

### FOUNDATION FOR EXCELLENCE IN MENTAL HEALTH CARE

Expect Recovery. Hope Matters.



Dear Friends of Excellence,

We want to thank every one of our donors and volunteers who have made us so successful in funding independent research, education, and programs that support recovery-based practices in mental health care.

In this report, you will see a few of those projects and funds that foster recovery for people who experience mental health challenges and their families. You will also find some resources that are already available for use.

Here is our 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 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 inviting your friends to follow us on Facebook, Twitter, and YouTube and by sharing our eNewsletters.

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

With gratitude,

Larry Davidson, PhD

### The Excellence Board of Directors



Gina Nikkel, PhD President & CEO





Vice Chair







David Hughes, PhD Giovan Baza







Louisa Putnam, LPCC, LMT

### You're looking for answers. We're finding them, together.

The current medication-focused model of mental health care has let you down. You know recovery is within reach and you want to change the world. You've come to the right place.

We help donors achieve their dream of bringing the hope, knowledge and tools for recovery to every community by funding promising research and innovation in mental health care worldwide.

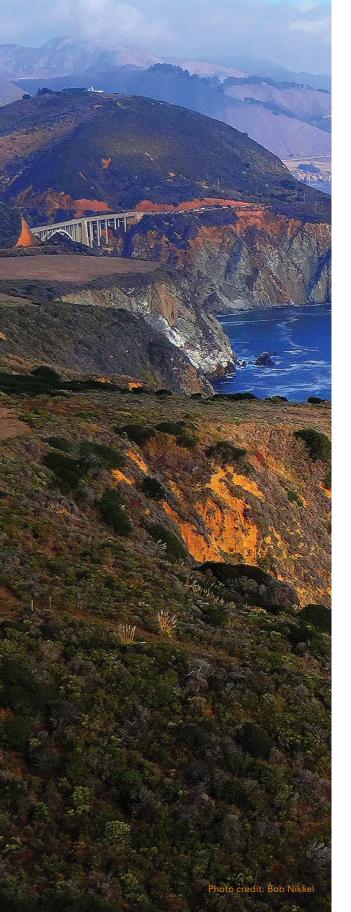
We are catalyzing a new paradigm of mental health care that centers on recovery-based treatment and programs. By uncovering the root causes of mental health challenges and finding treatments to match, we are moving toward a world of care which is safe and effective, fulfills our need for authentic connection and respect, and restores hope for a meaningful life.

We are spreading knowledge that will change the face of mental health care around the world.





Courtenay Harding, PhD David Healy, MD





#### FOUNDATION FOR EXCELLENCE IN MENTAL HEALTH CARE

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2016-2017

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### 'Expanding the Science and Practice of Recovery-Based Mental Health Care & Supports' Grant: New projects bringing fresh vision

Six grants for new research and programs were awarded in the fall of 2017 through the generosity of a single anonymous funder. These one-year grants of up to \$100,000 were selected for their vision and promise to effect cultural and system change, care innovation, and "slow psychiatry", especially as these impact the lives of children.

"I meet a lot of people who feel shamed and angry and traumatized by their experience with the mental health system. This was certainly my personal experience.

'We decided to fund the competitive grant program because we are deeply interested in changing how mental illness is conceived and treated. Our current systems of care are rife with problems and seem to be failing most, but there are pockets of hope, compassion, common sense and wisdom in many places. We hope our gift will help these ideas gain traction, develop an evidence base, and become widely available to help people get through episodes of crisis without becoming "mental health patients".

# in their own words why they gave

'It has been wonderful to see the vigorous response to the request for proposals and it has been an education in and of itself to see the many ideas that have been brought forth about how to improve care. I wish we could fund them all. I hope others in the philanthropic world will take notice and be galvanized to join in and help change the system."

### 2017 Competitive Grant Award Winners

Grant proposals were reviewed by the Foundation's Scientific Advisory Council and grantees were selected by the Board of Directors.

#### Qualitative and mechanistic aspects of "Micronutrients for ADHD in Youth": The

**"MADDY" Study.** A fully-blinded, randomized controlled trial with an open label extension in which all participants will receive the treatment; it is the first North America-based evaluation of a broad-spectrum micronutrient consisting of vitamins, minerals, amino acids and antioxidants. Evidence suggests that symptoms of ADHD respond well to treatment with nutrient supplementation, but more research is needed. Principal Investigator: Jeanette Johnstone, PhD, Instructor & Licensed Psychologist, Department of Child and Adolescent Psychiatry, Oregon Health & Science University.

