

The 2015 NIMH Outreach Partners Program Meeting was held August 18-20 at the National Institutes of Health's newest research facility, the John Edward Porter Neuroscience Research Center. NAMI-NYS serves as the Outreach Partner for New York State and participated in the meeting.

The meeting began with NIMH Director Dr. Tom Insel welcoming the partners and talked about how we have gathered in this state of the art facility at a very exciting time as we are about to take the next and boldest steps in the exploring the brain and neuroscience.

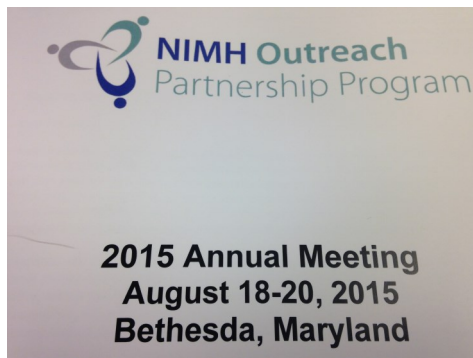
Outreach Partners have an important role in this mission as we serve as NIMH's ambassadors to the public, educating them on current news and developments from NIMH, disseminating the latest research findings and informing individuals and families impacted by mental illness on the vital role they play as partners in this effort.



NIMH Director Dr. Tom Insel

This last point was detailed in an inspiring opening plenary session entitled *New Era in Patient Centered Care*. This session focused on a theme that is central to this year's NAMI-NYS Education Conference-maximizing recovery: refining treatment and research and improving outreach to produce the most positive outcomes. This shift in philosophy is key to the future management of psychiatric disorders.

The first presentation of the plenary was on the U.S. Precision Medicine Initiative and was delivered by Eric Green, M.D., Ph.D., Director of the National Institutes for Health's National Human Genome Research Institute. Dr. Green detailed how the initiative is a combination of science and politics.



He also explained how it grew out of President Obama's longstanding interest in Genomics and championing of biomedicine and research which he began expressing during his tenure as a U.S. Senator. The President's goal is to make the Precision Medicine Initiative, which was introduced in the President's 2015 State of the Union, a major part of his presidential legacy.

The initiative's objective is to move from the medical care of today which is based on the expected response of the average patient to more precise medical care based on individual genomic, environment and lifestyle differences that enable more effective ways to prevent and treat disease.



Dr. Eric Green, NIH

In explaining the vision he explained how in the short term cancer is a model of precision medicine as there are different forms of cancer and each type has a different treatment that is most effective. Over the longer term the initiative needs to expand the model to other diseases. For instance today what we are now calling schizophrenia in five years may be viewed as multiple psychiatric disorders, each with its own most appropriate treatment.

In order to achieve this we will need to create a national research cohort of more than one-million volunteers, which will generate a knowledge base for precision medicine. To establish this policy changes are necessary to remove barriers to clinical implementation. These include updating federal rules protecting research participants and advancing FDA oversight of precision medicine products.

Dr. Green also discussed how it is imperative that researchers change the way participants in clinical trials are viewed. "In order to be successful we need to establish a participant partnership, participants must not be viewed as subjects but embraced as partners."



Dr. Andrew Nierenberg,

This view of the changing role and view of research participants was continued in the next presentation on *the MOOD Patient-Powered Research Network (PPRN)*, *Patient-Centered Outcomes Research Institute* by Andrew Nierenberg, M.D., Principal Investigator, MOOD PPRN, Professor of Psychiatry, Harvard Medical School, and Associate Director, Depression Clinical and Research Program, Massachusetts General Hospital. Dr. Nierenberg detailed the work conducted at the [MOOD Network](#) based out of Massachusetts General Hospital.

At the heart of the MOOD Network's mission is the role of patients who they call experts by experience, who are at

at the center of all governance and engage in shared decision making which leads to co-production and co-learning. One example of this is how their website was designed by the experts by experience.

