FALL 2020

# DYS/COURSE

NEWS FROM THE FAMILIAL DYSAUTONOMIA FOUNDATION

## HOME VISIT KITS NOW AVAILABLE FOR VIRTUAL CHECK-UPS

## MEET PATRICIO MILLAR, MD

## SCIENTIFIC ADVISORY BOARD DEVELOPING PROMISING NEW TREATMENTS

## SAVE THE DATE: "UNIFIED" VIRTUAL BENEFIT CONCERT ON DECEMBER 6

FAMILIAL
DYSAUTONOMIA
FOUNDATION, INC

The FD newsletter was endowed with a gift in memory of Elaine Jamie Lipson, whose love of life will remain forever in our hearts.

# MESSAGE FROM THE PRESIDENT AND EXECUTIVE DIRECTOR

This is our second (and hopefully last) newsletter written from social isolation. We are sure that each one of you is longing for a return to normalcy as much as we are. Unfortunately, "normal" does not appear to be in the cards for the foreseeable future. So in the meantime, we are all learning to make the best of the situation. We are sure that you've all become experts in Zoom meetings, binged every Netflix series, and perfected your sourdough starter (or not). At the FD Foundation, we are trying to focus not on the "clouds," but rather on the "silver linings" of the pandemic:

**Cloud**: We were unable to gather together for the 35th Annual FD Day at NYU Langone this year.

**Silver Lining**: We created a virtual event that enabled us to include triple the number of people, compared to last year, with more than 250 households joining from 9 countries and 25 states (read more on page 4).

**Cloud**: Many people cannot travel to NYU for annual check-ups.

**Silver Lining**: The Center's Pandemic Task Force created a Virtual Check-up Kit, and the Foundation funded the necessary equipment. Now, even people who were never able to travel to New York can be seen virtually by the medical team at the Dysautonomia Center, receive expert care and participate in the Natural History Study (learn more on page 5).

**Cloud**: Many people with FD are unable to see their friends in person.

**Silver Lining**: While certainly not the same as getting together in person, the Foundation has organized weekly Zoom "Hang-Outs" for people with FD from all over the world to gather virtually with old friends, make new ones, talk about current events and other topics of interest (more information on page 9).

Separate from the coronavirus pandemic, our community has suffered a number of losses since the last issue of the newsletter, including **Judy Fettman Dreyfuss**, **Joshua Field**, **Elliot Goldberg** and **Mitchell Joseph**. Together we mourn the loss of each one of them and send love and support to their families (please turn to page 7 to view tributes).

In news from the Treatment Center at NYU, we say farewell to **Dr. Alberto Palma**, after eight years at the Center, and wish him success in his new position at Novartis Gene Therapies. Please join us in welcoming **Dr. Patricio Millar**, last year's Autonomic Fellow, in his new role providing hands on patient care. Meet Dr. Millar in his interview on page 5.

And lastly, we depend on everyone's support and participation to be able to continue our important work, so we encourage you to join us for the following initiatives and events planned for the remainder of the year:

**Giving Tuesday**, an international day of charitable giving, on **December 1**.

**Champions for Charity** www.famdys.org/champions2020, a holiday shopping benefit hosted by Americana Manhasset, **December 3-5**.

**UNIFIED** www.famdys.org/unified, a virtual festival featuring popular Jewish and Israeli music to benefit FD, on **December 6**.

And watch for our **2021 FD Journal Mailing**, coming soon to your mailbox and your inbox.

Together we will continue to support the lives of people with FD in every way possible, as we have since 1951.

Wishing you a Happy Thanksgiving, a Happy Hanukkah and all good things in 2021!

Faye Ginsburg Lanie Etkind

Faye Ginsburg Lanie Etkind

## FD Foundation Board of Directors

## Staff

# WE ARE KVELLING!

## Congratulations to those in our FD community who have shared wonderful news and milestones with us:

**Rebecca Newman** graduated magna cum laude from Pace University as a Communications Major. She “walked” with her class virtually May 20 and will officially finish her studies in December.

