

Maine Behavioral Healthcare Brings the Largest Autism Study to Northern New England

SPARK: Simons Foundation Powering Autism Research for Knowledge

Maine Behavioral Healthcare was recently chosen as the Northern New England clinical site for the largest autism study ever undertaken in the United States. Known as the SPARK study, the goal is to enroll 50,000 people in three years to collect information and DNA for genetic analyses to further explain the causes of autism. The Developmental Disorders program at Maine Behavioral Healthcare has been chosen as the Northern New England study site responsible for recruiting any person with autism, along with their family members, in Maine, New Hampshire or Vermont.

“We were selected because of the work we have led in studying the genetics of autism in the past,” explained Dr. Matthew Siegel, Director of the Developmental Disorders program. Autism is already known to have a strong genetic component and the Simons Foundation is building a resource of genetic data that investigators can use to learn about autism. The goal of the study is to identify subgroups of individuals with autism to develop more targeted treatments.

“We will be seeking any family or individual, of any age, with a professional diagnosis of autism in Northern New England to participate in this groundbreaking study,” said Dr. Siegel. Participation can be done entirely on-line and through the mail. Each study participant and their biological parents will be asked to complete a brief on-line questionnaire and provide a saliva sample collected with a kit they receive in the mail. The study has been carefully designed to make it as easy as possible to participate, and to provide benefits to the subjects, in addition to contributing to the advancement of autism science.

“We will look back in thirty or forty years and see this study as a major milestone in the advancement of autism science,” explained Dr. Siegel. Maine Behavioral Healthcare’s



Laurie Raymond, LCSW, and Dr. Matt Siegel

Developmental Disorders research program in partnership with Maine Medical Center’s Research Institute, is one of four sites to be added to this multi-million dollar project this year. In total, 21 university-affiliated clinical sites and many local autism organizations are partnering across the United States to help recruit participants.

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As the Northern New England site, MBH has received a \$500,000 grant over a three-year period to fund the acquisition of samples and participant information, supported by two staff members: Dr. Siegel as principal investigator and Laurie Raymond, LCSW as the research coordinator. The goal for the MBH site is to enroll annually 250 sets of the individual with ASD and his/her biological parents. Privacy and confidentiality are protected, as all data collected will be de-identified so that personal information is removed when they are added to the study.

“In addition to a small stipend paid, study participants also have the large potential benefit

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Stephen M. Merz

FROM THE CEO:

In celebration of Autism Awareness month in April, we are proud to share the news about our participation in a national autism research cohort known as SPARK – the *Simons Foundation Powering Autism Research for Knowledge*. While there have been considerable advances in autism re-

search, there is a long way to go to better understand the causes and potential treatments of autism.

The cover article of this *Mind & Body* issue describes our involvement in this national study. As the Northern New England partner, our Developmental Disorders program will be reaching out to individuals with a professional diagnosis of autism and their family members to share information. This national compilation of data will accelerate the understanding of autism.

In other celebratory news, Dr. William Brennan, the Assistant Medical Director at Spring Hospital was recently selected by the Tufts University School of Medicine (TUSM) as a faculty member to be recognized for *Accomplished Teaching in the Psychiatry Clerkship at Maine Medical Center during 2015-2016*. As an outstanding role model, he describes his passion for teaching and psychiatry.

Finally, I would like to personally congratulate our Board of Trustees member, Creighton Taylor, for being honored with the Heart of Gold Award at this year's Heroes with Heart fundraiser. She has been instrumental in developing the Purdy Family Navigator position, as part of the Lunder Family Alliance at Spring Harbor, to support family members and caregivers of a child or adolescent who is hospitalized. We are honored to have this tireless patient and family advocate on our Board.

Steve Merz

Creighton Taylor: Heart of Gold Award Recipient Paying it Forward

Creighton Taylor has been on the Maine Behavioral Healthcare Board of Trustees for three years, and chair of the MBH Advisory Committee since 2013. She is a past president of the NAMI (National Alliance on Mental Illness) Portland chapter, and served as a support group leader and teacher of the Family-to-Family course (a 12-week, evidence based curriculum designed to educate caregivers).