Dr. Nierenberg also described the work of the [Patient-Centered Outcomes Research Institute](#) (PCORI) and their mission to “improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions.” The goals of PCORI are to improve the nation’s capacity to conduct comparative effectiveness research; create a large, highly representative, national patient-centered clinical research network; and conduct clinical outcomes research and comparative effectiveness research.

Communication plays an integral role in the network. Dr. Nierenberg discussed their ECHO survey where respondents discussed how many times they felt that doctors had talked to them in a threatening way, “you MUST take your medicine.” He also detailed how many participants are not as concerned about finding a cure but are more interested in management of their disease which they feel is part of their identity.

This lack of information led families of children with PMS to band together and form a national registry as an education network for families. Patient Centered research is also a focal point of the network. Ms. O’Boyle explained how patient centered is a cultural shift and not just a catch-phrase.

The purpose of the registry is to bring together families, researchers and industry to work together to find a cure for PMS. Examples of how patients are driving the research of PMS include: the registry; biorepository where samples are collected at family conferences and the samples are managed at Rutgers University and owned by NIMH; clinical trial recruitment and education; using social media to poll families; and having a “McPosium, a research symposium where families inform researchers about their priorities.

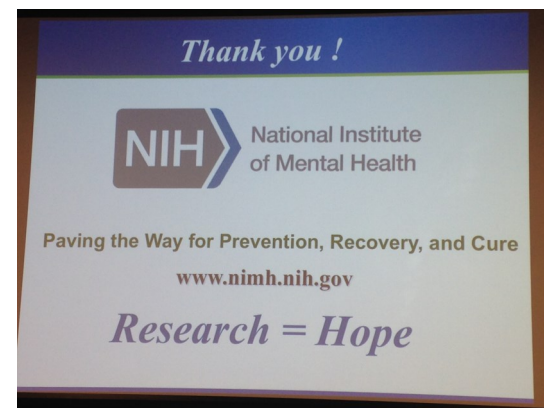


Dr. John Kane, Matthew Shapiro and Dr. Tom Insel

The next plenary session was led by NIMH director Dr. Tom Insel who provided a look at the *State of Mental Health Research*.

Dr. Insel started by detailing how psychiatric disorders are still the most disabling disorders for people less than 50 years old and they are still the leading category of Disability Adjusted Life Year (DALY). After presenting this sobering information, Dr. Insel asked the key question of our movement; “how do we use scientific traction to bend this curve?”

He started to answer this question by talking the current research breakthroughs. One example was how new genetic findings has allowed



researchers to figure out the cellular dysfunctions that are playing a role in schizophrenia and bi-polar disorder.

He detailed the results which have already derived from the BRAIN Initiative. This includes a detailed look at structure and function and identifying the 21 transient co-activation networks. While Dr. Insel admitted that researchers do not yet know what this means exactly but it demonstrates that they are making traction leading to a different world of diagnostic ability.

Along with federal initiatives such as the BRAIN Initiative and NIMH’s Research Domain Criteria (RDoC) project, Dr. Insel mentioned how everyday technology such as smartphones will also help drive increased diagnostic ability as there are apps that will help track biomarkers.

Converting this new traction into better outcomes will require new approaches to diagnosis, therapeutics and research. Dr. Insel explained this is why NIMH has revised their strategic plan to emphasize three transforming goals: 1) Transforming diagnostics from behavioral disorders to brain disorders and have diagnosis rooted in biology and behavior. 2) Transforming therapeutics from chemical imbalances to circuit dysfunction and treatments aimed at circuit tuning. 3) Transforming culture from “my data” to data mining leading to standardization, integration and sharing.