**Keshi Taryan-Kigel** participated in a virtual production of Shakespeare’s Twelfth Night this past summer. Keshi contributed her personal artwork as well as her acting talents as the priest/servant. To view the performance, go to: youtu.be/qTlsHJpKpxQ

**Alberto Palma, MD** has been with the Dysautonomia Center for eight years, most recently as Assistant Director. Beginning October 1, Dr. Palma joined Novartis Gene Therapies. We wish Dr. Palma well in his new position, where he will have the opportunity to learn about gene therapy and become familiar with the drug development process. Dr. Palma plans to remain affiliated as a part-time faculty at NYU in order to continue collaborating on some ongoing research projects at the Center.

**Susan A. Slaugenhaupt, PhD**, a member of the Foundation’s Scientific Advisory Board who discovered the FD gene (among other things), is the inaugural Elizabeth G. Riley and Daniel E. Smith, Jr. Endowed Mass General Research Institute Chair. This award fosters and accelerates scientific knowledge and discovery at Mass General. To learn more, go to www.massgeneral.org/research/support/mgh-research-institute-chairs

**Dr. Gail E. Sonenshein, PhD**, a member of the FD Scientific Advisory Board, and Professor in the Department of Developmental, Molecular, and Chemical Biology at Tufts University School of Medicine (TUSM), was awarded the Zucker Research Prize, given annually to a woman scientist on the TUSM faculty for outstanding career achievements in research. To learn more about Dr. Sonenshein’s pioneering discoveries in cancer biology and women’s health, go to medicine.tufts.edu/news/2020/08/2020-recipients-zucker-research-prizes

**Steve** and **Judy Fass** recently celebrated their 50th wedding anniversary. Mazel tov!

**Samantha Myers** was featured in The Hope Scenarios, a nine-part web series about rare diseases and the need for natural history studies to better understand them. The videos feature FD as one of their cases and are produced and moderated by Louise Tiranoff, Director of GeneticaLens. The videos will be released soon, and are intended to educate the public as well as the medical community about what it means to live with a rare disease.

**Dr. Felicia Axelrod** wrote a children’s book called, “*Why Won’t Willy Fly?*” The book comes out this fall; Dr. Axelrod plans to donate royalties from book sales to the FD Foundation

**Maria Cotrina Vidal**, who manages the Natural History Study at the Dysautonomia Center, became a naturalized citizen on June 20, 2020.

**Do you have some exciting news to share? Simchas such as weddings, special birthdays or anniversaries, graduations, bar mitzvahs, new jobs, or awards received? Please email us at info@famdys.org so that we may include your news in our next KVELLING section!**

## Host a Facebook Fundraiser to Benefit FD

If you’re celebrating a birthday, anniversary or wedding, ask loved ones who would normally give you presents to make a donation to FD in your name instead, or set up a campaign yourself on Facebook to collect donations. Whether you are tech savvy or new to Facebook, we are happy to help you set this up! Contact Natasha at the FD Foundation at nweinstein@famdys.org for more details.

# THE “JACK ATTACK” FANTASY FOOTBALL LEAGUE

Jack “Attack” Posnack is interviewed by ESPN’s Matthew Berry

Throughout the pandemic, **Jack Posnack**, a 14-year-old boy from New City, New York, who was born with FD, has been quarantining by himself in his family’s pool house to keep safe, with only his mother and nurses coming to visit him. He hasn’t been able to be with his brothers and sister and only sees his friends virtually on screens.

With a gamut of respiratory, cardiovascular, orthopedic and digestive issues, he has not let these limitations deter him in the past from doing many things other teenage boys do. He goes to school when he can. He had a bar mitzvah. Balance can sometimes be a challenge for him and he tires quickly, but to the extent he can, Jack plays sports, joining his younger brother’s basketball and flag football teams. He watches his beloved New York Giants football team. He does everything and anything he can, going at it with gusto.

Referred to as “Jack Attack” by those lucky enough to know him, he always has a megawatt smile. Upbeat and full of life, Jack has an infectious spirit and a personality that quickly turns strangers into friends, be it in person or online playing video games, because Jack sure does love those video games.

This past summer, he gathered a bunch of friends from the area for the first draft of the Jack Attack Fantasy Football League. With cheat sheets in front of them, they drafted players for a standard 10-team ESPN league. It’s just a normal, typical league, which is precisely what Jack loved about it. The league used to meet on Sundays at a local restaurant to watch the games or sometimes go to Jack’s house. There were moves and trades and Jack was just another player, sweating his weekly flex spot, just like the rest of his friends. And throughout it all, you could see Jack’s famous smile from miles away.

