

HOLIDAY NEWSLETTER

It's been a busy year, but we wouldn't have it any other way.

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SEASONS GREETINGS FROM PERC



CT-R Tip of the Season

Keeping your mind & body active with new interests and activities can help ward off the winter blues. It could be anything, such as playing bridge, learning a new skill, singing, knitting, joining a gym, or starting a journal.

The important thing is that you have something to look forward to and concentrate on.

STAFF SPOTLIGHT

An Interview with Dr. Aaron Alexander-Bloch, MD, PhD





I did my undergraduate studies in Philosophy at Harvard University. I then studied Computational Biology in a master's program at the University of Cambridge in the UK. I completed my medical training at UCLA, and then a PhD in Neuroscience at the University of Cambridge through a combined intramural NIH program. I did my psychiatry residency at Yale where I was also faculty for 3 months before coming to Penn and CHOP.

What areas of research are you most interested in?

Using magnetic resonance imaging (MRI), my lab explores changes in brain development of people at genetic risk for neurodevelopmental disorders. I want to understand how genes and the environment influence the brain, and why some individuals experience symptoms like psychosis. I've always been interested in how the brain works to create our subjective experiences. My PhD work was in brain MRI, looking at how brain function may be different in people with schizophrenia. I saw breakthroughs in genetics and learned more about how to combine genetics and imaging to study risk for mental illness.

What do you enjoy most about working at PERC?



What do you like to do in your spare/free time?

I have two small kids and I love spending a lot of my time with them. I live in West Philly and enjoy spending time with friends in the community. I also love cooking and trying different foods. I enjoy watching and playing sports like tennis. I also like to read science fiction.

Lived Experience Testimonial

What advice would you give other support persons trying to find care for their loved one?

Start with PERC. Inquire about first steps if your loved one is exhibiting symptoms of mental illness (MI) or struggling with mental health (MH). PERC can provide updated educational materials and supports for family members trying to find care for their loved one. Understand why, how, when, and where to file 302 Emergency Petitions (EP). The first time can be daunting and difficult, and a competent, caring team like PERC will provide guidance and support every step of the way. Ask your local police department (PD) if they are equipped with a MH Crisis Team within their PD, and whether it can be mobilized in the event of a crisis or EP filing. If you're not already familiar with MH / MI, then joining a support group for caregivers can be a source of valuable education, support, and insight on how to best develop a personalized plan, skills, and resources to help your loved one living with MI.

Search for providers who will help you find ways to ensure that you are permitted to be part of both the in-patient and out-patient treatment teams. This may involve thoughtful negotiations with the treatment team and your loved one who needs medical treatment services. Then as a family member of the treatment team, your observations, suggestions, feedback, and perspective will likely be considered towards developing a viable and flexible treatment plan that everyone can agree on, modify as appropriate, and work to implement. I believe this is especially important when developing a long-term care plan for your loved one, particularly during: any periods of relapse; that nebulous in-between stage when your family member is not sick enough for in-patient stay and not well enough for safe out-patient stay; medication noncompliance; and other illness-related challenges.

What would you tell someone who's considering our program?

I believe that finding a competent provider who can guide you and your loved one through the first episode of psychosis is absolutely critical for patient recovery, stabilization, and identification of effective medications and support interventions. Had we started with PERC at the time of the first episode of psychosis, three years ago, I believe we would have arrived at the current effective medication treatment strategy and incredible progress much earlier. My son has had eight to nine hospitalizations during the first 1.5 years, primarily due to administration of ineffective medication strategies and lack of communication with the family from various in-patient hospitals. Although we joined PERC after the first year (and after four hospitalizations), within six months of joining PERC my son began to stabilize. PERC had identified and initiated the medication that proved most effective for my son. It's been over 1.5 years since his last hospitalization.

This December 2023 will mark 3 years since my son's first episode of psychosis, and he is now stable. He just passed the driver's road test and received a driver's license. About 6 weeks ago, he was hired for a part-time job. His behavior and actions are organized and appropriate. He's demonstrating responsibility, effective coping skills, flexibility and thoughtfulness, and enjoyment and excitement over little and big things. Every member of our PERC team has helped us achieve all this through their support and guidance at every step, each day. It has been a great comfort to be able to reach and consult with members of the PERC team, particularly during moments of crisis and difficult decisions. I believe we have achieved significant milestones in my son's recovery because of PERC's outstanding program and staff.

