



National Alliance on Mental Illness

nami

New York State

**Incorporating Research
in All Aspects of Our Work
And The Key Collaborations That Make It Happen**

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RESEARCH=HOPE

NAMI-NYS Strives to Include Research Findings & Promote Participation in Clinical Trials in:

- **Communication Efforts**-Newsletter, E-Newsletter, *Mental Health Now* Television Show, Social Media,
- **Education Efforts**-Annual Education Conference, Signature Programs
- **Advocacy Efforts**-Use Research to Argue Points & Partnering with Researchers to Introduce Legislation

Key Partnerships



National Institute
of Mental Health
Outreach Partner



BRAIN &
BEHAVIOR
RESEARCH FOUNDATION

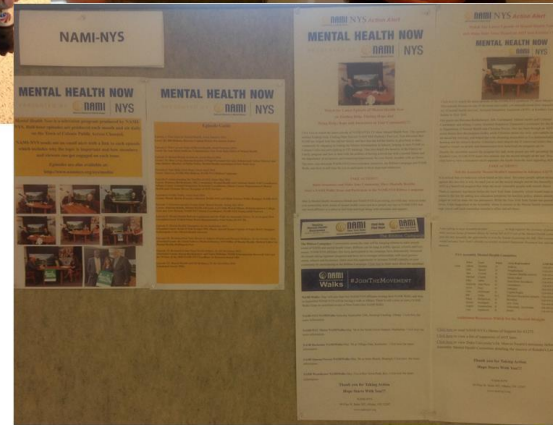
Awarding **NARSAD** Grants

New York State
Psychiatric Institute



NEW YORK
STATE OF
OPPORTUNITY.

Nathan S. Kline
Institute



Is honored to serve as the



For New York State and we are proud to have NIMH join us for the conference as together we *Redefine Recovery*

- **Be sure to visit Karen and Vince at the NIMH Schizophrenia Research Exhibit Table and attend their workshop on Saturday at 5:45 in Fort Orange 9 to learn how you or your loved one can be a partner in research.**
- **Learn how the NIMH Research Domain Criteria (RDoC) Project is changing the way research of mental illnesses is being conducted with Dr. Sarah Morris on Saturday at 9am in King St. Ballroom.**
- **Learn the latest research on Schizophrenia conducted by NIMH with Dr. Joseph Callicott on Saturday at 2:30 in Town Hall.**

RESEARCH=HOPE!!!

New York State Psychiatric Institute





New York State

Annual Educational Conference



November 11-13, 2016
Desmond Hotel and Conference Center in Albany

2016 Featured Researchers

Robert Heinssen, Ph.D., ABPP, Director, Division of Services and Intervention Research, National Institute of Mental Health

Donald Goff, MD, Director, Nathan Kline Institute
Oscar Jiménez-Solomon, MPH, Research Coordinator, Center of Excellence for Cultural Competence, New York State Psychiatric Institute, Columbia University

Nina Schooler, PhD, Division Chief, Schizophrenia Research Division, SUNY Downstate Medical Center

Lloyd Sederer, MD, Medical Director, New York State Office of Mental Health

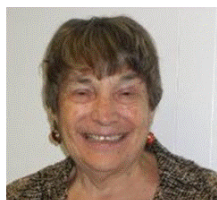
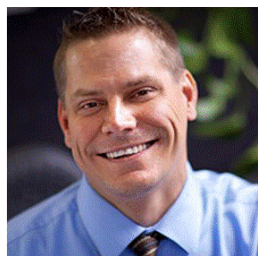
Thomas Jewell, PhD., Project Manager, Center for Practice Innovations, New York State Psychiatric Institute

David Kimhy, PhD, Associate Professor of Clinical Psychology, Department of Psychiatry, Columbia University, Director, Experimental Psychopathology Laboratory, New York State Psychiatric Institute