Jack started his second annual fantasy football league, Zoomed from his pool house, as a way to see his friends and keep up with his favorite pastime. In August, he was featured with Matthew Berry on ESPN Fantasy Focus Football, discussing his picks while full of smiles. According to Jack’s mom Robin, “The beauty of fantasy football is that it levels the playing field for every single one of us. Jack is just a regular kid and he loves that.”

**To watch JackAttack in action, click on the attached video and go to 42:40** youtu.be/AD8pfJH10U8

# GRATITUDE TO:

Xuan Zhang

**National Organization for Rare Disorders (NORD)** for awarding the Foundation a Seed Grant of $15,000 which funded a part-time grant writer and a subscription to the Foundation Directory, providing the FD Foundation with access to resources that may help us identify new sources of support.

**Xuan Zhang** (pictured left) who joined the FD Foundation as an intern in January 2020, and continues to assist with social media, marketing initiatives and special events. Xuan is a senior marketing student at the New York Institute of Technology. She moved to New York in September 2017 from Beijing, where she was born and raised.

**Jessica (Goldblat) Cohen**, who raised $2,500 for the FD Foundation by hosting a Facebook fundraiser in honor of her birthday and in memory of her late sister, **Jamie Goldblat**.

**Robin Landau** who raised more than $2,000 for the Foundation by hosting a Facebook fundraiser in honor of her birthday.

**Daniel Kantrowitz** who selected the FD Foundation as the beneficiary of funds received from his letter in Unsealed, a platform featuring letters that shed light on social inequality and personal experiences. “What Matters Most is Not the Memories We Are Missing” was written this past Spring during Daniel’s senior year of high school, in honor of his friend **Jack Posnack**. To read the letter, visit theunsealed.com/what-matters-most-is-not-the-memories-we-are-missing/.

# FD DAY 2020 - A VIRTUAL SUCCESS

The 35th Annual FD Day did not look like any of the previous 34 years' events. While pandemic restrictions prevented us from gathering in person at NYU Langone, instead, the Foundation, together with the Dysautonomia Center, brought FD Day directly to the homes of our families, friends, caregivers, medical team and scientists. The "silver lining" of our first ever Virtual FD Day is that thanks to modern technology, we were able to reach three times the usual number of people, with 250 households logging in from 9 different countries and 25 states.

The program included a clinical update by **Horacio Kaufmann, MD**; research updates by **Lucy Norcliffe-Kaufmann, PhD**, **Sue Slaugenhaupt, PhD** and **Frances Lefcort, PhD**; and live Q & A panels for both clinical and research topics. For the first time, again thanks to virtual technology, we were pleased to be able to feature panelists from Israel including **Boaz Kotik** from the Israel FD Organization, **Bat el Bar Aluma, MD** from Tel HaShomer Hospital, **Alex Gileles-Hillel, MD** from Hadassah Hospital, **Miguel Weil, PhD** from Tel Aviv University and moderator (and co-chair of the SAB) **Adrian Gilbert, PhD**. This year's Dystinguished Awards were presented to: **Mara Clawson**, **Yehuda Blonder**, **Ezra Kress**, **Beni Vasibih**, and **Karin Blumenfeld**. Feedback from the event was overwhelmingly positive, including from people who had never been able to attend before. Folks were especially encouraged to learn about several exciting pending treatments currently in the pipeline. If you missed a segment, would like to re-watch or view the research booklet, please visit www.famdys.org/fdday2020.

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## DON'T MISS

# UNIFIED

A VIRTUAL CONCERT TO BENEFIT THE
FAMILIAL DYSAUTONOMIA FOUNDATION

## DECEMBER 6 • 12PM - 2PM EST

Don't miss our first ever virtual concert, **UniFieD**, featuring contemporary Jewish and Israeli performers. **Daniel Landau** of Ramat Beit Shemesh in Israel, father of 7 month-old Rafi, who has FD, came up with the idea of a virtual concert to raise awareness and funds for FD. At press time, scheduled performers include: **Nissim Black**, **Zusha**, **Portnoy Brothers**, **Baruch Levine**, **Lenny Solomon "Schlock Rock"** and **Pey Dalid**. The concert is free but donations are most welcome. Explains Daniel, "We came up with the name "Unified" because we want to unite people together, whether they have a child with FD or not, and we also noticed that the name has the letters FD in it." The concert, scheduled for **Sunday, December 6** from 12-2pm EST, will air live on YouTube and Facebook Live. To register, donate or learn more, visit: www.famdys.org/unified.

