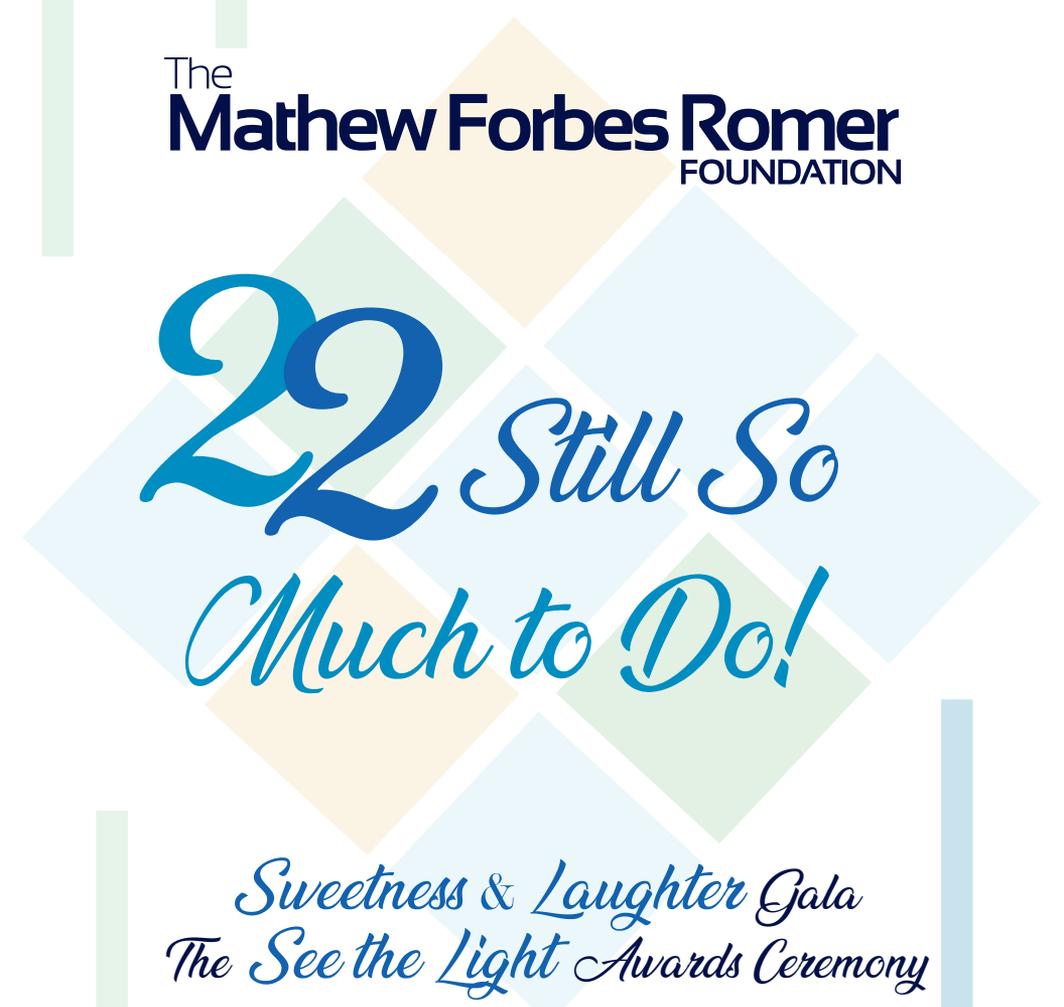
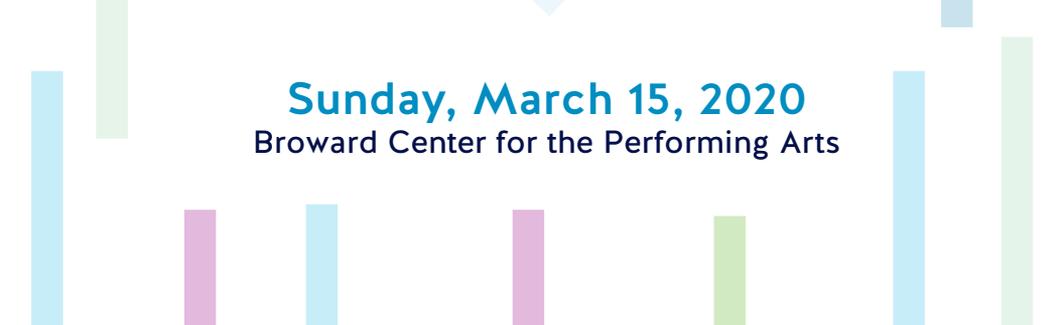


The
Mathew Forbes Romer
FOUNDATION



22 *Still So
Much to Do!*

*Sweetness & Laughter Gala
The See the Light Awards Ceremony*



Sunday, March 15, 2020
Broward Center for the Performing Arts



THE MATHEW FORBES ROMER FOUNDATION

The Mathew Forbes Romer Foundation (MFRF), founded in 1998, was inspired by the strength of a little boy with Tay-Sachs Disease and so many other children and families that have shared this battle.

MFRF has celebrated wonderful progress in gene therapy patient trials, education, and genetic testing for many affected children and families with fatal genetic diseases of the brain. Still there is so much more to do including earlier detection and expanding treatment availability.

