



Living Well at Every Stage of Life

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Michele DeMeo, CRCST, CSPDT, is a self-described “high-functioning autistic international healthcare expert.” She is internationally recognized for her work in the medical services field of Central Sterile Supply, and she is an expert in all aspects of sterile processing of medical instruments. She has had an illustrious career, including writing standards for sterile processing, sitting on an FDA panel, and publishing over 200 articles. Michele was diagnosed with ASD at the Seaver Autism Center approximately 10 years ago. In addition to participating in several adult research studies, Michele continuously

provided clinicians at the Center with valuable insight into the trials and triumphs of living with Asperger’s through her writings and artwork. Sadly, Michele was diagnosed with amyotrophic lateral sclerosis (ALS) in 2010. She has confronted this diagnosis with the same strength, optimism, and dedication that she has used to



“This picture is meant to abstractly show that through difficulty, with determination, peace can be found...you just have to keep moving forward.” – Michele

approach all the challenges presented to her in life, and she has even written a book. It is about finding peace and living well at every stage of life, and it is entitled *The Beauty of a Slow Death: Understanding Acceptance and Learning to Live Differently Can Lead to Peace* (Volume 1). In

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News and Events

► UNLOCKING THE MYSTERY OF AUTISM: FROM GENES TO NOVEL THERAPEUTICS

Earlier this summer, the Seaver Autism Center hosted a panel with experts Drs. Joseph Buxbaum (second from left), Director; Alex Kolevzon (second from right), Clinical Director; and Latha Soorya (right), formerly Chief Psychologist and currently Adjunct Professor at the Center, and Assistant Professor of Psychiatry at Rush Medical Center. The panel was moderated by Alison Singer (left), President of Autism Science Foundation, and it included an extensive discussion about the best ways to move forward in the field of autism research and treatment.



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addition to writing, Michele also enjoys painting as a way to express her thoughts. Her painting, "The Canvas" (see photo), will be on display at the Center during March 2013 while it travels to 12 sites around the world in its yearlong journey.

The following is an excerpt from an interview between the Seaver Autism Center (SAC) and Michele DeMeo (MD).

SAC: What was your experience in becoming diagnosed with ASD, and how did that affect you/your career, etc.?

MD: After years of being given an ambivalent label as "just odd," receiving a diagnosis was freeing, in a sense. Once I was diagnosed with ASD, I began an internal process of logically organizing what really did separate me from others, then tried to leverage my strengths in context of my work goals so much so that my weaknesses were overshadowed. The diagnosis put to ease my personal frustrations of why I was different, enough so that it freed me to be okay with why I loved my focus and my profession so much.

SAC: How did you become interested in the healthcare field, specifically sterile processing?

MD: It was a calculated decision. I knew I had little education or money and was on my own at a young age. I asked myself, "What could I do that will never go out of business?" What popped up into my mind was something in a hospital or the healthcare field. After some research, I came to sterile processing. It was perfect: technical, detail-oriented, less people interaction (or so I thought) as a technician and I could wear a pair of scrubs (I hated worrying about what to wear...I have always had a sort of "uniform" style and preferences anyway).

SAC: How did you get into writing? What made you want to start?

MD: I had always wanted to write, but had so little education so I did not pursue it. My publications were initially prompted by others who requested them from me. I have recently finished *The Beauty of a Slow Death*, which is my sole book that has been published. Currently I have three others in the works. I feel that writing is a means to reach more people and hopefully effect some positive change in my field.

SAC: How were you able to accept your ALS diagnosis and move on to write a book?

MD: I stepped back from the situation and decided that sick-

ness requires action, and action requires determination, information and even drive. The book was simply something I thought would serve some purpose. It would allow me to may-

be help others, create my own new purpose in the world I am still a part of, give me something to do...

SAC: What do you think are concrete ways that society can help people become more comfortable with discussing death and dying earlier in life?

MD: Talk about it earlier in age appropriate ways. Explain to children that pets die, and so do plants, projects, etc. These are things in life that are just natural. Avoiding the topic until the day a significant loss occurs may cause children or even adults to be emotionally

harmful as they haven't adequately learned meaningful coping methods to deal with change...not just death.

