

Fall 2023

# DYS/COURSE

NEWS FROM THE FAMILIAL DYSAUTONOMIA FOUNDATION



**FAMILIAL  
DYSAUTONOMIA  
FOUNDATION, INC**

**NYU CENTER TO LAUNCH CRISIS STUDY**

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**BIOBEATS MONITORS ARE A GAME  
CHANGER**

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**SAB HOSTS SCIENTIFIC MEETING IN NYC**

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



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## On the Cover

"Self-Portrait in Purple" by Keshi-  
Taryan Kigel, which was a winner of the  
2023 FD Art Competition

If you have an image you'd like to share  
for a future issue of DYS/COURSE, please  
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## DYS/COURSE Fall 2022

Written by: Lisa Denburg and Lanie Etkind  
Edited by: Faye Ginsburg and Lanie Etkind  
Designed by: Albulena Prelvukaj

## MESSAGE FROM THE PRESIDENT AND EXECUTIVE DIRECTOR



Faye Ginsburg



Lanie Etkind

Dear Families and Friends:

Most of you are aware that the FD Foundation provides an annual grant to fund the exceptional work of the Dysautonomia Center at NYU Langone, including the Center's expert team of physicians, nurse practitioners and researchers; the FD Natural History Study; clinical research initiatives; the telemedicine program and more. Your donations and fundraising efforts throughout the year support this essential grant, and we are grateful to be able to ensure top-quality medical care for our community. Without the Dysautonomia Center (and your support for it), the specialized care our community needs would be difficult if not impossible to provide.

In addition to funding the Dysautonomia Center, the Foundation also supports programs and services aimed at enhancing quality of life for people living with FD. We wanted to take this opportunity to highlight some of these programs and services, which are also made possible through the generous support of our families, friends and other donors:

**Scientific Advisory Board:** The Foundation provides organizational support and occasional seed grants for an esteemed group of scientists, clinicians and pharmaceutical experts who steward and foster FD research and researchers. [Read more page 5.]

**Oxygen Concentrator Loan Program:** Most people living with FD require supplemental oxygen to fly (or to visit high altitudes). The Foundation owns and maintains portable oxygen concentrators and batteries, and will provide them to families, free-of-charge, upon request, including to those living outside the NY metro area.

**Mental Health Counseling Program:** Established by the Schwartzberg family in memory of their son Stevie, the Program continues to offer virtual therapeutic support by an outstanding mental health professional who has been working with our community since 2018. [Read more page 6.]

**Virtual Hangouts:** Launched at the start of the COVID pandemic, virtual Hangouts offer a warm and welcoming place for people with FD to gather, meet and socialize, organized according to age groups with shared interests. Led by experienced friend of the FD community Michelle Schwab, groups meet weekly or bi-weekly and new members are welcome. [Read more page 7.]

**Game Night:** Organized by the FD Social Committee, Virtual Game Nights are open to all. Held monthly (usually on the 3rd Thursday), game nights bring together teens and adults with FD to play popular games like Jeopardy and Beat Shazam. [Read more page 7.]

**FD Day:** For 38 years, the Foundation has brought our community together (in person and in recent years virtually) to learn the latest advances in care, treatment and research from FD clinicians, scientists and other professionals. [Read more page 4.]

These are just some highlights of the ways in which the FD Foundation works to make life better for people living with FD and for those who love and care for them. We could not do any of this important work without the support of our community, and we thank you for helping sustain our efforts, raising money and awareness.

Sincerely,

Faye Ginsburg

Lanie Etkind

# DYSAUTONOMIA CENTER BIDS FAREWELL TO NURSE PRACTITIONER ZENITH KHAN

The FD community bade farewell to nurse practitioner **Zenith Khan**, who left the Dysautonomia Center in August. Zenith moved to Los Angeles to join her husband who started a fellowship in emergency medicine at UCLA. After completing her doctorate at NYU and graduating as class valedictorian in May, Zenith is now working at UCLA in a clinic for patients with neurodevelopmental disabilities. She is also expecting her first child, a boy, at the end of November! “I like to stay busy,” she jokes.

Zenith worked with the FD Center for four years and was instrumental in developing its telemedicine program. “It was near and dear to my heart,” says Zenith. “During Covid, when severe isolation measures were in place, telemedicine enabled the Center to continue to provide essential care to the FD community.” Post-Covid, telemedicine remains crucial to extending FD care to patients who cannot travel to the Center because of health, mobility or financial limitations.