The Desmond Hotel, Albany

Saturday, November 12th, 9-10:30am



#IWillListen #BetterTogether #RecoveryTeams

Communicating Research

MENTAL HEALTH NOW

PRESENTED BY  **NAMI** | **NYS**
National Alliance on Mental Illness

 **NAMI** | **NYS** *E-Newsletter*
National Alliance on Mental Illness

 **NAMI** | New York State
National Alliance on Mental Illness **NEWS**

Summer 2016

Communicating Research

NIMH CONFERENCE

NAMI-NYS Continues Work as Outreach Partner of the National Institute of Mental Health and Examines the Realities of Research Participation

By Matthew Shapiro

The National Institute of Mental Health (NIMH) held its annual Outreach Partner Meeting on March 12 through March 14. An NIMH Outreach Partner is a non-profit organization from each state chosen by NIMH to help deliver science-based information to communities in their respective states, and NAMI-NYS is proud to serve as the Partner for New York State. This year's meeting was unique because it was held at the National Institutes of Health (NIH) campus in Bethesda, MD. This allowed the Outreach Partners to interact and learn from many of the world-class researchers conducting clinical trials on the campus. A summary of the meeting can be found on the NIMH section of the NAMI-NYS website.

After the conference concluded I got to take advantage of another beneficial aspect of the meeting being held on the NIH campus, the ability to see first-hand how research trials are conducted and view the process from the perspective of those participating in the trials. I met Vince Del Balzo from the NIMH Schizophrenia unit who gave me a tour of the NIH Clinical Center where all NIH research trials are conducted. I was amazed by the facility and the unique relationships forged between the medical staff and the research participants. The first thing you notice is that despite the fact that this is an in-patient medical facility, it does not have the feeling of a hospital. The building is warm and welcoming and you do not see people wearing scrubs or anyone in hospital gowns, all the nurses and staff wear normal clothes. All the staff members I came across were very friendly.

The facility goes to great length to eliminate the traditional barriers that exist in the health care



Matthew Shapiro, NAMI-NYS, with Dr. Thomas Insel, Director, National Institute of Mental Health

settings. Vince explained to me that participants are not merely considered patients, they are viewed as "research participants." He walked me through what a typical participant experience includes. NIH covers most of the travel costs and participants who fly into Washington are met at the airport by a taxi or shuttle and taken to a hotel-like facility on the campus for the night before being admitted to



TV section of recreation room in Schizophrenia Unit of the National Institutes of Health's Clinical Center



Library at the National Institutes of Health's Clinical Center

the Clinical Center. Vince took me to the intake center of the out-patient clinic where I met with the head nurse. One of her goals is to make all research participants know how happy the team is to have them there, and make sure they feel important and welcome.

My next stop was at the psychiatric floor and the schizophrenia unit. Vince explained that each disease has its own unit to house research participants, but that they are free to come and go as they please, and he showed me some of the common areas where participants from all units congregate. For privacy reasons I was not allowed to speak with any of the participants, but they all seemed

content. For the most part, each participant gets their own room, which was quite large. Vince explained that they have a fixed number of participants in the unit at a time to ensure everyone gets their own room. The only time rooms are shared is when one of the participants is preparing for discharge.

I also got to see the unit's recreation room, this room was quite large and had a section with a ping-pong table and exercise equipment along with a sitting area with a large screen television. Participants in both the Schizophrenia Unit and the Bi-Polar/Depression Unit had access to that room. Vince explained that some of the services offered, such as group sessions, take place in this area as well. Along with group sessions, individual consultations are also offered. Vince also detailed how staff work extensively with the research participants leading up to their discharge to ensure they maintain their recovery. Along with medical and psychiatric services, recreational services are also available such as organized weekly trips to sites in the DC Metro area. The day I visited, people were preparing to go on a trip to the Smithsonian Air and Space Museum.

