Julia’s Fund: Bringing Big Data to Psychiatry

Harry Kasparian has spent more than 35 years as a leader in the technology field. An engineer and business man who founded a successful data analytics company, Kasparian understands the value of science, data and research.

Fueled by the grief of losing his beloved daughter, Julia, in 2016, Kasparian focused his intelligence and expertise into creating a unique research collaboration aimed at increasing our understanding of the neurobiology of trauma. He established the Julia Kasparian Fund for Neuroscience Research at McLean and, in doing so, brought together two organizations that mean a great deal to him. Julia’s Fund is forging an innovative partnership between clinical researchers at McLean and data scientists in the department of Bioinformatics and Computational Biology at Worcester Polytechnic Institute (WPI), his undergraduate alma mater.

“Julia was smart, kind, loving and giving,” said Kasparian. “She always put the needs of others first. She was a straight-A student at Bates College and devoted extraordinary energy to volunteering and raising funds for causes she believed in, especially ending the stigma of mental illness.”

Despite the outward image of a bright and happy young woman, Julia battled mental illness.

“She was incredibly committed and worked tirelessly to get healthy,” continued Kasparian. “But she also hid her pain from those who cared so much for her. In the end, hopelessness prevailed and, tragically, she gave up. No one should have to suffer the loneliness and despair that Julia did.”

Kasparian is doing his best to make sure of that.

Julia’s Fund is underwriting a project that uses machine learning — a branch of artificial intelligence — to make sense of large-scale imaging and symptom data from McLean. These data, gathered with permission from a group of patients with histories of dissociation, depression, trauma and suicidal behaviors, will be analyzed using machine learning methods in collaboration with WPI scientists. The ultimate goal is to help clinicians begin to recognize different psychiatric disorders through their neural signatures in order to provide better interventions earlier in the course of illness.

 Harry Kasparian sits in Julia’s bedroom with her dog.

“No one should have to suffer the loneliness and despair that Julia did.”

Harry Kasparian

continued on page 2
Dear Friends

Our Summer 2019 edition of Horizons highlights the importance of building relationships and making connections.

Our first story is about a father who created a fund in his daughter’s name that is leveraging McLean’s neuroscience expertise together with data science capabilities of Worcester Polytechnic Institute. This unique partnership is bringing new research power to bear on trauma-related disorders.

You’ll also read how philanthropy is helping McLean connect people across the country and around the world through enhanced education. Thanks to donor support, McLean is expanding our portfolio of webinars, podcasts, educational videos and our Deconstructing Stigma campaign to bring information and hope to many more people.

Another expansive, community-focused effort — McLean’s Center of Excellence in Women’s Mental Health — is showcased through the eyes of its new executive director, Dr. Kimberlyn Leary.

And our final story is about the connection one man made with a dear friend when they were children, and how that friendship has inspired his long-time philanthropy.

Enjoy, and I hope the rest of your summer is warm and wonderful.

Lori Etringer
Vice President and Chief Development Officer

Julia’s Fund continued from cover

“If we can predict the disorder and really understand what’s going on, then we may be able to target areas of the brain for treatment using different modalities,” explained Milissa Kaufman, MD, PhD, director of the dissociative disorders and trauma research program at McLean. “The hope is also to do brain imaging before and after treatment to measure effectiveness.”

The Trauma Link

The patients being studied have a type of PTSD that includes dissociative symptoms — a sense of disconnection from their bodies, their sense of self and their surroundings. “The patients I work with say things like, ‘I live in my head,’ or ‘I feel that my body somehow doesn’t belong to me,’” said Dr. Kaufman. “The world around them feels dream-like — or they feel like they’re watching a movie.” Often, but not always, these patients have histories of overwhelming trauma and stress during childhood, according to Dr. Kaufman. Between one to three percent of the population suffers from a complex dissociative disorder.

McLean will gather and provide extensive data on 110 research participants, including brain images from several types of MRIs, genetic information and clinical data on their symptoms, suicide attempts, trauma history and more. The beauty of the computational techniques the WPI scientists use is that they get “smarter” as more data is fed into them, so in years two and three of the study, information from additional patients will be analyzed, perhaps with even more revealing results. While research on complex dissociative disorders has been done for a quarter of a century, funding has been scarce, Dr. Kaufman said, in part because they are still heavily stigmatized compared to illnesses like depression.

“What moves me most is how Julia’s father has initiated this research in his daughter’s name,” said Dr. Kaufman. “This is how we will make progress in helping other people who are suffering. And that’s the most important thing.”