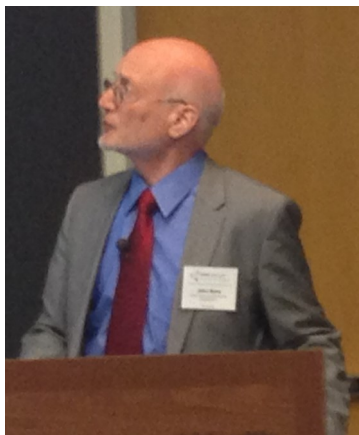
Dr. Insel explained the envisioned transformation from the treatments of today which is fragmented (medication vs. psychosocial), mostly focused on symptom control and where access is limited, adherence is poor and treatment begin too late. The treatments of tomorrow will move from the belief in a “magic bullet solution” to “network solutions” where therapeutics will focus on circuit tuning and early intervention will be key.



The final presentation of the plenary was on *Patients Informing Research: How Patients are Driving the Outcomes They Want* by Megan O’Boyle, Principal Investigator of the Phelan-McDermid Syndrome Data Network. Ms. O’Boyle explained how there was a severe lack of resources when her daughter Shannon was diagnosed with Phelan-McDermid Syndrome (PMS)-a rare condition caused by a loss or deletion of the 22q13 chromosome.



The afternoon plenary session focused on the NIMH Recovery After Initial Schizophrenic Episode (RAISE) study and featured Dr. John Kane, chairman of psychiatry at New York's Zucker Hillside Hospital and principal investigator of the RAISE Early Treatment Program.



Dr. John Kane

Dr. Kane's team lead the NAVIGATE portion of the RAISE study which introduced the program in clinics and their primary outcome measure was to gauge the Quality of Life scale. Their primary hypothesis is that RAISE intervention compared to community care will improve quality of life. Other measured outcomes of the study is that RAISE will increase service utilization, decrease cost, improve consumer perception, increase the prevention of relapse and leading to enhanced recovery.

The conclusions from his portion of the study are:

- Recipients of NAVIGATE were significantly more likely to remain in treatment and experienced significantly greater improvement in the primary outcome measure (i.e. quality of life)
- They were more likely to be working or going to school
- NAVIGATE participants showed a significantly greater degree of symptom improvement.
- These results show that a coordinated specialty care model can be

Implemented in a diverse range of community clinics and that quality of life of first episode patients can be improved.



Matthew Shapiro and Linda Rosenberg

The next morning featured the keynote address *The Mental Health Landscape: 2015 and Beyond* delivered by Linda Rosenberg, M.S.W., President and Chief Executive Officer of the National Council for Behavioral Health (and former deputy commissioner of NYS-OMH and current member of NAMI-NYS).

Ms. Rosenberg began by explaining we are at a time of a social and technological revolution. As part of this revolution behavioral health is "coming out of the closet." She detailed how leaders such First Lady Michelle Obama and New York City First Lady Chirlane McCray have made mental health a priority and how presidential candidate Hillary Clinton has been talking about mental health and addiction on the campaign trail.

However, despite this increased visibility mental health care is not even close to being where it should be. She stated that "stigma is not the issue-limited access is the issue." She cited how of the ten major causes of death suicide is the only one where the rates are increasing. Six out of ten people with a mental illness are not getting proper treatment. The brain is still

the final frontier of understanding and too many people are getting their psychiatric services from a primary care physician as 30 million people are getting their medications from a primary. 2/3 of primary care provider's report poor access to mental health care for their patients and even with insurance the average wait is 25 days to see a mental health specialist.

She stated how "everyone wants change but change is hard." However she explained how Congress is waking up to this crisis with the *Helping Families in Mental Health Crisis Act* and the Senate's *Mental Health Reform Act of 2015*.

Ms. Rosenberg also detailed the goal of collaborative care, where primary physicians are utilizing psychiatric consultations to more adequately treat their patients. She also discussed how things will change once health homes are more fully integrated and we can reintroduce family involvement in health homes.

She ended by explaining seven requirements as we move forward with health homes.