MFRF has provided leadership and raised over \$2.2 million of funding for projects spanning its mission and vision across three pillars: Research of Treatments and Cures, Education and Genetic Screening, and care through Nursing School Educational programs.

Research:

- Conceptualized and grew the National Research Initiative with NTSAD to 64 projects, and over \$4 million in grants leading to many promising therapies. This has generated over \$20 million in funding from the NIH and similar institutions
- Supporting the University of Florida Powell Gene Therapy Center to help develop Gene Therapies for fatal genetic diseases of the brain
- Helped establish the Tay-Sachs Gene Therapy Consortium reinforcing pre-clinical and extraordinary efforts toward clinical trials
- Sponsors the Medical and Scientific Sessions at the annual NTSAD Family Conferences showcasing progress and opportunities

Screening:

- Hosted 23 South Florida Genetic Testing and Education Fairs
- Screened over 1,600 potential parents with as high as 50 percent detection, with JScreen and many other partners
- Programs range from prevention to now identifying opportunities for early intervention

Nursing:

- Funded more than 40 nursing scholarships with Florida Atlantic University, Florida International University, and Nova Southeastern University
- Helped conceive and implement nursing school training programs
 - ◇ Classroom-based from caring to treating
 - ◇ Lab simulation of in-home/community based family care

See the *Light* AWARD HONOREES



Barry Byrne, M.D. , Ph.D

Director of the University of Florida Powell Gene Therapy Center and Child Health Research Institute, Earl and Christy Powell University Chair in Genetics, and Associate Chair of Pediatrics.

Dr. Barry Byrne has been a true pioneer of AAV Gene Therapy vectors since the 1990s and is now accelerating the center's focus on genetic diseases of the brain. The work is also supported by several National Institutes of Health and foundation awards. Byrne serves as the chief medical adviser of the Muscular Dystrophy Association. He is an adviser to the Pfizer Rare Disease Therapeutic Area Advisory Committee and co-founder of AavantiBio.

Dr. Byrne, has set a goal to save Jordan by rapidly developing a new gene therapy. He and his group have had important progress with Pompe, Canavan, and GM-1 diseases while also providing clinical care for patients in Florida that are detected with fatal genetic diseases through newborn screening.

He earned his M.D. and Ph.D. from the University of Illinois.



Oralea Marquardt, M.S.W.

Member of the MFRF Advisory Board, and Vice President of National Tay-Sachs and Allied Diseases Board of Directors.

In 2014, the Marquardt family was selected to participate in the MFRF Nursing Pilot Program because of the tremendous in-home care she provided William and his unaffected sister, Kyla. Tragically, William lost his eight-year fight to GM-1 Disease just days before the program's start.

William inspired his mother to play an integral part in the MFRF's nursing educational program. She leads classes on children's and family care needs across multiple college campuses at the Nova Southeastern University Ron and Kathy Assaf College of Nursing and helps to design community based simulation training programs with NSU and Florida Atlantic University.

In parallel, she completed a master's degree at Walden University to become a Youth and Family Grief Counselor for families dealing with fatal genetic diseases at Treasure Coast Hospice.

MEET OUR FEATURED GOLD SPONSORS

Thank You

FOR YOUR CONTINUED SUPPORT

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Sheila, Dave, and Sherry Gold Foundation

Joan and Mike Siegel

Our Special Stories

The Ogman Family...our Special Guests



Boca Raton couple David and Stacey Ogman recently faced terrible news. Their 4-year-old son Jordan was diagnosed with TECPR2, a fatal genetic disease of the brain that causes rapidly progressive sleep apnea leading to death possibly within a year.

Shortly after receiving the diagnosis, the Ogmans were introduced to The Mathew Forbes Romer Foundation. The Ogmans' meeting transported the Romers back 25 years to when they received Mathew's fatal Tay-Sachs diagnosis where there was no hope for a treatment or cure. By leveraging the MFRF supported research, especially with Gene Therapy, there is new hope.

The Ogmans' urgent quest to find a potential treatment for Jordan led them to the University of Florida and the Powell Gene Therapy Center. Together they are working tirelessly to develop a new gene therapy and to raise money to accelerate it.

We Remember a Very Special Founding Leader of MFRF



Carl Meyers, Mathew Romer's maternal grandfather, the MFRF Vice President of Growth and Development, and a founding member of our Board of Directors, passed away on February 8, 2020.

Since the inception of our Foundation, Carl has been a leader in our strong growth. One of his greatest vision and accomplishments was establishing the College of Nursing Scholarship Programs with Florida Atlantic University and Nova Southeastern University. These programs have led to funding more than 40 nursing scholarships with FAU, FIU and NSU and created school training programs, including simulations demonstrating in-home family care.

He applied his extensive professional experience and skills to promote MFRF to its vast network of supporters. For over 60 years in the Sports and Entertainment industry, his accomplishments included creating the National Hockey League Monday Night game of the week, working with the Madison Square Garden Network Giants Journal as the Executive Producer, and promoting and growing the Miss America Pageant and American Black Achievement Awards.

MEET OUR VIP SPONSORS

Thank You

FOR YOUR CONTINUED SUPPORT

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Drs. Lorrie and Lloyd Berkowitz

Monica and Gary Gettleman

Johnson Controls Security Products

Aimee and Rabbi Dan Levin

Katherine and Ken Overby

Christa and Argy Petros

Carole Romer



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Thank You

FOR YOUR ONGOING SUPPORT

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