Other McLean faculty and staff involved with the WPI collaboration include Blaise Frederick, PhD, Staci Gruber, PhD, Lauren Lebois, PhD, Cori Palermo, MA, Kerry Ressler, MD, PhD, and Sherry Winternitz, MD.
"I have three generations of serious mental illness in my family and not all of them have always had good outcomes ... I will never forget that I am a family member first," said Marylou Sudders, secretary of the Massachusetts Executive Office of Health and Human Services, in her keynote address at the 2019 McLean Board of Visitors (BoV) annual meeting. The Secretary shared with the more than 80 attendees that her mother battled chronic depression and substance use and that, as a teen, she was her mother’s caretaker.

Sudders explained that her early experiences with mental illness greatly influenced her professional journey. Her passion for creating a better and more accessible behavioral health system and reducing the stigma associated with mental illness was evident in her deeply personal and inspirational remarks.

The McLean Board of Visitors is a group of nearly 200 individuals who serve as McLean ambassadors and advocates and who share a keen interest in mental health issues. They come together annually to hear updates about the hospital and stay current on recent innovations and trends in behavioral and mental health research and treatments.

The May 1 meeting fell on the first day of Mental Health Awareness month, and guests were offered green ribbons to show their support and encourage open discourse about mental illness throughout their circles.

The half-day meeting included an update on the state of the hospital by McLean President and Psychiatrist in Chief Scott L. Rauch, MD, and a presentation by Chief Scientific Officer Kerry J. Ressler, MD, PhD, on trauma and how research can advance treatment and prevention. Guests also had the opportunity to participate in small group round-table discussions led by McLean clinicians and researchers.

As Board of Visitors members since 2015, Joe Fiorello and Brian Hyde value the annual meetings as a venue for connecting to others with common goals as well as a chance to learn from the world-class faculty and staff at McLean.

“Brian and I are so happy to have the opportunity to serve on the Board of Visitors,” said Joe. “We’ve met so many wonderful people while knowing we are helping to spread the word about the good work that McLean does to assist individuals and their families to overcome challenges of dealing with mental illness in any form.”

Building and deepening relationships with fellow members is a common theme with attendees, many of whom travel from great distances to attend and have established lasting friendships within the group. ♥
Kimberlyn Leary, PhD, MPA, Executive Director, Center of Excellence in Women’s Mental Health

Dr. Leary joined the McLean faculty as executive director of policy outreach in 2016, and in late 2018, she took on an additional role as executive director of the Center of Excellence in Women’s Mental Health, working closely with Center Chief Shelly F. Greenfield, MD, MPH. This critical externally-facing role is charged with advancing strategic planning, leading policy outreach and developing partnerships locally, nationally and globally.

The Center’s leadership triad, which also includes Amy Gagliardi, MD, as clinical director, oversees McLean’s extensive clinical, research and training programs focused on girls and women as well as a growing effort to engage these issues in the community. We sat down with Leary to talk about the Center, its current goals and its aspirations for the future.

HORIZONS: Why do we need a center focused on the mental health of females?

DR. LEARY: Women’s and girls’ emotional and mental health needs — through the lifespan — have long been overlooked. Women suffer disproportionately from certain conditions and receive inadequate treatment for others. But we have limited understanding of the complex interplay between biological vulnerability and sociocultural and environmental factors — and how they uniquely affect women.

McLean is working to create awareness of these mental health disparities, pursue research to investigate their causes, and establish better standards of care to benefit women and girls worldwide.

HORIZONS: What is the Center’s current focus?

DR. LEARY: We’ve been engaged in a strategic planning process with Harvard’s Community Action Partners over these last eight months, which has helped us define our strategic direction. We are currently evaluating a range of opportunities — from serving as conveners of the public conversation to incubating new programs and collaborations to engaging in deeper research, policy analysis and direct consulting. Our overarching aim is to disseminate evidence-based insights that advance mental health outcomes for women and girls.

HORIZONS: What is the connection between your two roles — heading up policy outreach at McLean and directing the Center of Excellence in Women’s Mental Health?

DR. LEARY: There is a global gap in knowledge about health disparities and social determinants of the mental health of women and girls, yet, no single entity is established as a dedicated “think tank” focused on these issues. Over time, the Center will bring leading voices in policy, practice and research to focus on specific topics addressing the mental health of women and girls. We believe the Center is uniquely positioned to build bridges across different sectors to ensure that the needs of women and girls are understood fully.

My prior work with the Obama Administration focused on improving life outcomes for women and girls of color and has given me the experience of bringing together government, public and not-for-profit leaders to make progress toward a specific set of aims — which is exactly what we need to do in the realm of mental health for women and girls.

