropriate treatment.

Training campus security to recognize the signs of mental illness, respond appropriately to the situation, and get the young person in crisis into treatment can make all the difference to that individual, his or her loved ones, and the members of the community.

For more information, contact NAMI Ohio at 614-224-2700.



Ask the Doctor

Marion E. Sherman, M.D.

Dear Doc,

I am 55 and going through menopause. I worry that the hormonal changes I am experiencing will cause my depression medication to quit working. Is this a legitimate concern?

-Over-the-Hill-Autumn in Akron

Dear Over,

While certainly menopause may seem to stop your depression medication from working, actually the depression medication works through a different mechanism in the brain. Menopause can certainly aggravate your depression, as well as complicate the emotional symptoms and add new physical symptoms. Sometimes it may be difficult to differentiate your depression symptoms from your menopausal symptoms.

Also, autumn is a beautiful season, and yet may also symbolize approaching death of winter. Viewing your menopausal life as "autumn" may exacerbate your symptoms, as this view impacts the important area of HOPE, so vital to recovery. You may notice that savvy marketers are now referring to menopausal women as being at the "peak" of life, rather than the more traditional ads as the "autumn season" of life.

Bottom line: work with your doctor to achieve the maximal medication effect for your depression, and for help with your menopausal symptoms if they are severe. In addition, become an active participant in exercise, nutrition, spiritual practices, and social activities to appreciate the "summer" of your life.

Dear Doc,

My identical twin boys are college sophomores. One has just been diagnosed with schizophrenia. What is the likelihood that my other son will have the same disorder? (You should know that their paternal grandfather has schizophrenia as well.)

-Scared in Circleville

Dear Scared,

Genetics play a role in schizophrenia, but no one knows exactly how that works. About one person in one hundred in the general population will develop schizophrenia. In studies of families with schizophrenia, about one person in ten with a parent, sibling, or child with schizophrenia will develop schizophrenia, and about half of the identical twins with schizophrenia will develop schizophrenia. This happens whether or not the twins are raised together, so this tells us that there is a strong genetic component.

Since half of the twins do not develop schizophrenia, this tells us that there is a complicated inheritance pattern, which probably includes biologic and environmental factors as well, such as malnutrition, prenatal infections, or brain injuries. This complicated genetic inheritance is called multifactorial polygenetic, meaning multiple genes on multiple chromosomes interacting in an unknown way to produce schizophrenia.

One caution as you read this: statistics apply to populations, not to individuals, so one cannot use the above figures to know specifically about your sons. Your unaffected son may or may not have the genes in the specific pattern to produce schizophrenia, and your knowledge in helping him may have the ability to provide some environmental protection for him. None of us know how long we have in any particular condition, and our best approach is fully living each moment of the now with life and with each other.

Warm Regards in Recovery,

Marion E. Sherman, M.D.

Chief Clinical Officer, Twin Valley Behavioral Healthcare
Past-President, Ohio Psychiatric Physicians Association



Ask the Child Psychiatrist

By Dr. Steven W. Jewell

Dear Dr. Jewell,

It seems like there are more and more kids these days being diagnosed with mental illness? Why is this? - Overwhelmed in Oberlin

Dear Overwhelmed,

I think your observation is accurate, and I think it's a good thing. While it is impossible to be certain why more kids are being diagnosed, I think the primary reason is the success of many coordinated local, regional, and national efforts to improve the assessment and recognition of mental health needs in children.

In fact, this was one of the eight goals articulated in the "National Action Agenda" that was the outcome of the 2001 Surgeon General's Conference on Children's Mental Health (see <http://www.surgeongeneral.gov/topics/cmh/childreport.htm#pan1> for details). The need for enhanced recognition and assessment of childhood mental illness was driven by a number of sobering statistics, including most importantly the finding that in the United States, 1 in 10 children and adolescents suffer from mental illness severe enough to cause some level of impairment. Yet, it is estimated that less than 1 in 5 of those children receives needed treatment.