SAC: How long have you been painting?

MD: Since I was two...before I ever spoke. I identify myself as an artist even though the healthcare world sees me as a Sterile Processing/Distribution tech expert.

SAC: What inspired you to start painting?

MD: I realized as a small child that the images in my head were in greater detail and meaning than words I could ever utter. In school I doodled all day long until 8th grade. I communicated by way of my hands. My "feelings" were not really traditional feelings, but rather a continuous stream of plans, ideas, inventions, problem solutions. My right hand did what my voice could never keep up with. Silence is natural when a room is laden in perceived chaos...too loud, colorful, too busy. Drawing or painting kept me in my natural preferred state - oblivious of what was around me. My painting told my thoughts, at least I understood them.

SAC: I know that you have completed a painting that you would like displayed in several places. What was the inspiration for this painting, and what is your goal?

MD: Determination and passion...that out of darkness, there is lightness, hope and improvement is possible. You just need to move...look ahead or in another direction...but then move. Put action behind the inner thought of "What if..."

If you would like to purchase *The Beauty of a Slow Death : Understanding Acceptance and Learning to Live Differently Can Lead to Peace (Volume 1)*, please visit <http://tiny.cc/micheledemeo>.

► NEW DISTINGUISHED LECTURER SERIES

Dr. Joseph Buxbaum (left), Director of the Seaver Autism Center, and **Dr. Tobias M. Boeckers** (right), Director of the Institute of Anatomy and Cell Biology at Ulm University, Germany, after Dr. Boeckers' presentation. Dr. Boeckers was the first speaker in the Seaver Distinguished Lecturer Series, a unique new series where the researcher gives one lecture specifically for professionals and one specifically for parents, friends, and family. Dr. Boeckers presented on anatomy and cell biology in autism spectrum disorders. Keep an eye out for future lecture announcements!



► NEW RESEARCH STUDY: SENSORY PERCEPTION IN CHILDREN WITH AND WITHOUT AUTISM

The purpose of this study is to explore sensory perception in children from 4-17 years of age. The information collected from the study will help to increase knowledge about sensory issues in children with and without clinical conditions, such as autism spectrum disorders and Sensory Processing Disorder (e.g., over-sensitivity and under-sensitivity to touch). We will explore children's responses to sensory stimuli, such as lights, sounds and touch. Children will be observed as they are exposed to various harmless stimuli while the parent completes questionnaires. If you would like to learn more about this study, please call the Seaver Autism Center at 212-241-0961.



► INTERNATIONAL CONFERENCE AWARD

At the recent 2012 Phelan-McDermid Syndrome Foundation International Family Conference and Scientific Symposium, Dr. Hala Harony-Nicolas, Seaver Postdoctoral Fellow, won the award for best poster presentation: "A novel Shank3-deficient rat model to understand the neural basis of autism" (Hala Harony-Nicolas, Ozlem Bozdagi Gunal, Joseph D. Buxbaum).

Stefanie Miles, Miss New York Intercontinental 2012, as an advocate for individuals with autism spectrum disorders. Leah Iannacone (left), Administrative Assistant, and Jessica Brownfeld (right), Communications and Marketing Associate at the Seaver Autism Center, with Miss New York at the annual Walk Now for Autism Speaks event on June 3, 2012.



Seaver Center Athletes

THANK YOU TO ALL WHO SUPPORTED THE SEAVER AUTISM CENTER TEAM AND TEAM DRIVE4REBECCA IN THE NEW YORK CITY TRIATHLON THIS SUMMER! The money raised by the Seaver Autism Center's Team is being used to support active research at the Center.



seaver autism center

for Research & Treatment at Mount Sinai

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



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SPECIAL GUEST SPEAKER:

SIMON BARON-COHEN, PHD
*Director of the Autism Research Centre
at the University of Cambridge*

**DISTINGUISHED SCIENTIFIC
SPEAKERS:**

JOSEPH BUXBAUM, PHD
WALTER KAUFMANN, MD
TIMOTHY ROBERTS, PHD

COURSE DIRECTOR:

JOSEPH BUXBAUM, PHD

REGISTER NOW at www.seaverconference.eventbrite.com

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