At this year's Heroes with Heart event, honoring volunteers and first responders to crisis calls, Creighton Taylor received the Heart of Gold Award for her dedication to mental health. She became involved with Spring Harbor Hospital after her son's first hospitalization in 2009. He had been missing for almost two years. "When we found him, we thought the nightmare was finally over but, in truth, it was just beginning."

"I had no idea how to deal with someone who was psychotic, and because we were not considered part of the treatment team, we were on our own. Luckily I had a sister who worked in the field and she gave our family a list of tips on effective communication and coping strategies." After her son was discharged she learned that "it is a huge responsibility to care for someone who is still acutely ill, and the stigma of mental illness added to our sense of isolation. No one brought us casseroles."

The development of the Linking Families committee was the start of several initiatives in a mission to provide support to families who are facing similar challenges. "My first experience at Spring Harbor was in 2010 when I talked to a group of social workers about what it is like when someone you love has a serious mental illness, which led to a growing awareness of the important role that family members play. They listened to what I had to say," she explained.

Today she can see the remarkable change between her son's first hospitalization and his most recent stay in 2015, after a hiatus



Mary Jane Krebs, President of Spring Harbor Hospital, and Creighton Taylor at Heroes with Heart

of six years in recovery. "I remember the moment my son's social worker handed me the family information packet that the Linking Families committee had developed (including the list of tips my sister had written), which is now routine procedure to give to families. I knew then that we were beginning to make a difference."

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With the generous support of The Lunder Family Alliance, Creighton played an important role in developing a 'Family Navigator' position at Spring Harbor Hospital, staffed by social worker Betsy Oakleaf, whose sole focus is to support family members and caregivers. Soon after her son was admitted in 2015, Creighton promptly received a call from Betsy, checking in to see if there was anything she could do to help. "It was like a dream come true," Creighton said.

Creighton is also in the process of launching a blog to expand the circle of support to other parents, especially moms. "We need each other and have such a wealth of collective wisdom to share," said Creighton.

The importance of family support is essential to promoting recovery. The more education around mental illness and its causes, the more people will be able to talk about it personally without shame or fear of being labeled. "Cancer used to be like mental illness is today. There was fear around the illness because people did not understand the disease."

Today there are more resources for education and support, especially through NAMI. "The NAMI Portland support group saved my life. So I believe we have a responsibility to pay it forward to others who are just beginning their journey when they feel hopeless and overwhelmed. They need to know that recovery is possible and life will go on, even with a broken heart." The hope she has is to make a difference by providing family support and reducing stigma. As the Heart of Gold award recipient, she is making a difference every day.

Our Mission

Maine Behavioral Healthcare will provide a seamless and compassionate continuum of care through a community of providers collaborating to promote recovery and the overall mental and physical well-being of those we are privileged to serve.

Dr. Brennan Receives Tufts University Teaching Award



Dr. Brennan

"Medical students are bright, curious, and eager to learn," said Dr. William Brennan, Asst. Medical Director at Spring Harbor Hospital. He enjoys teaching students about psychiatry because it's all about the clinical encounter. "I model the conversation I have with a patient to demonstrate how to establish rapport and get their story."

Recently selected by Tufts University School of Medicine (TUSM) as a faculty member to be recognized for Accomplished Teaching in the Psychiatry Clerkship at Maine Medical Center during 2015-2016, Dr. Brennan has been teaching third and fourth-year medical students for more than a decade. He explains his approach as helping students understand how to get inside the patient's head.

"Psychiatry can be challenging and emotionally draining. You have to have good boundaries. But it puts your own life in perspective when you meet people living in a shelter disowned by their family. Relatively speaking, you feel fortunate."

Dr. Brennan's expertise is schizophrenia and he is fascinated by the study of people. "It helps to have a thick skin. Even though encounters can be adversarial, the people you see appreciate the humanity." He describes

human behavior as the last frontier in medicine. Even though medicine is fairly mature, the opportunities in psychiatry are still wide open.