As the tour continued I visited the large library. The librarian explained that a lot of the research participants spend a good deal of time at the library and many enjoy volunteering. The library offered books, DVDs and VHS cassettes as well as periodicals. Next I saw the Clinical Center's interfaith chapel. Vince explained to me that along with the recreation and leisure options available, the research participants are free to use many of the open spaces and parks located on the NIH campus as long as they are accompanied by a staff member. He told me how one of the NAMI-NYS members who participated in research jogged around the perimeter of the campus every day.



Dr. Frances Collins, Director of the National Institutes of Health

Continued on page 21

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Summer 2013 ■ NAMI | NYS News

NIMH PARTNERSHIP AND UPDATE

NAMI-NYS Continues Partnership with the National Institute of Mental Health

NAMI-NYS has been selected to continue as the National Institute of Mental Health (NIMH) Outreach Partner for 2015 for the state of New York. NAMI-NYS joins a nationwide network of 55 mental health organizations committed to disseminating science-based information from NIMH about the causes, diagnosis, treatment, and prevention of mental disorders, and educating the public about the importance of research and the opportunities to participate in studies.

For over a decade, NIMH has supported organizations from every state, the District of Columbia, and Puerto Rico through the Outreach Partnership Program to increase the public's awareness about the importance of mental health to overall health as well as the recognition that mental disorders are brain-based disorders, and that research is the way forward to understanding how best to treat, prevent, and ultimately cure mental illness.

NAMI-NYS is honored to continue to partner with NIMH to bring New Yorkers the most updated information on mental health and brain research. NAMI-NYS often proclaims that

research is our hope for the future and NIMH is the generator of the most cutting-edge research unlocking the mysteries of the brain and developing an understanding of the causes and treatments of psychiatric diseases.

NAMI-NYS will continue to feature an NIMH News section in both our weekly E-Newsletter and our print Newsletter along with the NIMH widget streaming the latest news on the NIMH website. Our annual Education Conference will continue to benefit from a strong NIMH presence, including presentations on the work conducted by NIMH and a workshop on participating in NIMH research studies. NAMI-NYS members will also have the opportunity to participate in NIMH sponsored webinars, Google+ events and Twitter chats. Be sure to visit the NIMH section of the NAMI-NYS website for the latest information.

The National Institute of Mental Health is one of 27 components of the National Institutes of Health (NIH), the Federal government's principal biomedical and behavioral research agency. NIH is part of the U.S. Department of Health and Human Services. ■

NAMI-NYS Encourages Our Members to Participate in NIMH Clinical Trials

NIMH Nationwide Recruitment: Bipolar Disorder (Pediatric) Research Study—Treatment of Severe Mood Dysregulation (Inpatient: 12- to 15 weeks). This study tests the efficacy of different treatments for decreasing irritability in children with severe mood and behavioral problems. Participants have symptoms of severe irritability and are not doing well on their current medications. The child must be currently in treatment with a physician, medically healthy and not currently hospitalized, psychotic or suicidal. The study includes day or full hospitalization to discontinue medication, followed by either methylphenidate plus citalopram, or methylphenidate plus placebo. Recruiting ages 7-17.

For more information on research conducted by the National Institute of Mental Health in Bethesda, MD visit www.nimh.nih.gov/JoinASTudy. ■

Play an Important Role in Research Participate in a Clinical Trial Breakaway Study Seeking Participants

The Breakaway Study is a clinical research study evaluating an investigational medication for treatment of adults with schizophrenia who abuse alcohol.

The Breakaway Study may be appropriate for those who meet the following criteria:

- Men and women 18 to 65 years old
- Have had a recurrence of schizophrenia symptoms within the last 6 months
- Have experienced at least 10 drinking days in the last month
- Have a stable living arrangement

This is a partial list of requirements for study qualification. You will be evaluated by a study physician who will review all of the requirements to determine your eligibility.

If you are interested and qualify, you will receive the investigational medication, study-related medical exams, and lab tests at no cost. Compensation for time and travel will also be available.