### A learning and self-development approach for mood-related distress in young people.

This project will deliver and evaluate a novel, multi-pronged approach for supporting young adults, age 18-26, experiencing intense or extreme mood-related distress, without the use of psychiatric diagnostic labels or medication. The *Learning & Self-development Collaborative* aims to shift conversation away from an exclusively medical understanding of mental and emotional distress towards a holistic, self-development approach that values body, mind, social connections, and spirituality. Young adults will participate in critical, consciousness-raising psychoeducation, peer support groups, counseling on nutrition and lifestyle, and social networks in the community. Principal Investigator: Shannon Hughes, MSW, PhD, Assistant Professor, School of Social Work, Colorado State University.

#### OnTrackNY with the option of social

**network meetings.** OnTrackNY treats young adults within two years of experiencing an episode of psychosis. This project aims to expand the role of family engagement and support within that model, borrowing from the Needs Adapted and Open Dialogue models, to improve treatment and recovery outcomes. It will create a family therapy service that brings together both the individual and members of their social network to effectively navigate crises and assist in negotiating treatment planning in collaboration with OnTrackNY at The Mental Health Association of Westchester. Principal investigator: Lisa Dixon, MD, MPH, Professor of Psychiatry, Columbia University Medical Center and Director of the Division of Behavioral Health Services & Policy Research and the Center for Practice Innovations, New York State Psychiatric Institute.

Personal narratives of public mental health care in America. A video library and online curriculum for health care students and professionals to inspire the attitudes and values essential to a health care system predicated on the principles of recovery. Project Coordinators: Lucy Winer, Director/ Producer, Wildlight Productions, Inc., and Nancy Tomes, PhD, Distinguished Professor of History, Stony Brook University.

#### Creating educational web-based resources: Training effective advocates for choice.

This project honors everyone's potential to be a leader, even those in the back wards of the most restricted psychiatric facilities. It will equip and provide opportunities for mentorship and training by and for people with lived experience of mental health challenges to change the system of care in their communities. Project Coordinator: Sarah Smith, MindFreedom International.

### Can micronutrients reduce symptoms of antenatal depression and anxiety? A

double blind, randomized placebo controlled trial examining the efficacy of a micronutrient intervention on symptoms of depression and anxiety in pregnant women. Principal Investigator: Julia Rucklidge, PhD, Professor and Clinical Psychologist at the University of Canterbury, New Zealand.



### Revealing the power of nutrition in mental health

Dr. Bonnie Kaplan, professor emerita and researcher at the University of Calgary has powerful stories to tell of individuals who suffered life-changing mental health challenges restored by multi-nutrient treatments.

Nearing the end of her academic career, Dr. Kaplan opened the Nutrition and Mental Health Research Fund in 2015 to support the next generation of nutrition scientists to research and educate on the ability of broadspectrum 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.

The Fund has already raised over half a million dollars from private donors.

Grants have been awarded to clinical scientists conducting trials of micronutrient treatment in New Zealand, Canada, and the U.S. The trials involve children with ADHD and mood dysregulation and adults with bipolar disorder. Most of these trials are beginning recruitment this fall.

All of the existing funds have now been distributed, but we are nowhere near finished with the work!

In some of the currently funded projects, biological samples will be drawn for microbiome analyses, epigenetic markers, and nutrient levels. These assays are very expensive and will require an additional \$150,000 in donations to complete.

Funding is also still needed for a study coordinator in a very busy laboratory in New Zealand and for an American scientist wanting to devote her career to this topic.

There are also additional clinical trials in need of funding: one would allocate children in mental health crisis in the emergency room to receive either micronutrients or medication, another in adolescents who are displaying self-harm, etc, etc. There is so much good yet to be done!

Nutrition & Mental Health Research Fund



Clinical psychologist Professor Julia Rucklidge, Director of the Mental Health and Nutrition Research Group at the University of Canterbury in New Zealand says valuing the role of nutrition as part of addressing our mental health statistics must become part of our future. The results of her clinical trial on the impact of multi-nutrient supplements to treat ADHD in children, supported by a grant from the Foundation for Excellence in Mental Health Care, were published in 2017 in the *Journal of Child Psychology and Psychiatry*.



