

Celebrating

5 Years of DISCOVERY &
INNOVATION at Excellence

Our donors bring the
hope and tools for
recovery to the world.

5TH ANNIVERSARY REPORT



FOUNDATION FOR EXCELLENCE
IN MENTAL HEALTH CARE

Expect Recovery



Dear Friends of *Excellence*,

I want to thank each of our donors and volunteers who have made our FIRST FIVE YEARS so successful in funding important research, education, and programs that support recovery-based practices in mental health care.

Throughout this report, you will see some of the projects and funds that are developing research, education and programs that foster recovery for people and their families who experience mental health challenges. In addition, we highlight the resources that are already available for use.

We also pay special tribute to one of our donors and member of our Dorothea Dix Think Tank, Al Bendich, who along with being a celebrated civil rights attorney was instrumental in keeping us aware of the history of the criminalization of mental illness.

Here is my challenge to you! There is so much more we can and should do together to make an impact. As a community foundation intent on leaving the legacy of mental health recovery and providing efficient financial stewardship of your charitable giving, we rely on your continued dedication of time and resources.

As you browse through these pages, please consider how much you can give this year and let us know where you would like your support focused. If you have special skills, talk to us about volunteer opportunities and help spread the word by getting your friends to like us on Facebook, and Twitter, subscribing to our YouTube channel or sharing our eNewsletters.

Thank you for taking part in building the *Excellence* community.

I know I can count on you!



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Our donors bring hope, knowledge & tools for healing to the world

Excellence is an international mental health community foundation which matches private philanthropy to independent research projects and innovative programs that lead to recovery. Our team of donors and volunteers embodies a rich diversity of knowledge and expertise including people with lived experience of our current system of care, family members, psychiatrists and other clinical professionals, researchers, and philanthropists.

OUR CALL TO ACTION

Industry data and clinical experience show antidepressant and antipsychotic medications do not provide effective symptom relief for more than half of the people who try them. Those who do find them helpful still risk irreversible side effects and declining effectiveness over time. If medication is not a long-term solution, then how do we better equip people for recovery? We're finding the answers, together.

A THREE-FOLD STRATEGY

The problems and the answers are not simple ones and so we target our funds and resources with both precision and diversity. Our donors fund independent research, develop and test innovative recovery programs, and offer high-quality professional and community education that empower people to move through mental health and trauma challenges to heal and live their best lives.



We shine a light on publication bias in medical research and bring world-class, independent researchers together to make reliable information about treatment safety and effectiveness accessible to professionals and the public. Innovators and social entrepreneurs team up to develop and test new and sometimes forgotten wellness practices and programs to establish a full array of evidence-based recovery tools.

A COMMITMENT TO HONESTY & RESPECT

Our educational activities and research and development grants are funded solely by community members and are free of industry and commercial influence. We are founded on the principles that:

- A person in distress should be an equal partner in their treatment team and their choice to use or not use medication should be respected.
- The path to recovery is unique to each person and the causes and solutions to mental health challenges should be explored holistically, carefully and with openness about treatment risks and the limitations of our knowledge.
- Recovery should be our expectation for everyone.

Our Donors

Fund Independent Research

Revealing the power of nutrition in mental health

Bonnie Kaplan, PhD, professor and researcher at the University of Calgary opened the [Nutrition and Mental Health Research Fund](#) in 2015 to support research and education on the ability of broad-spectrum nutrient treatments to reverse and prevent the onset of psychiatric symptoms.

It is an area of study that has not yet been considered a priority by traditional funding sources which tend to look for 'magic-bullet' single-nutrient solutions.

GLOBAL SCIENTIFIC ADVISORY COUNCIL

Distinguished researchers and clinicians come together on this international team to advise the [Excellence](#) board of directors in setting research investment priorities. They also evaluate research proposals invited for funding. Central to our mission is separating legitimate, well-designed research from biased or poorly designed studies to ensure that we support and share only helpful, reliable information.

Among the Fund's many supporters, two donors each gave \$100,000 in 2016 to cultivate and support young scientists to work in this promising area of study.

Fund grants will target a variety of topics, including:

- Evaluation of physiological changes associated with nutrient-induced symptom improvements.
- Further studies to demonstrate the clinical potential of nutrition to enable people with mental health challenges to recover and lead productive lives.
- Studies that investigate the ability of nutritional approaches to protect children from a lifelong dependence on psychiatric medications.

Do antipsychotic medications help or hinder recovery long-term?

