



seaver autism center for research & treatment @ mount sinai

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INTRODUCING THE SEAVER ELS INSTITUTE

In April, the Els for Autism Foundation joined forces with the Seaver Autism Center for Research and Treatment to create the Seaver Els Institute. The Els Center for Excellence, founded by PGA Tour golfer Ernie Els, Liezl Els and Marvin Shanken, will house the new research facility in Jupiter, Florida. Faculty members Silvia De Rubeis, PhD, Jennifer Foss-Feig, PhD, and Paige Siper, PhD will lead the project for the Seaver Center.

The Els Center of Excellence is dedicated to helping people on the autism spectrum fulfill their potential to lead positive, productive and rewarding lives. The Seaver Els Institute is scheduled to begin operations in August, and the primary goal of the partnership

is to provide the opportunity for students, clients and families to participate in research that will help advance the understanding of autism.

The collaboration will start with a two-year pilot study to gather and analyze data. The initial focus of the research will be large-scale genetic and phenotypic data collection, evaluation of intervention effectiveness, and the promotion of research at The Els Center of Excellence and the broader



(from left to right) Els for Autism Team members Ernie Els, Marlene Sotelo, Marvin Shanken and Liesl Els along with Joseph D. Buxbaum, PhD, Director of the Seaver Autism Center, and Kenneth Davis, MD, Mount Sinai Health System President and CEO

Florida community. This will include both genetic and behavioral testing as well as measurement of biological and behavioral markers using non-invasive tools. The facilitation of research at the new Institute will be coordinated by clinical research coordinator, Audrey Rouhandeh, who was hired by the Seaver Autism Center. The research data gathered in Jupiter, with advanced EEG and eye tracking equipment, will be analyzed in New York at the Seaver Center.

The Els Center of Excellence is a world-class facility that hosts game-changing programs and services

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Mount Sinai Health System President and CEO Kenneth Davis, MD signs the affiliation agreement, officially forming the Seaver Els Institute.

PHELAN-MCDERMID SYNDROME CLINICAL TRIALS

The Seaver Autism Center began patient enrollment in a new interventional study of an investigational therapy for the treatment of epilepsy associated with Phelan-McDerimid syndrome this spring. The investigational therapy, called AMO-01, is made by AMO Pharma, a biopharmaceutical company incorporated in February of 2015, that is working to identify and advance promising therapies for the treatment of serious and debilitating

diseases in patient populations with significant areas of unmet need, including rare, debilitating childhood onset neurogenetic disorders with limited or no treatment options.

“Collaborating with AMO Pharma is an important milestone, since it’s imperative for academia and industry to partner in recognizing the importance of this syndrome and its relevance to neurodevelopmental disorders more broadly. Targeting

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INTRODUCING THE SEAVER ELS INSTITUTE *Continued*

accessible to families and caregivers around the world. The 26-acre campus provides on-site education for up to 300 students with additional programs in six focus areas: adult services, education, global outreach, recreation, research, and therapy. Through the new strategic partnership with the Seaver Autism Center, the Els Autism Foundation is advancing and elevating its research focus area.

READ THE FULL PRESS RELEASE HERE:

<http://bit.ly/SeaverElsInstitute>

PHELAN-MCDERMID SYNDROME CLINICAL TRIALS *Continued*

epilepsy within Phelan-McDermid syndrome also presents a new opportunity for hope for people affected by this devastating condition” said Alexander Kolevzon, MD, Professor of Psychiatry and Pediatrics at the Icahn School of Medicine at Mount Sinai, Clinical Director of the Seaver Autism Center, and Principal Investigator of the study.

Phelan-McDermid syndrome is a rare genetic condition caused by deletion or mutation of the SHANK3 gene on chromosome 22 resulting in a wide range of medical, intellectual, and behavioral challenges. The majority of patients with the syndrome also meet the criteria for autism. Many patients with the syndrome also experience debilitating seizures, which are sometimes resistant to traditional anti-seizure medications. Although there are available treatments to help manage and mitigate the symptoms, there is currently no cure or treatment specific to the syndrome. SHANK3 deletions or mutations are thought to account for up to one percent of autism cases.