Lived Experience Testimonial

Our Timeline & Journey to Recovery with PERC

Nov 2020

1st ER hospitalization (voluntary) for psychosis

• Four in-patient hospitalizations and various outpatient programs

Dec 2021 - Enrolled in PERC

• At the time of in-patient discharge and during discussion, negotiation, and development of the Outpatient Treatment Plan with/among all parties (inpatient treatment team, PERC, patient (son), family caregivers)

• A rapid succession of hospitalizations via PERC's support and family engagement strategies to overcome limitations and ineffectiveness of in-patient treatment center programs and patient's medication non-compliance

Additional 4 - 5 in-patient hospitalizations

Jul 2022

• Last hospitalization and identification and initiation of current effective medication

Dec 2022

• Stabilization and medication titration towards therapeutic dose

May 2023

- Therapeutic dose and stabilization of symptoms achieved
- Resume/CV drafted with PERC support
- My son applied and received Driver's Learner Permit with PERC's support, and began driving practice with mom

<u>May - Sept 2023</u> My son applied for various jobs with PERC's and mom's support

Oct 2023 - Nov 2023

- Achieved three goals:
- Hired for part-time job (Oct 2023)
- Received PA Driver's License after passing Driver's Road Test (Nov 2023)
- Improved, strengthened, and rebuilt family relationships

Dec 2023

- Significantly improved behavior, responsibility, engagement with family and peers, and enjoyment of old and new interests and activities
- Ready to set new goals

Are there are any improvements you hope to see in the mental health field in the future?

There are so many improvements in the mental heath field that I hope to see in the future--the sooner the better, for all of us! Let's make it easier for families to file 302 Emergency Petitions (EP). Online filing or over the phone filing would help expedite the process and relieve the significant trauma that families go through as their loved one experiences a mental health crisis or is clearly symptomatic. Police and first responders should be equipped with MH Teams, which are members of the PD unit and easily deployed in response to MH crisis calls or requests for wellness check. There should be a special 911 response team for MH calls, like there is for the police and fire department. We should have a consistant standard across all safety and health-related emergencies (MH, police, fire, etc.) without stigma, ignorance, or discrimination, where "false alarms" or low level threats and concerns ("see something, say something") are acceptable, investigated, and tolerated by first-responders in a compassionate and competent manner. All first responder organizations should develop programs and plans for how to best identify and respond to MH crisis situations. All first responders should receive effective training for identifying and managing MH concerns and crisis situations. In-patient MH providers should develop effective policies and evaluation plans that are designed to achieve active engagement and communication with the out-patient treatment teams and family caregivers, especially while the loved one receives in-patient care. would like to see community outpatient programs specifically and carefully designed with input from family caregivers for situations when a loved one is in that "inbetween stage" where they are not sick enough to be hospitalized and not well enough to function properly in an out-patient program or home (with or without family caregivers).

Lived Experience Testimonial

When an in-patient provider gets pressure from medical insurance providers to discharge a patient who's in that "inbetween stage", the hospital should not be permitted to discharge the patient to the doorstep of a homeless shelter (when they are closed or open). Family caregivers should always be notified in the event that such a plan has, in fact, been developed by the in-patient provider, and caregivers should always be allowed to provide input in developing a reasonable and rational out-patient treatment plan. HIPPA rules should be changed specifically for MI to allow family caregivers to receive a reasonable amount of information to adequately care for their loved one. Current HIPPA laws place family caregivers in an unreasonable, irrational, extremely difficult, dangerous situation when critical medical information is withheld. I would like to see a policy where all parties (in-patient treatment teams, out-patient treatment teams, patient, and family caregivers) discuss the appropriateness of disclosure of medical information to family caregivers.

The entire MH community, from providers to government programmers, to family should develop and implement community-wide MH education and awareness programs to eliminate the stigma of mental illness. We need increased funding for research and development of a cure for psychosis-related illnesses, and all neurodevelopmental illnesses, as a high priority area. We need to establish innovative career and workforce development programs tailored for those living with MI, including educational, retraining, vocational, peer support, social skills building, and other programs. We need to develop screening and diagnostic criteria and processes for early detection of MI and symptoms, which would facilitate rapid evaluation and identification of early warning signs of MI in middle school and high school students. Parents, teachers, coaches, and everyone should be as familiar with these symptoms as they are for the common cold.

Replace the illness name "schizophrenia" or psychosis with words that are neutral or more accurately describe symptoms, eg, "hallucinations" as related to a sensory perception and transmssion disorder. I would like to see an initiative to develop a separate and exclusive category for MH insurance programs that are specifically designed with input from family caregivers and MH professionals. This team would establish the criteria to achieve therapeutic goals, competent care, holding providers accountable, and wholistic evaluation of patient progress that's based each patient's unique situation. Family caregivers should be involved in setting the rules, to help reduce the number of hospitalizations and medical expenses incurred by all.

Recent Events



PERC & CHOP at NAMIWalks Philadelphia

NAMIWALKS PHILADELPHIA

This year's NAMIWalks Philadelphia event was a resounding success thanks to all of you! The PERC community raised a total of \$2,326 to help NAMI raise awareness, provide support, and advocate for individuals and families affected by mental illness

VETRI KITCHEN GROUP

Thank you to everyone who helped to make PERC's first Vetri Kitchen Cooking Group an informative & funfilled evening!

We're looking forward to organizing more community events and activities in the coming year. Take a look at some of our upcoming groups and events!