Zenith will be missed by her colleagues as well as by people with FD and their families. Says **Alejandra Gonzalez-Duarte**, CO-Director at the Dysautonomia Center, “Zenith is amazingly empathetic and was greatly loved by the FD community.” Zenith reflects, “I’ve learned so much from FD parents and truly believe that they are the world’s experts on their own kids. It’s been such a privilege to work in the clinic and serve them. There was never a dull moment.”

The FD Foundation is grateful to Zenith for her heartfelt dedication to our community, and we wish her much happiness and success in the years to come.



## HONOR OR THANK ZENITH - OR YOUR FAVORITE NURSE PRACTITIONER - IN THE 2024 FD JOURNAL

“Nurse practitioners are boots on the ground for the doctors”, says **Alejandra Gonzalez-Duarte**, Co-Director at the Dysautonomia Center. The Foundation invites you to pay tribute to your favorite nurse practitioner(s), past or present, in the 2024 FD Journal. Visit <https://familialdysautonomia.org/2024journal> for more details.



Held on May 22nd at Glen Oaks Club in Old Westbury, NY, the 26th Annual FD Golf Classic raised more than \$300,000 to support FD care and research. We are grateful to our co-chairs **Paul Wexler, Steve Fass, Steve Kietz** and **Rachel Schlau**, to our event sponsor the **Kopelman Foundation**, and to all those who golfed, sponsored, donated, dined and purchased raffle tickets and/or auction items to support the FD mission.

# FD FOUNDATION AND FDA TO FUND STUDY FOR AUTONOMIC CRISIS

The NYU Dysautonomia Center has received a significant four-year grant from the FDA to explore an innovative home-based treatment for FD crises. This new therapy, called IGALMI, is a user-friendly version of dexmedetomidine, typically given intravenously in the hospital. Although IV dexmedetomidine is the most effective choice for addressing autonomic crises, it presents a significant challenge: it can only be administered in a hospital intensive care unit, making it hard for many patients to access. Now, we have a new formulation that could be a solution for managing FD crises. If proven safe and effective, it could be a breakthrough, enabling patients to deal with FD crises anywhere.



**Dr. Alejandra Gonzalez-Duarte**, Co-Director, points out, "IGALMI is similar in appearance to a Listerine strip. It dissolves under the tongue, ensuring complete absorption. This offers a significant advantage because, during crises, patients may experience retching or vomiting, which

can hinder the effective absorption of the medications used at home. The sublingual strip eliminates this concern."

However, as the FDA grant covers only the clinical trial to establish efficacy, a small pilot study was required to determine the optimal procedures for the study. To support this vital initiative, the Foundation is tapping into the **Clare and Philip Wexler Research Fund**, generously underwritten by the **Kopelman Foundation**.

The preliminary pilot study, referred to as "hospital at home" because of the device used, will entail assessing more than ten physiological variables while the patient is experiencing a crisis. Variables encompass EKG, heart rate, blood pressure, oxygenation, and other vital signs, all monitored by a Bluetooth-connected device manufactured by BioBeat [see article below], with data sent live to the physician's screen. According to **Dr. Horacio Kaufmann**, Director of the NYU Dysautonomia Center, "This groundbreaking pilot study allows us to observe patients in real-time and ensure their safety during a crisis, all within the comfort of their homes."

Autonomic crises pose a significant burden for FD patients and their families. In light of this, the Dysautonomia Center made a compelling proposal to the FDA to direct their resources toward this innovative trial. The collaboration with the FD Foundation is the key ingredient that in the near future will potentially help reduce hospitalizations resulting from autonomic crises in the near future. The trials are anticipated to commence next month.

## FOUNDATION GRANT ENABLES DYSAUTONOMIA CENTER TO ACQUIRE CUTTING - EDGE EQUIPMENT

The FD Foundation has recently acquired 100 BioBeat blood pressure monitors for utilization at the NYU Dysautonomia Center. These single-use monitors, developed by an Israeli company, represent a transformative advancement for patients. Unlike previous equipment that necessitated the use of a cuff and was uncomfortable to wear continuously for 24 hours, the BioBeat monitors, roughly the size and weight of an Apple watch, adhere to the chest and can be worn throughout the day and night while patients carry on with their usual activities. This breakthrough eliminates the need for patients to remain connected to a cumbersome monitor. **Dr. Alejandra Gonzalez-Duarte**, Co-Director, emphasizes, "They can go to the movies or school wearing it, and we obtain a more precise understanding of their condition throughout a typical day."