## ARE YOU

# Forever DEVOTED?

During these turbulent economic times, planned giving remains a strategic way to ensure continued support for causes that are important to us. Planned giving can be achieved through a variety of methods, depending on your personal situation. We encourage everyone to include the FD Foundation in your estate plans by naming the Foundation as a beneficiary of your will, trust, retirement fund, life insurance policy or bank account. You can instruct that the Foundation receive a specified amount or a percentage; you can also name the FD Foundation as a residual beneficiary (to receive remaining assets once specified bequests have been fulfilled) or as a contingent beneficiary (to receive assets in certain circumstances). **Questions? Consult your attorney, financial advisor or contact the FD Foundation.**

We are pleased to acknowledge recent members of **FOREVER DEVOTED**:

**Birdie H Blaine Living Trust** – Mrs. Blaine directed that a distribution from her Trust be made to the Foundation in memory of her late daughter, Miriam Amy Blaine, and that the funds be used for "research purposes related to the treatment and the discovery of possible cures for" FD.

**H. Strauss** – Mrs. Strauss had a niece and nephew both born with FD, and she generously remembered the Foundation both through her IRA and through a revocable trust.

For more information or to learn how you can become a member of FOREVER DEVOTED, *please contact Lanie Etkind* at letkind@famdys.org or call 212-279-1066.

# UPDATES FROM THE DYSAUTONOMIA CEN

## VIRTUAL CHECK-UPS ARE HERE!

As the coronavirus pandemic stretches on with no end in sight, the medical team at the Dysautonomia Center came to a very important realization that it could be quite some time before those living with FD would be able to safely leave their homes to travel to the Center for their annual check-ups. With that in mind, the Center's Coronavirus Task Force developed a strategy to conduct virtual check-ups by creating a Home Visit Kit. They identified the key information to collect during a telemedicine visit and researched the best, most cost-effective and most user-friendly tools available. The Task Force assembled comprehensive medical kits that include iPads, heart buds, thermometers, blood pressure monitors and more, with simple instructions and shipped them out to patients in advance of their scheduled annual virtual check-ups. Additionally, they created an easy-to-use instructional video that families could watch on-line.

In this frame from the instructional video, NP Zenith Khan demonstrates how to use a component from the virtual check-up kit.

> *"We just had our virtual visit with the FD Center and I have to say it was fantastic! [Nurse practitioner] Kaia facilitated the whole visit and she is just lovely. I enjoyed meeting the new fellow, Patricio Miller, as well. We zoomed with them for 3 hours and they were very thorough! Honestly, virtual visits would be nice in the future, even after Covid, for those who have to travel for the appointments."* -- Marsha Cohen, mother of Frannie Cohen

The Virtual Check Up Program ensures enhanced access to care for people with FD, especially during this prolonged health crisis when travel is not safe. Additionally, offering check-ups by telemedicine means that the Center is able to provide medical care to those with FD who were never well enough to travel to the Center, to those who could not afford to travel to New York, and to people living with FD across the globe. Additionally, through telemedicine, the Team will be able to continue to collect data for the Natural History Study, the basis for all current and future FD research, essential to the development of new treatments. The Center hopes that this initiative can be used as a model for other health care organizations to replicate down the road. To inquire about scheduling a virtual check-up, please contact the Dysautonomia Center at 212-263-7225.

Patricio Millar, MD

## DYSAUTONOMIA CENTER WELCOMES PATRICIO MILLAR, MD

**Patricio Millar** moved to New York last August from Buenos Aires, Argentina to join the Dysautonomia Center as a Research Fellow. This past August, he transitioned to a Clinical Fellow and is directly involved in patient care. Explains Patricio, "The best part about my job is that I am working with a fantastic team. They are incredibly motivating to work with and inspire me every day." Patricio completed his neurology residency at Fleni Hospital in Buenos Aires and specialized in movement disorders. Adds Patricio, "My mentor there knew Dr. Kaufmann and suggested I look into positions at the Center. When I first arrived, I was solely doing research and managing data. Now I am involved in physical exams and recommendations for treatments. It is great to track the progress of the patients. There is no substitute for the human touch."