HORIZONS: What are McLean’s strengths when it comes to women’s mental health services?

DR. LEARY: As the top-ranked free-standing psychiatric hospital in the country, McLean has a world-class reputation for providing innovative care for mental health conditions for both genders. But unlike other hospitals, many of our clinical services focus specifically on women — women with substance use issues, eating disorders, trauma, borderline personality disorder and more. We also have ongoing research programs that focus on how these illnesses differ in women. So, we have these strengths already in our clinical care, training and research. Now, we want to go from a site where we provide these critical services to a Center that also serves as a convener, a clearing house and a center of engagement around the broader conversation about women’s mental health.

HORIZONS: What sorts of conversations are you hoping the Center will encourage?

DR. LEARY: If you look at the proportion of federal dollars spent on behavioral health, it’s much less than other health spending. And if
you further drill down into the proportion of dollars focused on women's mental health, it’s not well funded at all. So, part of the Center’s role will be to elevate an understanding of the importance of a discrete focus on women’s mental health.

HORIZONS: Why is that important?

DR. LEARY: We know that women experience or are the victims of trauma disproportionately to men, and that trauma is a major risk factor for many severe and chronic mental illnesses. Women are twice as likely as men to suffer from mood disorders. In the substance use realm, women metabolize substances very differently than men. So, if research and treatment protocols are based solely on the male standards, they may not address the unique and specific needs of women. We already know that women fare better with gender-specific treatments for substance and alcohol-related disorders. But there is much we don’t know yet about prevalence, course and outcomes for many other mental illnesses, and McLean’s leadership can help narrow this knowledge gap.

HORIZONS: How did you get into the field of women’s mental health?

DR. LEARY: I have a long-time interest in equity and healthcare — looking at the social determinants of health, for example, how access, or lack of access, to things like safe, affordable housing and healthful food affects your health. I worked with The Office of National Drug Control Policy on initiatives that focused on neonatal abstinence syndrome in the context of the opiate crisis. My work with the White House Council on Women and Girls was focused on helping to develop and direct an initiative to improve health, education and economic outcomes for women and girls of color. As a result, my research and scholarly interests have become ever-more focused on gender and health.

HORIZONS: Anything else you’d like to add about the Center?

DR. LEARY: I’ve talked a lot about the external-facing aspects of the Center, but it also has become a center of gravity within McLean as a whole. We celebrated Women’s History Month this spring with a lively discussion about women, ambition and power, inspired by the TEDWomen’s conference. We also co-sponsored, with Harvard Law School, a documentary screening about Jessica Lenahan, whose husband killed her three daughters. She and the lead lawyer in her case participated in a Q&A afterward. It brought McLean into an important conversation, not only about the impact of trauma, but also about the other public systems that are encountered by those who have experienced trauma.

Internally, we are also training clinicians in the growing evidence base around women’s mental health. We offer a unique one-year clinical psychiatry post-graduate fellowship, which provides training in behavioral and mental health disorders that most impact females. The fellow spends time in each of McLean’s women’s treatment programs and does a rotation in reproductive psychiatry in the women’s health program at Brigham and Women’s Hospital.

Gender-specific research is essential for closing a gap and creating new treatments in a field that conducted research primarily — or only — on men until the mid-1990s. So, we also sponsor pilot research and help mentor young, emerging scientists to pursue new discoveries and acquire the data and skills to successfully compete for federal grants.

Taken together, our efforts are aimed at promoting mental and physical health and well-being for women and girls at every age.
Philanthropy Expands Public Education Effort at McLean

Like other family members of McLean patients, Jim and Doreen Clappin attended a four-week educational program at the hospital while their loved one was in treatment. They learned about her illness, how best to provide support, and ways to employ some of the same coping skills she was learning. “After four weeks, the program is over, but your experience with your loved one isn’t,” explained Jim. He wondered if there was a way to extend that education beyond the four walls of the hospital and over time.

With a gift from the Clappins in 2015, the Borderline Personality Disorder (BPD) Patient and Family Education Initiative was born. The initiative, led by Christopher Palmer, MD, director of Postgraduate and Continuing Education at McLean, and Dawn Sugarman, PhD, was created to support individuals and families affected by borderline personality disorder. The duo worked with colleagues across the hospital to produce educational webinars on an array of topics specific to living with this diagnosis as well as the intersection of BPD with other diagnoses. A hit with families and clinicians alike, the webinars were watched across the country and around the world with a live attendance of nearly 4,000 viewers and more than 60,000 archived views over the three-year pilot period.