Martin Harrow, PhD, Professor Emeritus at the University of Illinois College of Medicine, has collected 20 years' worth of data tracking individuals who experienced at least one psychotic episode.

His research has been the basis for a number of peer-reviewed papers describing the effect of medications on those he interviewed. His multi-year grant from [Excellence](#) has yielded new articles published in [Psychological Medicine](#) and [Schizophrenia Bulletin](#). Study results suggest antipsychotic drugs may hinder rather than enhance recovery, especially long term.

Dr. Harrow's forthcoming paper, currently in review by a major journal, examines the impact of antipsychotic use on work functioning.

WEBSITE EXCLUSIVE

Check out Dr. Kaplan and colleagues' latest published research on the [effect of nutrient supplements after a natural disaster](#) and the effect of micronutrients on insomnia, [Dr. Harrow's papers](#) on the outcomes of long-term antipsychotic use, and Dr. Murphy's analysis of treatment guidelines for kids at [MentalHealthExcellence.org/Learn/Library](#).

Lived-experience research

When the risks and side effects of psychiatric medication lead someone to reduce or discontinue use, they may struggle to find the information or support they need. Providers who want to help often lack evidence to guide them. A team of researchers led by Laysha Ostrow,

PhD, of [Live & Learn, Inc.](#) are analyzing new survey data on the experience and strategies of individuals who have come off or reduced their psychiatric drug intake. The results will be published online at the end of this year. Project members all have personal experience with psychiatric treatment and coming off psychiatric medications.

Empowering parents to make safer choices for their kids

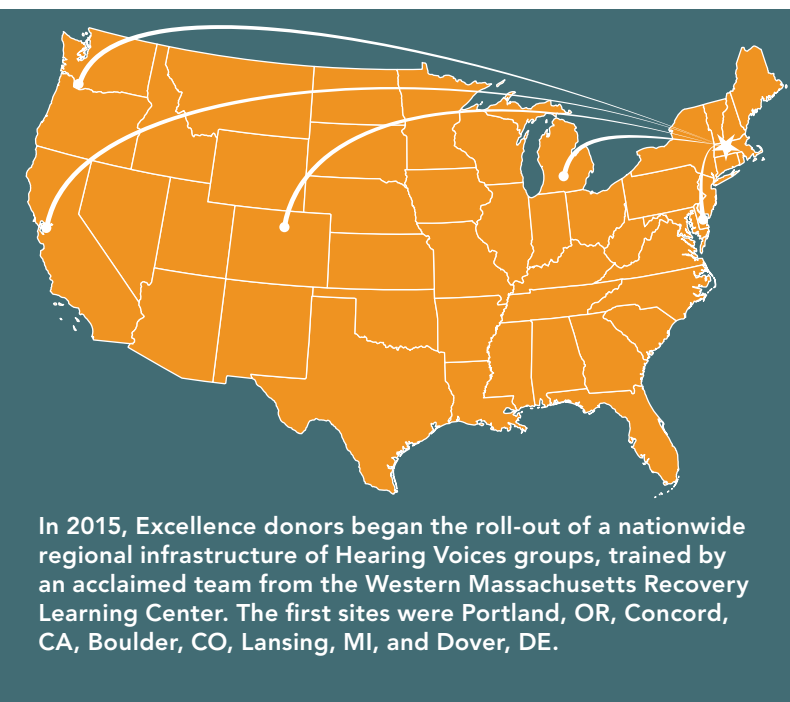
Doctors Michael Murphy and Lee Baer at Massachusetts General Hospital received one of our earliest grants to analyze children's treatment guidelines in the United States in comparison to guidelines used in the United Kingdom. [Study results](#) were published in the [Harvard Review of Psychiatry](#) in 2014:

"This [British] stepped care approach could be characterized as 'Begin with no, then (only if necessary) start low and go slow' when using psychotropic medication. In the US, by contrast, although there is a range of accepted practices, the official guidelines are generally more active in their tone than those from the UK... based on at least one study, there appears to be virtually no difference in outcomes for US children with ADHD whose primary treatments were psychopharmacological versus behavioral."

Although the authors make an urgent call for deeper study of diagnosis and prescribing to children and teens, this article does give caregivers, clinicians and policymakers in the US a solid explanation of the origin and limitations of today's guidelines and some scientific rationale for using less or no medication when helping kids move through their challenges with attention and depression.