The safety and potential efficacy of an infusion of AMO-01, an inhibitor of the Ras-ERK pathway, will be examined in subjects with Phelan-McDermid syndrome aged 12 to 45 years who have epilepsy.

To learn more about this and other research studies happening at the Seaver Autism Center, please call 212-241-0961.



Researcher Hala Harony-Nicolas, PhD

INTRODUCING NEW FACULTY AND STAFF

CHRISTINA GUSTAVSSON MAHJANI, R.N, MSN



Christina Gustavsson Mahjani, R.N, MSN, joined the Seaver Center in March 2018 as a Clinical Research Coordinator. She was formally a Psychiatric Clinical Nurse Specialist at Akademiska sjukhuset in Sweden, where she, for the past 6 years, had been working at a forensic psychiatric care unit for rehabilitation of mentally disordered offenders. Prior to that she worked as a registered nurse at Sahlgrenska Universitetssjukhuset in an adult psychiatric inpatient unit and at a Psychiatric Emergency Department. As a Clinical Research Coordinator she is working on our studies in Sweden, which include autism and comorbid diagnoses such as intellectual disability and OCD.

MAUREEN MULHERN, MS, CGC



Maureen Mulhern, MS, joined the Seaver Center in March 2018 as a senior genetic counselor. She received her Master's degree in Genetic Counseling here at Mount Sinai. Prior to coming to the Seaver Center, she worked as a research genetic counselor at the Institute for Genomic Medicine at Columbia University Medical Center, focusing on the genetics of epilepsy. Before becoming a genetic counselor, Maureen worked as a middle and high school science teacher. At the Seaver Center, Maureen manages clinical genetic services for the Center's research participants, works closely with the rare genetic disorder program leads and has an active role in the Autism Sequencing Consortium.

AYESHA FAISAL



Ayesha Faisal, BS, recently graduated from the Pennsylvania State University with a Bachelor's of Science in Health Policy and Administration and a minor in Information Sciences Technology in Health. She joined the Seaver Center as an Administrative Intern, where she assists in the day to day operations, develops content for marketing, public relations and social media and provides support to the Administrative Director. She hopes to cultivate new skills, foster knowledge and gain experience in order to continue to grow in the field of healthcare administration.

BLOGS AND FACEBOOK LIVE

In order to increase awareness about important research on autism and related disorders, the Seaver Autism Center is hosting Facebook live segments on various research and treatment topics related to ASD, such as:

- **RARE DISORDERS** (2/28/18)

WATCH HERE: <http://tiny.cc/dn4juy>

- **DIAGNOSIS AND TREATMENT** (4/10/18)

WATCH HERE: <http://tiny.cc/9n4juy>

- **CELL AND ANIMAL MODELS** (6/5/18)

WATCH HERE: <http://tiny.cc/6r3juy>

UPCOMING

- **BIOMARKERS** (8/7/18)

- **ENVIRONMENT IN AUTISM** (10/16/18)

TJASA VELIKONJA, PHD



Tjasa Velikonja, PhD, joined the Seaver Center in October 2017 as a postdoctoral fellow. She was formerly a postdoctoral fellow at the Institute of Psychiatry, Psychology and Neuroscience (King's College) in London. Her research is focused on childhood trauma, schizotypy and psychosis as well psychological (and biological) underpinnings of the trauma-psychosis association. In addition, she will be investigating the etiological link between autism

and schizophrenia.

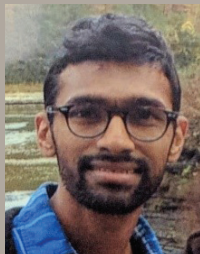
AUDREY ROUHANDEH



Audrey Rouhandeh, BA, joined the Seaver Center in March 2018 as a Clinical Research Coordinator. She graduated from Georgetown University in May 2017 with a degree in psychology and worked as an intern at the Center before joining full-time. Audrey will facilitate research at the new Seaver Els Institute at the Els Center of Excellence in Jupiter, FL. Her role will involve large-scale genetic and phenotypic data collection and the application of EEG and

eye tracking to measure biological markers in the context of ongoing manualized interventions at the Els Center.