Today there are more students coming through rotations doing a third year psychiatry clerkship than ever before, which is good news for mental healthcare in Maine where only 35% of the need is met, according to the Kaiser Family Foundation (health professional shortage areas as of January 1, 2017).

Students stay at Spring Harbor for three weeks before moving to Maine Medical Center for three weeks. "Spring Harbor is an exceptional training environment with a wide variety of patients and levels of acuity. Students see everything here," explained Dr. Brennan. Maine Medical Center, on the other hand, is more specialized with Emergency Department and geriatric psychiatry patients.

This is Dr. Brennan's second career. He decided to go to medical school at age 38 and found a passion for psychiatry. With a Phd in biochemistry, he had the science background of a critical thinker and the ability to condense different types of information succinctly. This has been instrumental as a clinician trying to make a diagnosis.

"I once met a surgeon who said that psychiatry and surgery were the most invasive specialties; surgeons use scalpels to uncover what's on the inside, psychiatrists use their questions. No two patients are alike. With every encounter with a patient, you are editing yourself and changing your approach."

As the Tufts University awardee, Dr. Brennan is recognized by his students for excellence in teaching, and as an outstanding role model. His exemplary leadership is something he does, not for recognition, but for pure passion of psychiatry. As he describes his teaching role: "If I didn't have students, it wouldn't be this much fun."

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THANK YOU!



Record Attendance at Heroes with Heart

Over 250 guests attended Maine Behavioral Healthcare's Heroes with Heart fundraiser on April 12th at the Holiday Inn by the Bay to benefit the Trauma Intervention Program (TIP). The fundraising event raised more than \$32,000 and served as a means to honor TIP volunteers and first responders who went above the call of duty to provide compassionate support to citizens in crisis.

Creighton Taylor was the 2017 Heart of Gold award recipient. The challenges her own family faced when they entered the behavioral health system motivated her to become a tireless advocate for mental health awareness (see interview on page 2).

Special thanks to Heroes with Heart sponsors, including silver heart sponsor **TruChoice Federal Credit Union** and other lead sponsors such as **Maine Medical Center, Martin's Point Healthcare, Attardo Pondelis, E4H Environments for Health Architecture, Edison Press, Jones, Rich & Barnes Funeral Home, Wright-Ryan Homes,** and **Churchill Catering.**

TIP trains citizen volunteers to provide support to victims of traumatic events in the first few hours following a tragedy. The program relies primarily on grants and private donations.

Olympia Sports Supports Autism Awareness in April

During Autism Awareness Month in April, Olympia Sports stores throughout the north-east raise money to advance autism research at the Center for Autism and Developmental Disorders and Spring Harbor hospital by offering point-of-sale promotions at more than 200 store locations. This is the fifth year of the month-long event that has raised nearly \$300,000 combined. The funds will directly support autism research through the Autism Inpatient Collection study founded by Matthew Siegel, MD, Director of the Developmental Disorders Program.

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of receiving results from extremely high quality genetic sequencing, far more sophisticated than what is available for most people through their health insurance. If there's a mutation that's discovered pointing to a risk of developing a psychiatric or medical disease, participants will have access to genetic counseling," said Dr. Siegel. "Participants can decide whether or not they would like to receive these results."

Participants can learn more and register for the study at: www.sparkforautism.org/mainemedicalcenter

The study coordinator, Laurie Raymond, is happy to talk with individuals, parents and providers about the study and can be reached at sparkkne@mmc.org or 207-661-7620.

"In addition to the benefits and access this brings to families in Northern New England," said Dr. Siegel, "this study also positions MBH and Maine to participate in future treatment studies and other opportunities for people affected by autism in our region."

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EVENTS

May is Mental Health Awareness Month

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| National Children's Mental Health Awareness Day | May 4 |
| National Nurse's Week | May 6 – 12 |
| National Hospital Week | May 7 – 13 |
| HOPE Conference | May 31 |

Save the Date:

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|--------------------|--------------|
| Signs of Hope | July 19 |
| Golf Tournament | August 25 |
| Glickman Symposium | September 15 |

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