Our Donors

Develop & Test Innovative Recovery Programs



Hearing Voices Research & Development Fund

For the past 28 years, the Hearing Voices Network – an international collaboration of professionals, people with lived experience, and their family and friends – has been working to develop an alternative approach to coping with voices, visions, and other extreme states that is empowering and useful and does not start from the assumption that people who have these experiences suffer from a chronic illness.

A large body of peer-reviewed research now provides support for key aspects of this approach, and the hundreds of support groups that have developed in countries around the world are enabling voice hearers – even those who have been chronically disabled – to learn to cope more effectively or rid themselves of the negative effects of their voices.

With a multi-year grant of more than \$250,000, **Excellence** donors are building a new, well-trained regional infrastructure of Hearing Voices groups in the United States. Those groups are bringing support to voice-hearers across the nation. They will also provide data for Dr. Gail Hornstein’s research to describe the mechanisms that lead to the program’s positive outcomes. In a 2015 interview with the Mount Holyoke College news, Dr. Hornstein shared:

“This approach argues that hearing voices...is not a symptom of psychosis but ‘an understandable response, often to traumatic situations, that can be interpreted, understood, and coped with.’

“The most important thing Hearing Voices groups do is encourage the person to ask, ‘Why are the voices there? What are they saying and why?’”

“And, unlike some other types of intervention in psychiatry, if it doesn’t work, this does no harm,” Hornstein said. “And most of the time, strikingly, it works.”

Can a remarkably effective Finnish early psychosis program also work in the US?

The Open Dialogue approach to early psychosis stands in striking contrast to the standard practice of immediate diagnosis and prescribing of antipsychotic medication. Instead, the ‘person at the center of concern’ and their family and friends team up with at least two health professionals and meet as a group as often as needed.

Treatment decisions are made collaboratively in the presence of the whole group. Diagnosis, and often drug treatment, are delayed while the team explores all aspects of the person’s health, environment and trauma-history that might be contributing to the crisis. The treatment plan is then built on the individual’s expressed desires and strengths.

Five-year outcomes for first-episode crises in those diagnosed with schizophrenia and psychotic disorders include 79% of participants symptom-free and only 20% on disability and using antipsychotic medication.

Dr. Doug Ziedonis, Chair of Psychiatry at UMASS Medical School, and Dr. Mary Olson, Director of the Institute for Dialogic Practice, are leading a multi-year **Excellence**-funded project to adapt the successful Finnish program for use in the United States.

Fidelity criteria were published in 2015. The clinical manual and implementation guide are currently in the works and will pave the way for US health systems to incorporate the approach and for insurers to understand the financial benefit of covering the program costs.

The results of the first **Excellence**-funded pilot program, undertaken at Advocates, Inc. in Framingham, Massachusetts, were published in the APA’s *Psychiatric Services* in July 2016 by lead author Dr. Chris Gordon.

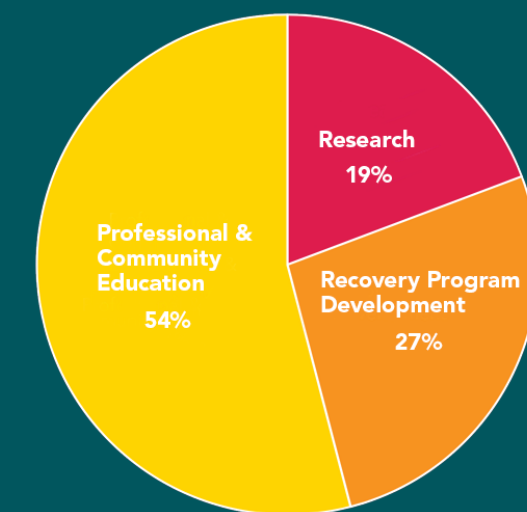
The UMASS team began training the latest pilot site in June 2016 in partnership with Emory Medical School and Grady Memorial Hospital. The Atlanta pilot will test a new, much shorter initial training curriculum which, if it achieves the same recovery outcomes, should further aid in spreading Open Dialogue across the nation.

The approach is already gaining momentum as communities in the US and the UK come together to organize and share the costs of training clinical staff in Open Dialogue practices.

“It was great that no one was trying to convert me into anything. That there wasn’t a whole bunch of pressure on me and that no one was making decisions for me.”

“This was really important to me. Because of the nature of the therapy, because of the talking, the back and forth, the listening, coming to our house, ALL of that...so much information, an openness was part of it, that helped remove some of the fear. I mean, this is a very scary thing for a parent to go through.”