The BioBeat monitor is designed for continuous and non-invasive monitoring of blood pressure, providing ongoing measurements at regular intervals, typically every few minutes. This continuous monitoring is particularly valuable in FD, where frequent blood pressure data is needed because of extreme labile blood pressure. BioBeat also monitors oxygenation percentage in the blood during sleep, adding valuable new data. BioBeat monitors are integrated into the clinic's operations and are also distributed to patients as a component of the telemedicine kit. **Dr. Horacio Kaufmann**, Director of the NYU Dysautonomia Center, remarks, "We've been employing them for approximately three months, and the patients are very happy with the outcomes."



# FRANCES LEFCORT RETIRES FROM MONTANA STATE UNIVERSITY

**Frances Lefcort** recently retired after 29 years as Professor of Neuroscience and Cell Biology at Montana State University. Frances, who co-chairs the FD Foundation's Scientific Advisory Board (SAB) with **Adrian Gilbert**, plans to continue in this role.

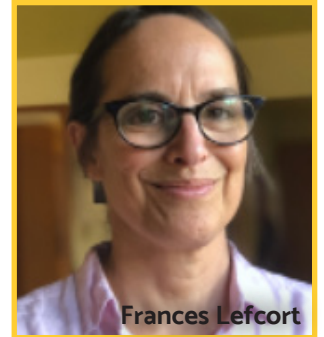
Because of her personal connection with FD (two of her first cousins had the disease), Frances says, "It was kind of inevitable that I would study neurology. I love working with FD families and having my personal interest in the disease converge with my career. My life brought me full circle."

Frances looks forward to moving to Washington State with her husband to a house they are building near the ocean and plans to return to Montana in the winters, where she enjoys hiking and cross-country skiing. Frances also plans to spend more time with her two grown children, a daughter who is in graduate school at University of Washington and a son who is a musician in New York.

Since leaving MSU, Frances has passed along her research (and her FD mice) to scientists at Harvard/Mass General and University of Georgia, where they will continue her work developing gene therapy as a potential treatment for FD. Frances plans on staying involved with the researchers and helping them with grants so the projects keep moving forward. She adds, "I can't just sit around drinking margaritas all day!"

Never one to sit idle, Frances is currently working on research papers and analyzing FD retina data with graduate student **Anastasia Schultz**. According to Frances, "We want to prevent death of neurons in the retina, and Anastasia was able to do so in an FD mouse model using gene therapy. Her paper was recently submitted to a scientific journal and is currently under review."

She concludes, "I definitely plan to stay actively involved in the community until we have effective therapeutics for FD, whether it's gene therapy or something else like small splicing molecules."



Frances Lefcort

## FOUNDATION HOSTS 38TH ANNUAL FD DAY CONFERENCE IN JUNE



Together with the team at the Dysautonomia Center at NYU Langone, the FD Foundation hosted our 38th Annual FD Day conference on June 11. This was the fourth year that the conference was held virtually, and it continues to attract attendees from across the country and internationally. Once again, the program opened with members of our community sending greetings from their home locations around the world as well as brief updates from FD representatives in Israel and Mexico. The program featured clinical updates from members of the team at the NYU Center as well as the latest news on the scientific front. There was also a live Q&A panel with doctors and scientists. The 2023 Distinguished Awards were presented to: **Joshua Knobel**, **Matthew Kutner**, **Aaron Menzel** and **Malia Ratner**.

### Thanks to our FD Day Sponsors

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The annual FD Art Competition, curated by NP **Kaia Dalamo**, included many incredible works, with awards going to **Morgan Asinowski**, **Bennie Taryan**, and **Keshi Taryan-Kigel**. And the 2023 FD Champion Awards were presented to **Barrie Rappaport** and **Liza Freed**. Post-event, we offered a virtual "After Party" for FD folks and a "Virtual Schmooze" for parents. The Center Team published a Research Booklet highlighting many important studies underway. To view the FD Day video or download the Research Booklet, please visit <https://familialdysautonomia.org/fdday2023>.