- 1-Language: Speak a different language with unfamiliar colleagues.
- 2-Understand all care will be managed, carved in, not out and payments will be bundled.
- 3-Prepare for competition.
- 4-Deliver world-class customer service and view patients as customers.
- 5-Implement measurement based care.
- 6-Adopt technology as technology will provide transparency.
- 7-Leadership must be fearless but not reckless in the face of change.



Dr. Ursula Whiteside



The second session on Wednesday focused on suicide prevention and was highlighted by a presentation by Ursula Whiteside, Ph.D, Chief Executive Officer, NowMattersNow.org who presented on *Public Health Approach to Suicide Prevention Research Informed by Lived Experience*.

Dr. Whiteside talked about creating a “learning healthcare system” where: All experience contributes to evidence; Evidence is truly based in experience; It all happens continuously, in real time; and Clinical data equals research data.

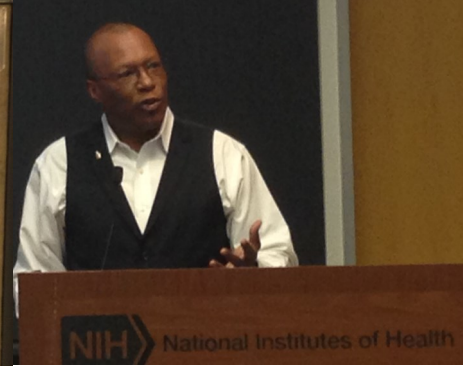
You can visit NowMattersNow.org to learn more and view videos.

Wednesday afternoon was the partner sharing session. NAMI-NYS shared information on the outreach and educational activities conducted by NAMI-NYS and our affiliates during mental health awareness month. Activities highlighted included:

- The Empire State Building being lit green.
- The Ribbon Awareness Campaign
- The What’s Great in Our State event
- NAMI Walks
- Exhibiting at the State Capitol



NAMI-NYS Partner Sharing Display

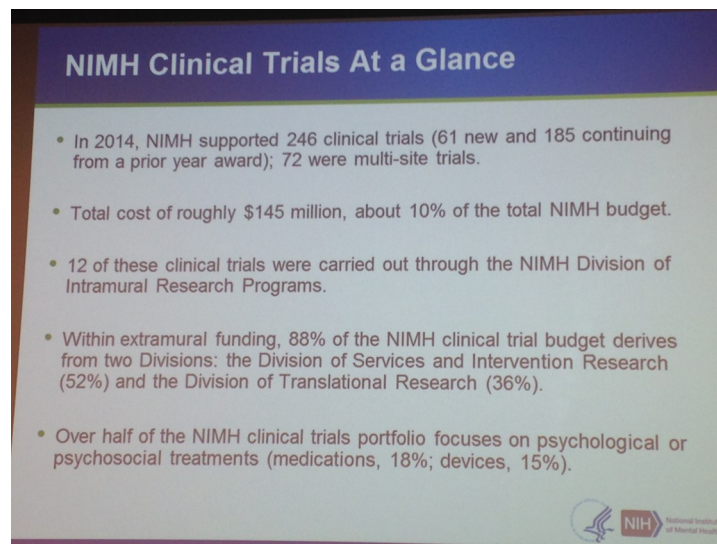


Dr. Stephen B. Thomas

The conference concluded with an update on NIMH Clinical Trials and the role Outreach Partners play in informing the public about trials and the importance encouraging participation in trials.

The last presentation was a compelling look at *Building Trust Between Minorities and Researchers* by Stephen Thomas, PhD, Director of the Maryland Center for Health Equity at the University of Maryland.

Dr. Thomas detailed how there is often mistrust of the medical field within minority communities and how there needs to be much done to improve cultural competency and improve the often “cold, miscommunication that leads to a disconnect between doctors and minorities. He showed videos of such communication which demonstrated how problematic this is.



Information on NIMH Clinical Trials



Group Picture of NAMI Outreach Partners