KEERTHI RAJMANI, PHD



Dr. Rajamani joined the Seaver Autism Center in the lab of Dr. Hala Harony-Nicolas in March 2018 as a postdoctoral fellow. He previously worked as a postdoctoral fellow at the Van Andel Research Institute in Grand Rapids, Michigan. The research Dr. Rajamani will be focused on studies the neurocircuitry underlying social behaviors with a particular emphasis on the oxytocin system. The overall goal is to identify and understand mechanisms

associated with the oxytocin system in animal models of autism.

JESSICA ZWEIFACH, PHD



Jessica Zweifach, PhD, returned to the Seaver Autism Center in February 2018 as a postdoctoral fellow, after working at Seaver as a psychology extern and a clinical research coordinator. Dr. Zweifach, was a Clinical Psychology Intern at NYU-Bellevue and received her graduate degree from the Ferkauf Graduate School of Psychology. Her work at the Seaver Center consists of administering and interpreting diagnostic, cognitive, adaptive, neuropsychological, and other standardized

clinical assessments as part of the ongoing research projects.

Spring Cultivation Event Recap

Associates Board members Jamie and Genie Egerton-Warburton, along with Genie's parents Donald and Genie Rice, hosted a wonderful cultivation event on May 15th at the Cosmopolitan Club in Manhattan. We had a wonderful turnout of Seaver Center supporters and friends who enjoyed lively and informative discussion about the Center's ongoing work and future initiatives. Thank you to all those who attended!

If you are interested in attending events like this in the future, please contact Lynn Hendrickson, Administrative Director at lynn.hendrickson@mssm.edu.

AUTISM AWARENESS MONTH

April was Autism Awareness Month and the Seaver Center celebrated by holding our annual Family Appreciation Day on April 22. In addition, we hosted information tables at Mount Sinai, attended the Autism Science Foundation conference, hosted a Facebook Live to discuss autism diagnosis and treatment, and more.

Annual Family Appreciation Day

This year the Seaver Autism Center celebrated its second Annual Family Appreciation Day. This special event, held during Autism

Awareness month gave us a chance to thank the amazing families and children who are current or past participants in our research studies. The day consisted of performances by magician JP Laramie and the Little Maestros musical group, as well as, face painting, arts and crafts, and cookie decorating. The fun-filled day allowed the Seaver team to interact with families outside of our research setting and also



gave families a chance to intermingle with one another in a casual environment. Thank you to all the families that attended this year!



ASF Day of Learning

On April 11, the Autism Science Foundation hosted its 5th Annual Day of Learning at the New York Athletic Club in Manhattan. The day included several TED-style talks by prominent members of the research community on important topics, including sex differences, diet, and how to improve outcomes for adults with ASD. Members of the Seaver Center attended to learn more about these important advances in the field.



Seaver Center team members Michael Breen, PhD and Lynn Hendrickson, MBA



Seaver Center faculty member Jennifer Foss-Feig, PhD



**Mount
Sinai**

*Seaver Autism
Center for Research
and Treatment*

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- SEAVER IS CONTINUING TO GO GREEN! Please send your email address to seavercentereditor@mssm.edu to receive this newsletter electronically.



SAVE THE DATE
THURSDAY, OCTOBER 4, 2018

**22ND ANNUAL
Seaver Autism
Center
Advances in
Autism
Conference**

PRESENTED BY
The Seaver Autism Center for
Research and Treatment

LOCATION
New York Academy of Medicine
1216 Fifth Avenue
New York, NY 10029

COURSE DIRECTOR
Joseph D. Buxbaum, PhD



SAVE THE DATE
25th Anniversary Luncheon

**A benefit for the
Seaver Autism Center for Research and Treatment**

*Honoring
The Beatrice & Samuel A. Seaver Foundation trustees
John Cohen & Hirschell Levine*

Thursday, November 1, 2018
Noon to 2:00

The Roosevelt Hotel
45 East 45th Street
New York, NY