# CROWDFUNDFUNDING CAMPAIGN #FDMATCH23 MAKES A SPLASH

At press time, our Fall Crowdfunding Campaign #FDMATCH23 was on target to meet its goal to raise \$250,000 to support the Foundation's mission. This year's theme honored our **FD Moms** for the loving care and dedication they provide. We are especially grateful to our campaign "chairmoms" **Lisa Newman, Becky Sernovitz and Stephanie Stillman**. Special thanks to our challenge donors who together contributed \$125,000 to match every dollar donated to the Campaign and to our crowdfunders who have been working hard to raise funds and awareness.


We appreciate all who have contributed, and if you still wish to participate, please visit <https://p2p.onecause.com/fdmatch23>.

## THANKS TO OUR CHALLENGE DONORS

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Barbra Waldfogel  
Tova and Howard Weiser

## #FDMATCH23

HONORING FD MOMS



**Rebecca Sernovitz**  
Mom of Sam age 15

**Describe a silver lining you've discovered through your FD journey.**

The silver lining that I've found from being a part of the FD community is the community itself! We received amazing support when we got Sam's diagnosis, have visited other FD families, our kids have gone to camp together, and the FD mom connection is unlike any other friendship! We're a family :)

## THANKS TO OUR FUNDRAISERS

Allan Cohen	Marsha Cohen
Alyson Brenner	Mike Zucker
Barrie Rappaport	Randi Goldberg
Becky Sernovitz	Rebecca Newman
Faye Ginsburg & Fred Myers	Susan LeVine
Freddi Baranoff	The Landaus
Jeff Newman	The Stillman Family
Lisa Newman	Vanessa Koltai

# FOUNDATION'S SAB HOSTS SCIENTIFIC MEETING IN NYC



The Foundation's Scientific Advisory Board, headed by **Frances Lefcort** and **Adrian Gilbert**, hosted an in-person Scientific Meeting at NYU Langone in October. Scientists and clinicians traveled from across the country and from Europe and Mexico to join members of the SAB and the NYU clinical team for a full day of learning, sharing and brainstorming. (Although our Israeli contingent was unable to travel because of the war, they joined by Zoom.) Several scientists who are prominent in their respective fields were also invited to share new ideas and perspectives with the group. Observes **Faye Ginsburg**, "The meeting was very generative, with new, younger scientists working in cutting edge areas such as CRISPR and Stem Cell research joining our group for the first time -- with considerable enthusiasm about working with the FD community. It was also encouraging to see projects going forward immediately that address some of the most difficult symptoms of FD - such as sublingual at-home treatment for crisis." [See article page 3]. Notes Frances, "The meeting was marked by very productive and interactive discussions between scientists, clinicians and FD families. The focus was on developing therapeutics for FD, including strategies for treating FD-related gastrointestinal problems. There was extensive discussion on therapies that will raise levels of Elp1, the protein that is reduced in FD. In summary, we have a highly collaborative, constructive dedicated community committed to developing therapeutics for FD."



# GOLF TOURNAMENT IN EDMONTON, CANADA RAISES FUNDS TO SUSTAIN THE STEVIE SCHWARTZBERG MENTAL HEALTH PROGRAM

On a sunny day in August, more than 100 friends gathered in Edmonton, Alberta for the second **Stevie Schwartzberg** Memorial Golf Tournament. Hosted by parents **Jack** and **Rowena** and sister **Daryl**, the event honored Stevie's legacy and celebrated his life while raising funds for the Montreal chapter of FD. Proceeds from the outing will ensure continuation of the **Stevie Schwartzberg Mental Health Program**, established in his memory at the NYU Dysautonomia Center soon after Stevie passed away in 2017 at the age of 35.



The first golf event, held in 2019, sustained the program through COVID; and in 2021 Daryl organized the Box Jump Challenge (modeled after the ALS ice bucket challenge) to raise funds to keep the program going. More recently, when the funds were running low, the Schwartzbergs realized it was time for another outing. Explains Rowena, "We know the program has been life enhancing for so many people with FD and we just didn't want it to end."

The Schwartzberg family were delighted with the robust response to this year's event which raised about \$100,000 CAN. Reflects Rowena, "This was not really about the golf. That was secondary. It was about Stevie. Everyone who came had a connection to him or to us. We are really proud that we were able to do this."