Laysha Ostrow, PhD, is the founder and CEO of Live & Learn, Inc., a California-based, woman-owned social enterprise that provides research, technical assistance, and knowledge translation services to behavioral health systems. Live & Learn was founded in 2014 to partner with practitioners, patients, advocates, and researchers to ensure that the experiences of people who have used mental health services are represented in research. Her Excellence-funded study findings were published in the journal Psychiatric Services in July 2017.

### Study finds that stopping psychiatric medication is difficult, but most are "satisfied with their choice"

Despite numerous obstacles and severe withdrawal effects, long-term users of psychiatric drugs can stop taking them if they choose, and mental health care professionals could be more helpful to such individuals, the study found.

While 1 in 6 Americans take a psychiatric medication, there is little research on people's experiences coming off of them.

In the first large scale study in the United States, Live & Learn, Inc. began to fill this knowledge gap, with a grant from the Foundation for Excellence in Mental Health Care and in partnership with researchers at UCLA, UCSF and New York University.

# Lived-Experience Research

Project members all had personal experience with psychiatric treatment and coming off psychiatric medications themselves.

Surveying 250 long-term users of psychiatric medications who had a diagnosis of serious mental illness and chose to discontinue use, the study found that more than half succeeded in discontinuing usage, despite having little professional support while experiencing severe withdrawal symptoms.

The majority of survey respondents cited the main reason they attempted to quit centered on health risks of long-term use and side effects.

Over 70% had taken medication for more than a decade. They reported having little to rely on when discontinuing except the Internet and social support.

Most were working with a provider but did not find them helpful in the process. Yet even though it was often complicated and difficult, the majority who were able to come off medication completely were satisfied with their decision to do so.

Of the study's 250 respondents, 54% managed to stay off psychiatric medication for at least one year, with few reporting relapse or rehospitalization. 82% of those who discontinued use reported being "satisfied" with their choice.

### Changing the lives of voice hearers

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 \$550,000, *Excellence* donors are helping to build a well-trained regional network of Hearing Voices groups in the United States.

**Hearing Voices Research** & Development Fund

Those groups are bringing support to voicehearers across the nation. They also provide data for Dr. Gail Hornstein's research to describe the mechanisms that lead to the program's positive outcomes.

"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."



Jacqui Dillon is a British trauma survivor whose life was changed by the Hearing Voices movement. She is now an international leader and partners with Dr. Gail Hornstein of Mt. Holyoke College to spearhead the expansion of Hearing Voices groups across the United States. They are co-founders and advisors to the Hearing Voices Research and Development Fund at the Foundation for Excellence in Mental Health Care.





A multi-disciplinary team at the University of California San Diego led by Dr. Douglas Ziedonis (above) is collaborating with many clinical and research groups around the world, including China, Denmark, Finland, Italy, Japan, Latvia, Lithuania, Norway, Poland and the United Kingdom. A primary focus of the work is to study and develop tools for training and research on the Finnish "Open Dialogue" approach and to work to adapt and implement it in the U.S. and with colleagues around the world. Materials developed are translated into 7 languages.

# Adapting Open Dialogue to the United States

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# Leveling the power imbalance, taking time to make wiser choices leads to astonishing results

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, Professor of Psychiatry at UC San Diego Medical School is 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 U.S. 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 journal *Psychiatric Services* in July 2016 by lead author Dr. Chris Gordon.

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

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

### RxISK.org is making medicines safer for all of us

RxISK.org fills the information gap left by weak drug safety regulations and sparse independent research, by crowdsourcing and sharing drug side-effect data from people's real-world experiences.

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 affect, and review potential harmful interactions when taking or thinking of taking multiple drugs at the same time.

The TaperMD<sup>™</sup> app was originally developed to help reduce the medication burden in seniors. It is now nearing its launch for clinic and patient use for all age groups.

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 RxISK Fund

### The RxISK Prize

Most people are aware that antidepressants can cause sexual side effects but almost noone knows these can endure permanently after treatment stops – sometimes only emerging after treatment stops. This a problem facing tens of thousands of people, leading to suicide, relationship and family



break-up, job loss and a lot of wasted money on dangerous options held out as cures. At present, there is almost no support for those affected.

RxISK is collecting donations from people around the world to offer a \$100K reward for a cure and encourages everyone to pitch in and spread the word. The interest and response from the public and the research community is already raising critical awareness and financial support for this growing epidemic.

Visit RxISK.org to join in the fight.