PERC team and community at our first ever Vetri Kitchen Cooking Group

December 2023 Sisue 12

<u>Upcoming Groups</u>

- **DECEMBER 18TH, 2023**
 - Family Group
 - Supporting Autonomy with Ariana Rivens, MA
 - o Participant Group
 - Cultivating Independence with Steven Lawley, MA, LPC
- **JANUARY 8TH, 2024**
 - *Combined* Participant & Family Group
 - "What do we know about sleep and brain health?" with Jerome Taylor, MD
- January 2024 (Start Date TBD)
 - o Stigma Group with Arielle Ered, PhD
- FEBRUARY 12TH, 2024
 - *Combined* Participant & Family Group
 - Supported Education & Employment Services with Bridgette Patton



Upcoming Events

JANUARY 24TH 2024

Pizza & Movie Night





FEBRUARY 21ST 2024

Arts, Crafts & Listening Party



Winter Activities Around Philadelphia

- Winter at Dilworth Park
- Free Museum Days During the Philly Holiday Experience
- Winter in Franklin Square
- Wild Lights at the Elmwood Park Zoo
- LumiNature at the Philadelphia Zoo
- Tinseltown Holiday Spectacular in FDR Park
- Festival of Trees at Christmas Village
- A Longwood Christmas at Longwood Gardens
- Seasonal Celebrations at Sesame Place
- Holidays at Peddler's Village
 - Christmas Village in Philadelphia
 - Holiday Light Show at Shady Brook Farm
 - The Comcast Holiday Spectacular and The Universal Sphere
 - Independence Blue Cross RiverRink Winterfest
 - Holiday Garden Railway and Nighttime Express at Morris Arboretum & Gardens
 - Macy's Christmas Light Show and Dickens Village
 - Yuletide at Devon
 - Miracle on South 13th Street
 - Visit Philadelphia Holiday Tree at City Hall
 - Holiday Parade in Center City
 - George Balanchine's The Nutcracker at the Academy of Music
 - New Year's Eve in Philadelphia
 - Mummers Parade



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<u>Coordinated Specialty Care Services:</u>

• Recovery Planning: The individual and the treatment team work collaboratively to develop a recovery plan that identifies goals and plans for services, and methods based on the individual's needs and preferences.

- <u>Cognitive Behavioral Therapy (CBT)/Case Management:</u> A Master's Level Specialist provides a form of CBT developed to treat psychosis by Aaron Beck and colleagues.
- <u>Psychopharmacology</u>: The program provides ongoing evidence-based psychopharmacology for early-episode psychosis, with emphasis on minimizing medication exposure and side effects.
- <u>Multi-family Group Psychoeducation</u>: Ongoing monthly meetings provided by an experienced clinician provide education, support and coping strategies for families.
- <u>Recovery-Oriented Cognitive Therapy for Families</u>: A closed, 12-week group for families aimed at improving families understanding, coping, and communication skills with their family member in the early stages of psychosis.
- Supported Employment and Educational Services: A dedicated support person establishes plans for functional goals and recovery with the participant. The support person assists possible return to school, access to jobs and training programs.
- <u>Peer Support Services</u>: Individuals in recovery offer peer support and education services in the community to young persons currently experiencing psychosis in an effort to help maintain functioning.
- <u>Telehealth Services</u>: Optional telehealth services available for therapy and case management appointments.
- <u>Additional Treatment</u>: We coordinate with IOPS, PHP's, and local substance use treatment programs when participants are enrolled in multiple programs.
- <u>Participant Process Group</u>: The program offers ongoing monthly process groups that are facilitated by a licensed psychotherapist to support psychosocial skill development & functioning.

Research Opportunities

at



Department of Psychiatry



Eligibility Survey



You can also call us at 833-LiBI-BBL (833-542-4255) to complete the screener over the phone.

Additional Resources & Links:





SAMHSA



Heads-Up PA



Focused on ending the stigma around psychosis

headsup-pa.org



<u>NAMI</u>



FindHelp.org







UNIVERSITY OF PENNSYLVANIA - DEPARTMENT OF PSYCHIATRY - NEUROPSYCHIATRY PROGRAM

Dear PERC Participant and Family,

As the year draws to its end, we want to let you know that our offices will be closed as of Saturday December 23rd, 2023 and will reopen Tuesday January 2nd, 2024.

Please be aware that during this period of time we may not be able to respond to phone calls, emails, or refill medications.

Medication Refills

Please check with your pharmacy to determine whether you will need additional refills prior to January 2nd, 2024 and inform us before December 23rd, 2023. Medication refill requests can be submitted online through MyPennMedicine.org

Emergency

In the case of an emergency, please call 911 or go to the nearest emergency room.

Pennsylvania Hospital Crisis Response Center

801 Spruce Street, 1st Floor, Philadelphia, PA 19107, 24-hr hotline #215-829-5433 From all of us, we wish you a joyful and happy holiday season!

With best wishes,

Christian Kohler, MD

Monica Calkins, PhD

Adam Rossano, MD PhD

Elisa Nelson, Ph.D.

H. Steven Lawley, MA, LPC Aaron Alexander-Bloch, MD PhD Ariana Rivens, MA

Joshua E. Mervis, PhD, RYT

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