## Dysautonomia Center Latest News

For the latest news from the Dysautonomia Center at NYU Langone, check out their blog at www.dysautonomiacenter.com

# TER AT NYU LANGONE

## MIGUEL PEREZ DREAMS BIG


Miguel Perez

In recent years, the Dysautonomia Center has taken in five DREAMers as volunteers from an inner-city health and human sciences high school, to help with the natural history study. "It's great experience for them and gives them something substantial to put on their college applications," explains **Miguel Perez**, Data Manager at the Dysautonomia Center. Miguel was a DREAMer himself, coming to the Center in 2011 as a volunteer without papers. Originally from Mexico, Miguel moved to New York in 2002. When he entered high school, he had a class that required some outside research which led him to the Center. "It was a wonderful experience for me as a volunteer at the Center," explains Miguel. "I felt very welcomed and my work definitely boosted my college application and helped me stand out, giving me the confidence I needed to apply to college." Miguel attended Hunter College and worked at the Center part-time to support himself. He now works full-time on the natural history study through rare disease research grants from NIH and the MSA Coalition and helps with documentation needed for clinical trials undergone at the Center. "It feels really nice to give back to the DREAMers now, particularly after my experience at the Center," adds Miguel.

## MENTAL HEALTH PROGRAM GOING STRONG

Thanks to continued funding from the **Montreal Chapter of FD**, made possible by the Schwartzberg family in loving memory of **Steven Schwartzberg**, we have completed two successful years of the Stevie Schwartzberg Mental Health Program. Coordinated through the Dysautonomia Center by licensed mental health counselor **Lily Armstrong**, the program offers psychotherapy sessions via telephone to people with FD. As the fall approaches, Lily is able to take on additional clients who may benefit from this support. Explains Lily, "We talk about issues of limited vision and mobility, possible resources...I help navigate feelings about isolation, particularly during quarantine."

For more information about the program or to request a referral, please contact the Dysautonomia Center at 212-263-7225.

## SCIENTIFIC ADVISORY BOARD CONTINUES TO BREAK NEW GROUND

Members of the FD Foundation's Scientific Advisory Board, led by co-chairs **Frances Lefcort, PhD** and **Adrian Gilbert, PhD**, met virtually on September 3 to hear updates on FD research and treatment initiatives currently underway. The group was encouraged to hear from scientists **Sue Slaugenhaupt, PhD** at MGH/Harvard, **Adrian Krainer, PhD** at Cold Spring Harbor Laboratories and **Frances Lefcort** at Montana State University about a number of promising initiatives for treatments that could enhance and extend the lives of people with FD, and which we hope will be available within the next year. **Horacio Kaufmann, MD** and **Lucy Norcliffe-Kaufmann, PhD** also shared an update on the Clinical Development plan they and their team at the Dysautonomia Center at NYU recently created to identify clear endpoints for clinical studies. SAB members agree that each of the projects holds merit and should continue to be pursued until one or more emerges as the best option. In the meantime, the group is exploring opportunities to make these treatments a reality and to identify potential sources of funding. A small working group of the SAB continues to meet; the full group will reconvene in late 2020/early 2021. Stay tuned for the latest news.

**Adrian Gilbert, PhD** and **Frances Lefcort, PhD**
Co-chairs of the Scientific Advisory Board

### ARE WE CONNECTED?

If you are not receiving email communications from the Foundation, we may not have your current email address. If you'd like to add or update your email address, please go to our website and **join our mailing list**. We look forward to connecting!