- Collaborative Pathway participants, dialoging about Open Dialogue



2015 GRANTS & PROJECTS

Total Assets as of Dec 31, 2015: \$1,669,075
Total Grants & Program Services: \$659,591

Our Donors

Create High Quality Professional & Community Education

RxISK.org, 'making medicines safer for all of us'

Crowd-sourcing drug side effect data from people's real-world experiences, [RxISK.org](#) fills the information gap left by weak drug safety regulations and sparse independent research.

In addition, personalized tools like the [RxISK Report](#) and [TaperMD](#), help you and your doctor make informed decisions about the risks and benefits of a given medication, assess whether a new symptom is actually a drug side effect, and review potential harmful interactions when taking or thinking of taking multiple drugs at the same time.

Visitors can also search by drug or by side effect to see manufacturer product information, warnings, and reported side effects in an easy-to-read format.

The TaperMD™ app is being developed by Data Based Medicine Americas Ltd. led by **Excellence** board member David Healy, MD FRCPsych, in conjunction with the Department of Family Medicine at McMaster University. A clinical research study with older adults will validate and improve the tool for clinical use with all age groups.

An independent grant of \$1 million secured in 2016 will allow developers to conduct the necessary research to gain "evidence-based" status, making it easier to get TaperMD into the hands of clinicians in both public and private health care systems.

Symposiums bring the best and brightest together to change the world

Treatment professionals and people with lived experience gathered in Portland, Oregon in 2011 for our first international symposium in response to Robert Whitaker's ground-breaking analysis of the research data on psychotropic drugs in his book, *Anatomy of an Epidemic*. The symposium led to a [set of foundational discussion papers](#) on medication optimization, schizophrenia treatment, depression treatment and public policy

and to the formation of **Excellence** as an international community foundation.

The next summit at Chapel Hill, NC later that year featured [innovative recovery programs and priorities for care](#) that is tailored to the unique desires and strengths of each individual.

Our Children's Mental Health Summit in 2012,

co-sponsored with Syracuse University and others, featured over [75 papers](#) which continue to be a valuable resource for professionals and laypeople alike.

In partnership with Yale University in 2015, **Excellence** brought together clinicians and researchers from the US and Europe to present [new data](#) on the treatment, course, and outcome of serious mental illnesses and their implications for clinical practice.

Our Dorothea Dix Think Tank Fund also partnered with the Saks Institute for its symposiums in 2013 and 2015, "Criminalization of Mental Illness" and "Mental Health on Campus, from Admission to Graduation: Keys to Success for University, Community College, and Veteran Students." at the USC Gould School of Law. The Saks Institute for Mental Health Law, Policy and Ethics fosters interdisciplinary and collaborative research among scholars and policymakers. Past speakers include Patrick Kennedy, American Psychological and American Psychiatric Association presidents, and Judge Steven Leifman, JD, 11th Circuit Court, Miami.

On-demand continuing education courses bring high-quality research and practice tools right to your desktop

[MadInAmericaContinuingEd.org](#) was successfully launched this year from its **Excellence** incubator fund to an independent nonprofit enterprise. Its faculty of world renowned researchers and clinicians create and present curricula in their areas of expertise, often based on their own peer-reviewed research. Fund leaders include **Excellence** board members Dr. Sandra Steingard, Louisa Putnam and Kermit Cole and Bob Nikkel.

"After viewing Dr. Eleanor Longden's presentation, I had a discussion with a client I have seen for two years. Hearing voices is a daily, nearly constant part of his life. I told him that this presentation made me think of him and asked if he felt that the voices were related to the childhood sexual abuse he has referred to. He nodded and said, 'Oh yeah.' He was willing to offer me more detail than he had previously about the perpetrators, and the conversation helped him touch and articulate his deep grief. It was Dr. Longden's suggestion that we ask not what is wrong with our clients, but what happened to them. Simply approaching those events may well have initiated a grief process that has not been addressed previously."

- PsyD, LP, Minneapolis, Course Participant

These accredited online courses review research on the effects and outcomes of antipsychotic and antidepressant drug use, how to recognize and evaluate bias in published research, peer services and other recovery tools, and alternatives to drug therapies. All courses are based on independent scientific literature.



Could it be my meds?

All drugs have side effects, but people often don't link the effect they are experiencing to starting, stopping, or changing the dose of a drug. RxISK provides free access to information and tools to help you assess the connection between a drug and a side effect.