## THE STEVIE SCHWARTZBERG MENTAL HEALTH COUNSELING PROGRAM

Through the Stevie Schwartzberg Mental Health Counseling Program at the NYU Dysautonomia Center, **Lily Armstrong**, a licensed mental health counselor who had a treasured relationship with Stevie, offers psychotherapy sessions via telephone or video to people with FD across North America.

Thanks to funding made possible through the Schwartzberg family, Lily has been working with our community since 2018, providing her services to people of all ages living with FD. "It can be very isolating to have a disability. When you have a chronic illness like FD, feeling that you have emotional support, strength and resiliency to navigate all of life's complexities gives meaning to life in a way that's so rich," says Lily. "Sometimes we discuss the impacts of FD, aging, parental relationships, emotional regulation, and more. We practice self-acceptance and work on normalizing their lives." Adds Lily, "Since the very beginning, the program has grown and solidified as an important if not pivotal aspect of wellness. What started as a small seed of an idea has flourished into something very impactful for this community.

Concludes Lily, "It's has been an honor to partner with the Schwartzbergs to build the mental health program. I am so grateful to them for their vision and tireless efforts to push for positive mental health in this special community."

To learn more about the Stevie Schwartzberg Mental Health Counseling Program, contact the Dysautonomia Center at NYU Langone at [nyudysautonomiacenter@nyulangone.org](mailto:nyudysautonomiacenter@nyulangone.org)

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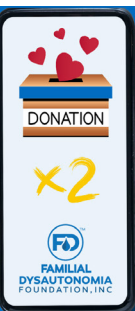
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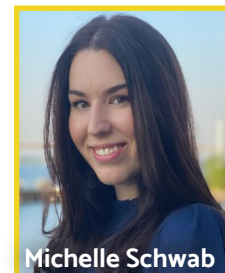




# FOUNDATION WELCOMES MICHELLE SCHWAB AS NEW HANGOUT FACILITATOR

The Foundation is pleased to introduce **Michelle Schwab**, who became the facilitator for FD Hangouts and Game Nights last May, taking over for **Liza Freed**. Michelle is no stranger to the FD community, having previously worked as a caregiver for **Samantha Myers**. Born and raised in Queens, Michelle graduated from St. John's University with a BS in psychology. She is currently enrolled in a master's degree program for clinical mental health counseling.

Born out of Covid, Hangouts enable people who have FD to meet and socialize with one another virtually. There are four hangout groups held weekly or biweekly on Zoom, divided by age. Says Michelle, "Hangouts are a wonderful way for participants to catch up with one another. Attendees give updates on any news, and some groups choose games or conversation starters." Since it's difficult for many to get together in person as they live far away from one another, socializing during the Hangouts is a great way to stay in touch with friends. The monthly Game Nights have grown in popularity and are open to all age groups. Remarks Michelle, "I'm blown away by the friendships within the FD community. I'm always humbled seeing the kindness within these groups."



Many thanks to the social committee members who help plan Game Night programming: **Rebecca Newman**, **Gabi Jassie**, **Frannie Cohen**, **Laura Bale**, and **Kyra Slive**. Adds Michelle, "Recently Kyra hosted Beat Shazam, preparing the game board and running the virtual event -- it was a great experience!"

 **Hangouts**



Michelle Schwab facilitates our popular **FD Hangouts** every other week on **Zoom**, providing an opportunity for people who have FD to meet and socialize with one another virtually.

- **ORANGE** GROUP (40S-60S) - EVERY THURSDAY AT 7:00PM EDT
- **GREEN** GROUP (30S) - EVERY OTHER THURSDAY AT 11:00AM EDT
- **YELLOW** GROUP (20S) - EVERY OTHER WEDNESDAY AT 8:00PM EDT
- **BLUE** GROUP (TEENS) - EVERY OTHER WEDNESDAY AT 7:00PM EDT

**Virtual Game Nights**  
*Hosted by the FD Social Committee*

Join your FD peers for a **GAME NIGHT**. No registration is needed.