When you add to that the fact that

- a) more children suffer from psychiatric illness than from leukemia, diabetes, and AIDS combined;
- b) half of all adults with psychiatric disorders report that their symptoms started before age 14; and
- c) suicide is the sixth leading cause of death for 5 to 15-year-olds and the third leading cause of death for 15 to 24-year-olds, it is clear that we need to continue all efforts to identify children with mental illness as early as possible, and get them the treatment they need!

Dear Dr. Jewell,

My 5-year-old son is very explosive. I am expecting another child in a few months and I am worried that he may harm the baby. What advice do you have for me? - My Boy's a Bully

Dear My Boy,

If you are truly concerned that your 5-year-old's explosiveness may be a potential danger to his sibling when he/she is born, I would urge you to pursue a mental health evaluation of your son as soon as possible. This is especially important because the birth of a sibling is one of those common life events that can be stressful to an older sibling, and can thus cause that child to demonstrate an increase in problem behaviors.

While many parents are reluctant to pursue evaluation for a child that young, it is important to understand that early diagnosis and treatment can yield a better outcome than delaying treatment until later in life. In general, the decision to seek professional help can be difficult and painful for a parent, but it is essential to recognize the signs that this might be necessary, and take action.

In younger children some of the signs that a psychiatric evaluation is indicated include: a marked drop in preschool or kindergarten performance; severe worry or anxiety (as shown by regular refusal to go to school, preschool or day care, go to sleep or take part in activities that are normal for the child's age); hyperactivity, fidgeting, constant movement beyond regular playing; persistent nightmares; persistent disobedience or aggression; and frequent, unexplainable temper tantrums. In the presence of such behaviors a parent should at the very least consult their child's physician or teacher, or their minister, priest, or rabbi for advice on how to proceed; and should seriously consider pursuing a mental health evaluation.

Thanks for Asking,

Steven W. Jewell, M.D.

Medical Director; Child Guidance and Family Solutions

Focus on Affiliates

NAMI Richland County and Mansfield Symphony Join Forces for Music and Moods Concert

On October 27th, the Renaissance Performing Arts Association presented Music and Moods, which featured guest pianist Carlos Cesar Rodriguez performing with the Mansfield Symphony under the direction of Music Director Robert Franz. Prior to the symphony, NAMI Richland County hosted a dinner which featured guest speaker, Dr. Kay Redfield Jamison (the author of several books, including *An Unquiet Mind*, and a distinguished Professor of Psychiatry at the Johns Hopkins University School of Medicine). Dr. Jamison enlightened the audience about the compelling connection between mental disorders and enhanced creativity.



▲ From left to right, Mary Kay Pierce, Executive Director of NAMI Richland County; Matt Joslyn, Executive Director of the Renaissance Theatre; and Terri Bergman, President & CEO of the Renaissance Theatre.



▲ From left to right, State Senator Randy Gardner, NAMI Wood County, Executive Director Judy Remele, NAMI Ward County, President Carol Asmus, and Wood County Commissioner Alvin Perkins.

NAMI Wood County Sounds Alarm and Raises Awareness

After 18 years in the community, NAMI Wood County has officially opened its doors. On June 18, 2007, NAMI-WC held a community Open House in its new office at 130 S. Main Street, Suite 316 in Bowling Green. Over 60 members of the community attended, including long time mental health supporters Senator Randy Gardner and County Commissioner Alvin Perkins. In fact, the attendance was so great that the increased usage of the aged elevator in the office building caused the elevator motor to burn out. The local fire department was called out and came on the scene with their siren's blaring! NAMI-WC is especially grateful to the Wood County ADAMH Board for providing the funds necessary to enable them to open an office and hire a part time Executive Director, Judy Remele.



Death By Smoke

By Shelly Kiser

Just recently my husband and his mother went to change the decorations on my sister-in-law's grave. Though she died over a year and a half ago, my mother-in-law remains dedicated to keeping her spot covered in pumpkins, four-leaf clovers, hearts or whatever the season requires. She still cries for hours, too, as though the grief were as new as the day of Allena's death.