If you or someone you know may be eligible, please refer him or her to BreakawayStudy.com.

If you have any questions about the Breakaway Study, please contact Dr. Jean-Pierre Lindenmayer, Benedicto Parker, and Abraham Goldring at 212-961-8992. Interested patients may write an email to Benedicto.Parker@nhi.nyu.gov and Abraham.Goldring@nhi.nyu.gov, or also visit www.BreakawayStudy.com for more information.

The New York Office of Mental Health sponsors this study.

To find a NIMH study to participate in please visit <http://www.nimh.nih.gov/labs-at-nimh/join-a-study/index.shtml>. ■

Communicating Research

NYSPI IRB Approved
7-170
8/9/2016 -> 8/2/2017

Do You Cut or Hurt Yourself on Purpose?

Researchers at the New York State Psychiatric Institute are conducting a study of an investigational, minimal risk, non-invasive treatment called Transcranial Direct Current Stimulation (tDCS), as a form of therapy for people who hurt themselves.

If you cut or hurt yourself, are between the ages of 18-60 and are interested in participating in a research study involving assessments of your mood and behavior, brain imaging, and tDCS, please contact Damaris Fuster at fusterd@nyspi.columbia.edu or 646-774-7361. More information is available at tdcsresearch.wordpress.com



NIMH News



Featured Session Update on NIMH Research

Robert Heinszen, Ph.D., ABPP, Director, Division of Services and Intervention Research, NIMH
Saturday, November 12th, 11:25am-12:00pm



Research=Hope!!!

#NAMINYedCon16

NAMI NYS is honored to welcome Robert Heinszen, Ph.D., ABPP, Director, Division of Services and Intervention Research, National Institute of Mental Health to present an NIMH research update at the 2016 NAMI-NYS Education Conference. [Click here](#) to learn more about Dr. Heinszen.

Treatment Advocacy Center NIMH Briefing With New Director, Joshua Gordon

NIMH Director Joshua Gordon outlines the future of the organization in a recent chat with the Treatment Advocacy Center. [Click here](#) to read.

NIMH Releases Strategic Research Priorities Update

To keep pace with rapid developments in research on mental illnesses, the National Institute of Mental Health (NIMH) recently released updates to its Strategic Research Priorities. These priorities serve as guidance to NIMH grantees, potential grant applicants, and staff for the design and implementation of future research.

[Click here](#) to read more.

New York State News

Dr. Jeffrey Lieberman Details How Its
Morning in America for Mental Health Care



Dr. Jeffrey Lieberman, Chairman of Columbia Department of Psychiatry and the New York State Psychiatric Institute, recently detailed in Medscape, how it is "Morning in America for Mental Health Care." Dr. Lieberman borrowed the famous phrase from Ronald Reagan's 1980 Presidential campaign to discuss his excitement about Hillary Clinton's announcement of a major policy focus on mental health reform and how rare this is in Presidential politics. Dr. Lieberman reflects:

Join A Study of Schizophrenia and the Brain: A Six-month Inpatient Evaluation Study

Have you been diagnosed with schizophrenia or schizoaffective disorder? Are you between 18 and 55 years of age? Would you be willing to live at the Clinical Center on the NIH campus for six months? If so, you may be eligible to participate in a study designed to understand the neurological basis of schizophrenia and to determine which symptoms are related to the illness and which are related to the medications used to treat the illness.

This six-month study has three phases: In the first phase you will participate in many comprehensive medical, neurological, cognitive, and psychiatric evaluations. In the second phase, the research phase, you will be tapered off of your medication for about 4 weeks. In the time that your medication is discontinued, research procedures will allow investigators to distinguish the effects of the illness on the brain without the interference of the medication's effects. In the third phase, you will have the opportunity to stabilize using the treatment selected to be most helpful to you.

To find out if you qualify, email NIMH or call 1-301-435-8970 (1-888-674-6464) [TTY: 1-866-411-1010].