# IN LOVING MEMORY

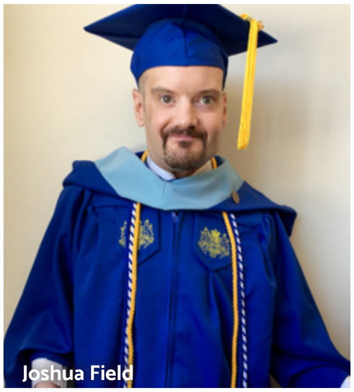
## Judy Tirza Channa Fettman Dreyfuss

### 1/8/70 - 6/6/20

Judy Fettman Dreyfuss was the eighth documented patient born with familial dysautonomia. While doctors said she had a 50 percent chance of living until age 5, Judy survived, thrived and celebrated her 50th birthday in January. Her 7-year marriage to Marc Dreyfuss was made in heaven, full of fun and love and laughter. A graduate of Kinneret Day School, she was bilingual. At Kennedy High School, she joined the gymnastics club, where she flew fearlessly on the uneven parallel bars. She completed her first year of college at the University of Haifa, and graduated from Hunter College. Her smile, kind nature and good spirits were contagious. Judy inspired others, and many people saw in her their own potential. She was social and enjoyed people, and they enjoyed her. The director of the JCC Adaptations program, Allison Kleiman, called her "a force." Her art class at the 92nd Street Y was her creative outlet.  She was an organ donor, and three people are alive today because of her final generous act. Judy's life was short, but full, and as beautiful as was possible. She was kind to everyone and loved beyond measure by family and friends. Her life was beautiful.

## Joshua David Field

### 10/24/1981 – 7/10/2020



Joshua was born in London and moved to New York at the age of 2, with his parents and older brother, to be under the care of Dr. Felicia Axelrod at the NYU Dysautonomia Center. After graduating high school, Joshua attended Hofstra University and earned his Bachelor's Degree in History. He then went on to earn a Master's Degree in Higher Education Leadership and Policy Studies. Upon achieving his Masters Degree, Joshua was inducted into the Delta Alpha Pi International Honor Society, established in 1974 for disabled students around the world who achieve the highest standards in their academic studies. When the President of Hofstra University learned of Joshua's passing, he ordered all the flags across the campus to be lowered to half staff to honor the courage and bravery of Joshua who epitomized the spirit of 'Hofstra Pride" and the values that Hofstra stands for. The University is establishing the Joshua David Field award for Advocacy to be given annually to a Hofstra student at the Delta Alpha Pi International Honor Award ceremony. Joshua will be forever mourned by his family and friends who deeply miss him. To read his full obituary, go to bit.ly/JoshuaFieldobit.

## Elliot Goldberg

### 6/27/73-7/18/20

Elliot was a man of all seasons. Sport seasons. He enjoyed watching basketball and football and was forever passionate about wrestling. He was an avid Yankees fan and knew all the ratings of each player in every sport he followed. He loved discussing sports and politics as well as '80s films. He possessed a subtle sense of humor that appealed to many. He was a biweekly participant in a monopoly meetup in New York City and rarely missed a game. Elliot received his BA from the New York Institute of Technology with a major in communication arts. He travelled extensively with his family to Israel as well as many countries throughout Europe. A Sherlock Holmes fan, he always stopped at the Sherlock Holmes Museum in London to add additional memorabilia to his collection. Elliot was a hero in all aspects of his life, teaching many how to be compassionate and to treat others with kindness and understanding.

## Mitchell D. Joseph

### 10/9/90 - 9/1/20

From Voorhees, New Jersey, Mitchell graduated from Eastern High School while attending HollyDELL School. He was a true superhero, fighting and overcoming daily challenges to his body. His bravery and positivity were a beacon of light to those close to him. He had unconditional love and kindness for his family, friends and dog, Reese. Mitchell's world revolved around his beloved friends each day - superheroes like Batman & Spiderman and villains like Ursula & Jafar. He also added other characters to his friends list as he was introduced to a variety of shows and movies. Dorothy, Tin Man, Elmo, Oscar the Grouch, Johnny Bravo, and SpongeBob helped get Mitchell through the good and bad times. He was an avid Disney fan and loved to sing along to his favorite songs with his family. Despite his struggles with FD, Mitchell shared his infectious smile with all around him.

# FIVE EASY WAYS TO GIVE BACK TO FD OR HOW TO BE PHILANTHROPIC EVEN DURING A PANDEMIC

## 1. Shop Amazon using AmazonSmile

AmazonSmile has raised more than $215 million for charity since its debut in 2013. Check out smile.Amazon.com – This holiday season and throughout the year, if you purchase a gift on Amazon, you'll be able to make an impact on the FD community.

amazonsmile
You shop. Amazon gives.