Now, with generous support from the Clappin and von Rickenbach families, McLean is expanding those webinars into a more comprehensive education and public awareness platform to create and distribute a huge array of content — via multiple vehicles and channels — about major mental health conditions, including borderline personality disorder, anxiety, bipolar disorder, depression and substance use disorders.

“We're thrilled to be supporting this expanded initiative,” said Jim Clappin. “People have a tendency to avoid talking about mental health because it’s still so stigmatized. The more public outreach a place like McLean can do, the more it will reduce stigma and offer the support families like ours need.”

McLean Trustee and donor Josef von Rickenbach and his wife, Therese, said that their family had a difficult and frustrating time finding the right treatment for a loved one, until they brought him to McLean. “We meandered around the mental health system for a long time, and also had a terrible time trying to educate ourselves about his condition,” said Josef. “We’d like to do what we can to get the word out about mental health and about McLean specifically.”

Expanding McLean’s Reach

While there is an overwhelming quantity of mental health information to be found on the internet, much of it is unreliable and of uneven quality. For this expanded initiative, McLean taps its staff experts to write articles and, when possible, the content is enriched by the patient voice, explained Adriana M. Bobinchock, senior director of public affairs and co-leader of the public education initiative. For example, McLean’s new twice-monthly podcast, Mindful Things, is hosted by filmmaker and former McLean patient Trevor Chamberlain, who lives with borderline personality disorder and works as a digital media specialist at the hospital.

“Trevor speaks candidly about his own ups and downs and injects his own experiences when he talks to guests,” said Bobinchock. “We are trying to weave in the lived experience of patients and families. Our approach is a little more forward-thinking than most of what’s currently out there. We also want to interest a younger and more diverse audience that might not be familiar with McLean.”

In addition to offering substantial written content and the podcast, the McLean team is developing short- and longer-form videos, webinars, and an expansion of McLean’s Deconstructing Stigma campaign, which features larger-than-life photographs of people affected by mental illness accompanied by narratives in their own voices. McLean also is
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Jim Clappin, McLean National Council Member

working with several clinical partners to develop courses targeting professionals and laypeople who want to go a little deeper into specific topic areas. The first one will be about borderline personality disorder. All of the educational content will be available on McLean’s website.

Reaching Diverse Audiences

For years, McLean has sent its clinical experts into schools to educate teachers and administrators on various mental health topics. Now, the hospital is broadening its reach to include other types of professionals, starting with a recently developed partnership with the Maine Department of Corrections. “There are a great deal of mental health concerns within the corrections population, so we want to help staff better understand their own challenges around stress management and managing post-traumatic stress disorder,” said Scott J. O’Brien, director of digital strategy for McLean and co-director of the public education initiative. “We’re developing a curriculum that we hope to make available to prison staff nationally. Knowing that the majority of offenders have experienced trauma early in life, we’re also working to create self-help resources for offenders to encourage them to seek help and hopefully make some positive changes in their lives.” The Deconstructing Stigma exhibit will also be displayed in Maine prisons, as well as in various locations in cities across the United States and around the world, including Ecuador and India.

“People are hungry for this information,” continued Bobinchock. “The support we’ve received from the Clapps and von Rickenbachs has enabled us to take our public education efforts to a whole new level.”

For information on supporting this initiative, contact Elizabeth Fieux at efieux@partners.org or 617-855-3453.
The Best Friend a Little Boy Could Have

Tuck Crocker has had a lifetime of unusual connections with McLean. For instance, Director Emeritus Francis de Marneffe used to be his next-door neighbor in New Hampshire, and a distant relative serves as an Honorary Trustee of the hospital. But the most significant — and personal — connection is with the boy he met on the first day of third grade at a private school in the Boston area.

“Jonathan was my best friend,” explained Tuck. “He was the absolute best kind of friend to have. He was fun, athletic and game for anything. We were inseparable for several years.”

When Jonathan Brooking took his own life in 1985 after a long battle with mental illness, Tuck was devastated. He heard about the fund to support mental health research established in his friend’s name from Jonathan’s sister Liz. “The Brookings are wonderful people. Of course, I wanted to contribute to Jonathan’s legacy. For me, making regular monthly gifts allows me to give more than I could otherwise. I’m supporting something important, and I’m remembering a friend who was such an important part of my childhood.”

Today, Tuck is a member of the McLean Board of Visitors and often makes the trip from his home in New Hampshire to Belmont to stay informed and connected to McLean.

BECOME A McLEAN SUSTAINER
To set up your recurring gift, contact Ben Ogilvy at bogilvy@partners.org or 617-855-3623.