My sister-in-law Allena had schizophrenia, but that wasn't what killed her. In fact, she was doing quite well. She had family and friends, even a boyfriend. She hadn't been in the hospital for many years.

At the age of 41, she was diagnosed with cancer. Her doctor told her that if she continued smoking she was unlikely to survive.

She didn't want to smoke. She had tried to quit before, but was terribly addicted, so hadn't been successful. She tried again now that she had cancer. I found out about a program that offered free nicotine replacement therapy. But the program required that she attend a number of group counseling sessions to qualify and that was too intimidating for her. She just couldn't stop smoking.

So, Allena's condition worsened. And she died at the age of 43.

People with severe mental illnesses smoke at alarming rates with severe consequences to their health. Recently a group of state agencies, foundations and health organizations has begun work to find ways to make sure that consumers addicted to nicotine get the



▲ Allena

help they need in the way that's most appropriate for them so they can stop smoking. I'm proud to be serving on the advisory group.

The clinical director of psychiatry at the University of Wisconsin, Dr. Eric Heiligenstein, studied the relationship between smoking and people with

psychiatric disorders. He said, "These people won't die from their illness. They will die from smoking."

Unfortunately, this is something I know only too well.

Below are resources for people interested in learning more about how to stop smoking themselves or to help their loved ones to stop to these resources:

- *Freedom From Smoking Online: The American Lung Association's free online smoking cessation program: www.ffsonline.org*
- *The American Lung Association Lung Helpline with free information on smoking cessation and other lung health issues: 1-800-LUNGUSA 1-800-LUNG-USA*
- *Ohio Tobacco QUIT LINE's FREE telephone service for stopping smoking, dipping or chewing tobacco (Some callers may be eligible for free nicotine replacement therapy): 1-800-QUIT-NOW*

Shelly Kiser is a consumer, family member, and Director of Advocacy at the American Lung Association of Ohio.



A Brother's Love

By Ronald Lutz

My sister, Nancy Lutz, was a war-time baby born in Springfield, Missouri in 1944 to Clifford and Margaret Lutz while he served at an Army hospital. Our parents returned to their Ohio community following the war and I (Ronald) was born in 1947. We were the only two siblings growing up together on a farm our parents rented south of Bucyrus, Ohio.

I think we had a normal upbringing. In retrospect, the characteristics I remember most about my sister in our formative years was her adventurous, take-charge attitude. For example, she led me on a daring (but probably ill conceived) climb through the rafters to the top of our large barn, much to the horror of our mother when she discovered what we had done. Later, she guided me on a mile walk through the back fields to our grand parents' house, to the surprise of both our grandparents and parents. Also, I remember returning from the fields with dad one day, and Nancy ran out of the house to greet me and announced she had learned how to turn our first, new television on and off. We both attended Mt. Zion, a rural school southwest of Bucyrus.

Nancy was an average student throughout her grade and high school years. At home she kept scrapbooks of movie stars and fashion clothing; she

was keenly aware of her own dress and appearance. Like me, she was a very shy person, but continued to challenge herself as evidenced by her desire to be a part of the church choir, to which she was soon accepted. She graduated

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from Mt. Zion in 1962. All her life she remembered her senior class trip to New York City and Washington, DC. It was in my high school senior class year she enrolled in a cosmetology in 1964. I am sure Nancy's journey to Columbus and her success in school there was an influence on my decision to seek a college degree. Our parents had never been able to go on to higher education,

and Nancy's success was a significant achievement.

After she received her cosmetology degree, Nancy began work in a beauty salon in Bucyrus, Ohio and soon attracted the attention of a local gentleman resident. They began a romantic attachment that lasted until the onset of her illness which began around the end of 1966 and the beginning of 1967 while I was away at college. Slamming door episodes was the only description our mom would offer of Nancy's condition. Eventually, it was diagnosed as catatonic schizophrenia. With no knowledge of how to handle her situation, our parents had Nancy admitted to a psychiatric hospital in Tiffin, Ohio. She stayed there about nine months.