- Simply go to: smile.amazon.com
- When prompted, choose to support Dysautonomia Foundation, Inc.
- Happy shopping!

## 2. Be a Champion, December 3-5

Shop at Champions for Charity Holiday Shopping Benefit

AMERICANA MANHASSET CHAMPIONS FOR CHARITY®

Americana Manhasset Champions for Charity® holiday shopping benefit is **December 3 - December 5, 2020**. Help support the FD Foundation by doing your holiday shopping at participating Americana Manhasset and select Wheatley Plaza stores during these three days, when **25% of your designated full- price, pre-tax purchases will be donated back to us!** To learn more, including how to register, go to www.famdys.org/champions2020

## 3. Use Empathy Mart to shop or donate from the comfort of home

The FD Foundation is excited to announce a new way to support the FD community – Empathy Mart! Shop or donate from the comfort of home! It's simple:

EMPATHY MART

- Pick an item to donate
- Choose FD Foundation as your charity
- Follow shipping instructions

To donate clothes and learn more about Empathy Mart, go to: www.empathymart.com

## 4. Participate in #GivingTuesday on December 1

**#GivingTuesday** is held annually the Tuesday after Thanksgiving, this year on **December 1,** as a global day of philanthropy. Whether you give your voice, goods, time, or money, being generous is a way to support the causes you care about, like FD. **Want to give back? Consider volunteering time or donating to the FD Foundation!** Contact Natasha Weinstein at nweinstein@famdys.org for more information.

#GIVINGTUESDAY™

## 5. Order from the virtual FD Store

Looking for a gift? The FD Foundation's online store is now open. Purchase items such as notecards, jewelry, books, art and more! Visit www.famdys.org/store

## If you are age 70 ½ or Older, you can contribute from your IRA

Did you know that the IRS allows you to make charitable distributions directly from your IRA to a qualified charity, like the FD Foundation? And did you know that these contributions, allowable up to $100,000, can be counted towards your required minimum distribution (RMD) for the year? Certain rules apply, so be sure to speak to your financial advisor, or contact the FD Foundation, 212-279-1066 or letkind@famdys.org for more information.

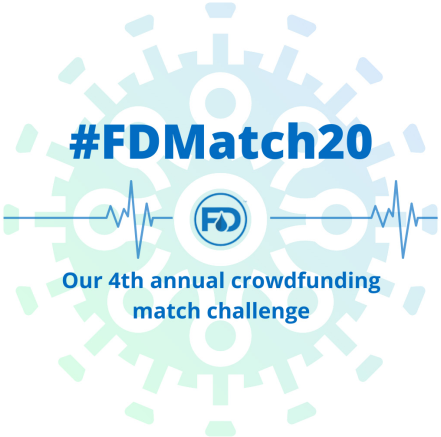
## JOIN OUR FD HANGOUT GROUPS!

To keep isolation at bay during COVID-19. The FD Foundation offers virtual "hangouts" for adults with FD. Hangouts meet every other week, hosted by **Natasha Weinstein**, the Foundation's Manager of Development and Operations. Hangout participants gather from across the United States, Brazil, England and Israel to share stories, play games and tell jokes. If you would like to join a "hangout," please email Natasha at nweinstein@famdys.org.

## THE FD FOUNDATION FONDLY REMEMBERS MARYON WEILL

The FD Foundation fondly remembers Maryon Weill, who passed away on October 10. Maryon, together with Lenore Roseman, ran the FD Foundation from 1988 to 2006. Said Maryon's brother-in-law Steve Fass, "She was an important part of the Foundation's growth from a small Mom and Pop organization to a large Mom and Pop organization. More importantly, she was always caring and helpful to the parents and children when they called the Foundation with any problems. She loved her work and made a difference for all in the FD family." We thank Maryon's children for requesting that donations in her memory be made to the FD Foundation, and we send our heartfelt condolences to Maryon's family.

## CROWDFUNDING CAMPAIGN #FDMATCH2020 CRUSHES GOAL!



For the 4th year in a row, the FD Foundation launched its annual crowdfunding campaign – #FDMatch2020. Thanks to the dedication of 20 fundraisers and the support of over 380 donors, we crushed our original goal.