### FINANCIAL STATEMENT HIGHLIGHTS

### SUMMARY OF CONSOLIDATED STATEMENT OF FINANCIAL POSITION December 31, 2016

ASSETS	\$
Cash & Cash Equivalent	877,349
Investments	263,585
Contributions receivable	207,500
Other assets	238
TOTAL ASSETS	1,348,672
LIABILITIES	
Payables & accrued expenses	51,050
Grants payable	157,788
Other current liabilities	4,695
TOTAL LIABILITIES	213,533
NET ASSETS	
Unrestricted	1,135,139
Temporarily restricted	0
TOTAL NET ASSETS	1,135,139

SUMMARY OF CONSOLIDATED STATEMENT OF ACTIVITIES 2016

REVENUE & GAINS	\$
Gifts, grants & contributions	1,266,087
Investment income (loss)	12,799
Program & other revenue	34,719
TOTAL REVENUE & GAINS	1,313,605
GRANTS & OTHER EXPENSES	
Grants	542,273
Fund expense & program services	514,340
Administrative expenses	221,388
TOTAL GRANTS & OTHER EXPENSES	1,278,001
CHANGE IN NET ASSETS	32,175
NET ASSETS, BEGINNING 2016	1,102,964
NET ASSETS, END OF 2016	1,135,139

If you would like a copy of financial statements audited by Carter, P.C., call EXCELLENCE's main office at 503-816-5676. Our 990's are available online at MentalHealthExcellence.org.

### TRIBUTES

Giving is personal. Each of us has a story. Many gifts have been given in memory of someone we've lost. Others were given in honor of an individual who has made a profound, live-giving impact on the giver or someone they love.

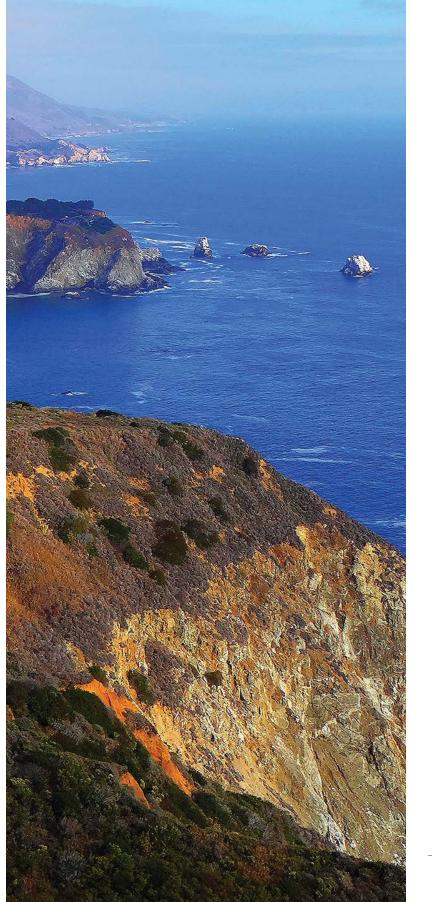
These are our tributes.

### Honoring

David Alt Oliver Armen Orvx Cohen Donita Diamata Nicholas Emlen Kevin Fitts Wendy Garfield Darla Ghanat Anne Graham Sheila Hamilton Mike Hlebechuk Julie Hunevcutt Yana Jacobs. MFT Aaron Jacobs-Smith Caleb Jacobs-Smith Lee Macht. MD John Mendez **Billy Muer** Mr. & Mrs. Nelson Gina Nikkel, PhD A mate on twitch xxs4rg3xx Kara

### In Memory of

Barbara Cohen Leonard Dedrickson Lucas James Finnegan Karl Frohnen David Hardy Christopher Hickey Anna Hunevcutt Our son Ian Susan Kelly Corbett Monica Loren Mosher Alan Roy Mountain John M. "Mickey" Nardo, MD Deb Parker Ellen Pasav Paul Peacock Kazadi Salwa Ryan M. Soper Robert Medford Wagner



### Lend a hand, find a hand

### Change the world

### Gift new knowledge and 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 espouse 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 ghostwritten research to reveal what the data and people's real-world experiences actually say about current psychiatric practices. They also review alternatives to a drug-based paradigm of care.

#### **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.

Find links to these and other resources online at MentalHealthExcellence.org or email info@MentalHealthExcellence.org.



### FOUNDATION FOR EXCELLENCE IN MENTAL HEALTH CARE

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### re·cov·er·y

 $ri-k = v = r\bar{e}$ 

: a person is successful and satisfied in the living, working, learning, and social environments of their choice.

## Foundation for Excellence in Mental Health Care

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