Protocol Number: [89-M-0160](#)



Communicating Research



Please Visit www.naminy.org/media to
Watch Episodes of

MENTAL HEALTH NOW

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NYS

Next Wave: Partnering with Researchers To Introduce Legislation



Why It's Time for the Incorporating Families in Mental Health Care Act:

*Family Education and Involvement Promotes Best Patient Centered Mental Health Care and Recovery Outcomes
Individuals Living With A Mental Illness, Family Members & Service Providers Must Work in Recovery Teams.*

- ♦ 20% of New York's adults (1.6 million) & children (359,360) experience a mental health disorder each year, with over half a million living with serious mental illness.^{1,2}
- ♦ For most in treatment, adults and children alike, recovery extends outside clinical settings and into their homes. In one New York Medicaid program that transitioned patients from long-term institutional to community-based care, more than 1/3 of patients moved in with their families. These family members/caregivers are likely to be most familiar with patients' symptoms and history of medication and therapeutic treatment and effects.
- ♦ But, more than one-half of families reported a healthcare provider saying they were unable to speak with them about the patient's condition (54%) and they were "included less than they felt they should have been" in conversations with providers about care (55%).
- ♦ Yet, a 2013 study of patients with serious mental illness who had family contact, but not family involvement in care, found that more than three-quarters (78%) wanted their families included in treatment.

WITH MENTAL HEALTH RECOVERY TEAMS EVERYONE WINS

Research, Practice and Policy Recognize Benefits of Family Involvement & Forming Recovery Teams with Open Communication and Shared Decision Making

Family education helps relatives gain an understanding of illness and treatment issues, improves the quality of family interaction with medical professionals and loved ones, and thus bolsters family involvement in care and recovery, which has been shown generate best outcomes.

Clinical and peer family education have been established as evidence-based practices.

- ♦ A randomized design study of Recovery-Oriented Decisions for Relatives that uses a patient-family shared decision-making process found that family involvement benefits patients with serious mental illnesses (by significantly reducing paranoid ideation and increased recovery).
- ♦ Another study found significantly improved health outcomes for first episode psychosis patients whose families were involved at first contact with mental health services.

New York State's New Medicaid Model Must Include Family Education & Recovery Teams

NYS is implementing a new Medicaid program-Home & Community Based Services (HCBS)-funding a range of services including family support. Unfortunately, this promising initiative has reached very few eligible Medicaid beneficiaries to date because of the program design, which makes it difficult to access services. For family support, the program requirements limit what providers can offer and who they can serve. In order for NYS to achieve its goal of transitioning to a recovery-centered mental health service delivery system, it must redesign HCBS to offer more flexible services that meet the needs of individuals *and* their families.

The Incorporating Families in Mental Health Care Bill Would:

- ♦ Require the New York State to produce materials to educate individuals, families and providers on the benefits of family education, engagement and working as a recovery team.
- ♦ Provide further education materials on HIPAA laws including a document that families can give to providers stating that providers must listen to their insights and concerns.
- ♦ Require distribution of family incorporation materials to hospitals throughout New York State.
- ♦ Provide information to providers on how to encourage family participation for clients served through the HCBS mode.
- ♦ Fund the developments of summits around the state to educate New Yorkers about the importance of including families as part of routine mental health care.
- ♦ Have the Office of Mental Health hold webinars on the importance of family engagement and recovery teams.



OnTrack  NY

My health. My choices. My future.

For More Information Contact Matthew Shapiro at 518-462-2000 or Matthew@Naminys.org

Next Wave: Partnering with Researchers To Introduce Legislation

Education and Communication



NAMI New York State
2016 Education Conference
November 11-13
The Desmond Hotel, Albany

Featured Session:
*New Horizons in Partnerships: The Importance of
Forming Recovery Teams*

Saturday, November 12th, 9-10:30am



#IWillListen #BetterTogether #RecoveryTeams



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Questions?

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