Search drugs A-Z



Lifesaving checklist



Complex withdrawal



Too many drugs?



SSRI sexual dysfunction



Search by side effect



Guides & papers



Interaction checker

Are you experiencing a drug side effect?

Get your free RxISK Report to find out

The RxISK Report takes 10 minutes to complete and provides you with a RxISK Score indicating how likely it is that your problem is caused by starting or stopping a prescription drug.



Albert Bendich, JD



Photo Courtesy of Jonathan Bendich

The **Excellence** family lost a dear friend on January 5, 2015. Al Bendich was a nationally renowned attorney and beloved colleague who worked tirelessly for mental health and civil liberties during a long and distinguished career.

In 1957, on behalf of the ACLU, he successfully defended legendary Beat poet and publisher Lawrence Ferlinghetti in his First Amendment trial. He also served as defense counsel for Lenny Bruce.

He was hired by Saul Zaentz in 1966 as a partner in Fantasy Records and later in the Saul Zaentz Film Co. Al was directly involved in the making of the movie, "One Flew Over the Cuckoo's Nest," filmed at Oregon State Hospital in 1975, where he met and became fast friends with Dr. Dean Brooks, the hospital's then-superintendent.

Dean and Al spoke often through the years of their shared concern for the laws and resources for care of people with mental health challenges in this country.

Al was the first person Dean thought of when the idea for the Dorothea Dix Think Tank Fund was born; Al served as a founding member when the fund was established by Dr. Brooks in 2012. An esteemed group of well-connected and largely retired professionals, the think tank's goal is to reverse public policy established in the 1970s. This policy has resulted in countless people with mental health challenges ending up in jails and prisons instead of getting the mental health care they need. It concentrates its support on activities leading to cultural and policy change.

TRIBUTES

The **Excellence** community gives generously out of gratitude and admiration for friends and family who have courageously battled mental health challenges or who have walked compassionately alongside others in distress. Donations have been made in tribute to the following:

In Memory of

Leonard Dedrickson
Lucas James Finnegan
Karl Frohnen
Christopher Hickey
Anna Huneycutt
Susan Kelly
Corbett Monica
Loren Mosher
Alan Roy Mountain
Deb Parker
Ryan M. Soper
Robert Medford Wagner
Ian

Honouring

Oliver Armen
Donita Diamata
Nicholas Emlen
Kevin Fitts
Anne Graham
Mike Hlebechuk
Julie Huneycutt
Yana Jacobs
Aaron Jacobs-Smith
Caleb Jacobs-Smith
John Mendez
Gina Nikkel

Give Some, Get Some

Get in on the action

Join the **Excellence** team of world changers: donate now to gift new knowledge and new tools for recovery to those in need

Donate now, pledge a monthly gift, or leave a legacy gift in your estate plan.

Donate to a specific project or donor-advised fund

Find the projects and funds that match your passion under the "How to Help" tab on our website.

Get help, be informed

RxISK.org

RxISK.org should be your first stop when considering a new drug treatment or deciding whether to stick with a current one.

Early Psychosis Program Directory

If you're looking for help for a young person experiencing psychosis, the programs in this national directory are tailored just for them.

Recovery Provider Directory

The psychologists, psychiatrists, therapists, and treatment programs you find on this site adhere to recovery principles which respect an individual's choice about the use or non-use of medications and they work collaboratively with the person in distress, operating from the core belief that recovery is not only possible, it's expected.

MadInAmericaContinuingEd.org

These accredited courses cut through industry marketing ploys and ghost-written research to reveal what the data actually says about current psychiatric practices. They also review alternatives to a drug-based paradigm of care. Course content can be viewed free of charge.

Families Healing Together

Recovering Our Families is an 8-week online support and education course where the family and friends of someone experiencing a mental health challenge can find moral support and become equipped with practical tools to maintain and strengthen their relationships.

Emotional CPR

eCPR is a way of connecting to the healer within each of us. It is designed to teach all community members how to assist others through an emotional crisis using three simple steps: C = Connecting, P = emPowering, & R = Revitalizing. Check out the national website for scheduled trainings or to bring a training to your community.



**FOUNDATION FOR EXCELLENCE
IN MENTAL HEALTH CARE**

Expect Recovery

29100 SW Town Center Lp W, Ste 140F
Wilsonville OR 97070-9315

YOUR GIFTS SPREAD THE HOPE &
TOOLS FOR RECOVERY AROUND THE
WORLD.



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