The next eighteen years she lived with our parents. The most evident outward manifestation of her illness was her lack of desire to communicate through speech. If pressed, she could give one word answers (usually yes or no) to a question. I was not involved in Nancy's life during these years except to see her during the holidays. My failure to see her was due as much to shame and embarrassment as it was due to it being inconvenient. Our extended family was ignorant, me included, of brain illnesses. Much anxiety, fear and shame could

have been avoided with some basic understanding of her condition, which we were unable, and in some cases unwilling, to get. The burden of care fell on our mother, and she performed it with what can only be described as diligent love. I do not know what medications were prescribed during this time, nor do I know what occurred while she was at Tiffin. I do remember talk about limited shock treatments being considered.

By 1985 it was becoming more difficult for our mother, now approaching 70 years of age, to care for Nancy. I have been told it was a miracle our parents were able to secure a bed in a nursing home that year for Nancy in Mansfield, Ohio. She lived 9 years, and it was during this time Clozaril was first used as a medication treatment. She also gained an excessive amount of weight, from 130 lbs to 300 lbs., although the weight gain was over the course of several years. In 1974 our parents secured a bed for Nancy in a nursing home in Bucyrus which was much closer to their home. The change in residence plus the continued use of Clozaril seemed to rejuvenate Nancy somewhat, as she could be more visibly happy at times and on occasion was able to talk in coherent sentences. She participated in bingo games and other games of chance, attended social

events and worked for 5 years at a workshop for the mentally retarded (her MR/DD status was a result of her being mentally ill for so many years).

The one constant for most of her life was her joy when going out to eat. Maybe it was a dislike of her living situations, but there is no doubt she



liked to get out of the nursing home and eat in restaurants. Our parents both died in 1996, but Nancy lived in Bucyrus until late 2006. In 2004 Clozaril was discontinued as our medication of choice due to blood pressure problems. Her condition deteriorated rapidly following the change. At the end of 2006, I secured a bed for Nancy at a Gahanna, Ohio nursing home. She was diagnosed with Melanoma at the beginning of 2007 and died from that cancer condition in May, 2007, two days short of her

63rd birthday, having survived 40 years after the onset of her illness.

"A Brother's Love" - The story above was written by Ronald Lutz as a tribute to his sister, Nancy. In the early 60's, when they turned 18, their father purchased a \$20,000 life insurance policy for each of them. When Nancy passed away at the beginning of this year, Ronald wanted this insurance money to be used in a way that would help others find meaningful housing. From the time Nancy was 41 until her death, she resided in nursing homes because of her mental illness. She would often tell Ronald, "The people are all old here." Ron has donated the \$20,000 to NAMI Ohio and we have made a commitment to him to utilize these dollars in her name to expand housing throughout Ohio. This was one of the most heart-felt gifts ever received by NAMI Ohio. The expression of this brother's love for his sister can be duplicated by any member of the NAMI family. If you would like to contribute to the Nancy Lutz Fund for the expansion of housing, please contact our office by phone (1-800-686-2646) or by e-mail (amiohio@amiohio.org). On behalf of the citizens in the State of Ohio suffering from mental illness, we want to thank Ronald Lutz for letting us recognize his love for his sister.

Wall of Honor

In Memory of Nancy Lutz

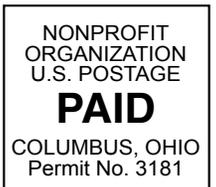
In Honor of Nell's Personal Care Home

*The person with the winner name will be acknowledged in our next issue.



NAMI Ohio News Briefs

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Ohio's Voice on Mental Illness

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NAMI Ohio Mission Statement

"To improve the quality of life,
ensure dignity and respect for
persons with serious mental illness,
and to support their families."