Raising more than $234,000 at press time, we are able to fund vital FD programs and services such as virtual check-ups at NYU's Dysautonomia Center and critical treatment initiatives.

Gabi Jassie

Sophie Meyers

## NEW! FD ADVICE CORNER

**Gabi Jassie** and **Sophie Meyers** invite you to join a newly formed FD advice group on Facebook! Open to individuals of all ages living with familial dysautonomia, the group offers a safe space for members of our community to connect and assist each other with all things FD. To learn more, search "**FD Advice Corner**" on Facebook.

# LIVING WITH FD: PROFILE OF BRIAN SOLOMONS

**Brian Solomons** is a 57 year old gentleman with FD who lives in Farmingdale, NY. Brian has lived on his own since college and has extensive experience advocating for other people with disabilities. He works for Silo (Suffolk County Independent Living Organization), a non-profit that helps people with disabilities transition out of nursing homes to a more independent life through a New York state grant program called Open Doors. "I find so much value in my job and feel blessed to continue to be able to work from home during the quarantine," adds Brian. He participates in a weekly conference call support group through work as he notes, "It's nice to be able to take what I learn from work and try to help others."

Prior to quarantining, Brian attended weekly karate, yoga and meditation classes through a non-profit called Third Eye Insight, Fitness for the Blind. According to Brian, "Since starting meditation, I fall asleep much faster and although I'm not attending classes anymore, I haven't had a sleep issue, which is a big problem for lots of people with FD." Recently, Brian has joined the bimonthly FD Zoom hangouts. "It's great to communicate with the FD community and provide peer support to each other," says Brian. "I enjoy the casual social aspect and also like to be a resource for others if they are interested in hearing more about the benefits of karate and meditation."


Brian Solomons

## Save the Date

**Giving Tuesday**
Tuesday, December 1

**Champions for Charity**
Thursday, December 3 - Saturday, December 5
**Americana Manhasset (also available for virtual shopping)**
[www.famdys.org/champions2020](www.famdys.org/champions2020)

**UniFieD Virtual Concert**
Sunday, December 6, 12pm - 2pm EST
[www.famdys.org/unified](www.famdys.org/unified)

## AND FOR YOUR 2021 CALENDAR:

**5th Annual Long Island Golf Outing, Monday,** May 24, 2021

**36th Annual FD Day, Sunday,** June 6, 2021

**12th Annual Chicago Ladies Lunch & Play, Monday,** July 26, 2021

## ON THE COVER

Electron microscopy image of the retinal cell layer

If you have a photo or artwork you'd like to share for a future issue of DYS/COURSE, please send it to letkind@famdys.org.

## DYS/COURSE Fall 2020

Written by: Lisa Denburg
Edited by: Faye Ginsburg, Lanie Etkind and Natasha Weinstein

## FOLLOW US ON:

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The Familial Dysautonomia Foundation is a 501 (c) (3) non-profit organization dedicated to funding treatment of, research on and awareness about familial dysautonomia, a rare, life-threatening, Jewish genetic disease that affects the autonomic nervous system.

A copy of our latest annual report may be obtained from the FD Foundation (315 W. 39th St., Ste. 701, New York, NY 10018) or from the New York State Attorney General's Charities Bureau (28 Liberty Street, 15th Floor, New York, New York 10005).

FAMILIAL DYSAUTONOMIA
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NEW YORK, NEW YORK 10018

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**DYS/COURSE** 2020-2

Your support means a lot to us. Please don't forget to use the enclosed envelope!

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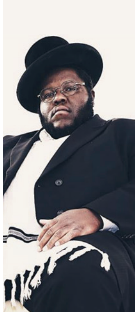
# UNIFIED

A VIRTUAL CONCERT TO BENEFIT THE FAMILIAL DYSAUTONOMIA FOUNDATION

**FEATURING:**



**NISSIM BLACK**

**ZUSHA**

**THE PORTNOY BROTHERS**

**LENNY SOLOMON**

**PEY DALID**

**MC ELI LEBOWICZ**

## DECEMBER 6, 2020

**12 - 2PM EST**

TO LEARN MORE,
REGISTER OR DONATE, GO TO:
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**APPEARANCE BY BARUCH LEVINE**

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