Game Night 7:30 PM ET	<b>21</b> Dec	Game Night 7:30 PM ET	<b>18</b> JAN	Game Night 7:30 PM ET	<b>2</b> FEB
Game Night 7:30 PM ET	<b>21</b> MAR	Game Night 7:30 PM ET	<b>18</b> APR	Game Night 7:30 PM ET	<b>23</b> MAY
Game Night 7:30 PM ET	<b>20</b> JUNE	Game Night 7:30 PM ET	<b>18</b> JUL	Game Night 7:30 PM ET	<b>22</b> AUG

If you would like to learn more about Hangouts or Game Nights, please email Michelle at [michelle61096@gmail.com](mailto:michelle61096@gmail.com)

## FD PARENT-CAREGIVER SUPPORT GROUP CONTINUES

We are so pleased to announce that that **Matthew Hertzberg**, MSW who recently completed his Social Work internship at the NYU Dysautonomia Center, has agreed to continue to host the parent-caregiver support group that he established. Matt observes that "this group provides an opportunity to exchange information, resources, strategies, and personal experiences of raising and loving someone with FD. The virtual meetings offer a convenient way for caregivers to carve out a moment to drop in and connect with others on a similar and often isolating path."

At this time, the group will meet on Zoom, once a month in the evening for 90 minutes. **All FD parents and caregivers are welcome to join.** To be added to the email list, contact Matt directly at [matthewhertzbergmsw@gmail.com](mailto:matthewhertzbergmsw@gmail.com). All are welcome.

# A SURPRISE BEQUEST

The FD Foundation gratefully acknowledges **Dena** and **Michael Raffler** who have included the FD Foundation in their estate plans in honor of dear friends **Marsha** and **Jeff Cohen** and their daughter **Frannie**, who was born with FD.

The Rafflers' friendship with the Cohen family dates back more than 32 years to when Dena and Michael first moved to Charlotte, North Carolina. According to Dena, "Most of us here in Charlotte are transplants. We have to choose our family here and the Cohens have been our chosen family since before Frannie was born. Marsha is my "sister from another mother" – we are only six weeks apart in age. We've been through a lot together with Frannie's FD, and the mission of the Foundation is incredibly important to us."

In fact, when the JCC hosted a summer camp in Charlotte for kids with special needs, the Rafflers' daughter **Rebecca** was Frannie's camp "buddy". She also volunteered for two years at the Dysautonomia Center before enrolling in medical school. "Because of our relationship with the Cohens, Rebecca wanted to give back. Rebecca is now a pediatrician completing her fellowship here in Charlotte," says Dena.



Since the Rafflers have not informed the Cohen's in advance about their Planned Gift intention, they hope the Cohens will be pleasantly surprised with this wonderful news. The Rafflers especially hope to inspire other friends and families to follow their lead, supporting the mission of the FD Foundation well into the future.

# WE ARE KVELLING FOR...

- Foundation Board VP **Eddie Baranoff** and his wife **Freddi** on the marriage of their daughter **Priscilla** to **Ricky Cohen** on May 18, 2023. This was a big year for Freddi and Eddie, who also become grandparents with the birth in October of Faye Baranoff, named in memory of Eddie's mother.
- **Alejandra Gonzalez-Duarte, Maria Cotrina-Vidal, Horacio Kaufmann** and **Lucy Norcliffe-Kaufmann**, whose article on familial dysautonomia was published in the June 2023 issue of Clinical Autonomic Research.
- Foundation VP **Steve Kietz** and his wife **Barbara**, who became grandparents of twins, Jordan and Madeleine, and to the babies' proud parents, **Adam Kietz** (who founded our NextGen group) and his wife **Liz**.
- **Frances Lefcort**, Co-Chair of the Scientific Advisory Board, who has retired from her position as Professor of Neuroscience and Cell Biology at Montana State University [to learn more, see article page 4].
- **Brian Levine**, cousin of **Josh Kietz**, member of TEAM FD and NextGen, who popped the question to **Claudia Libow** (she said "Yes!").
- **Elisabetta Morini**, Ph.D., Assistant Professor in Neurology at Massachusetts General Hospital and Harvard Medical School, whose paper on "Development of an Oral Treatment that Rescues Gait Ataxia and Retinal Regeneration in a Phenotypic Mouse Model of Familial Dysautonomia" was recently accepted and published in the American Journal of Human Genetics. <https://tinyurl.com/mr3sczne>
- Foundation Board member **Howard Weiser** and his wife **Tova**, who recently celebrated their 50th wedding anniversary.
- Foundation VP **Paul Wexler**, who was awarded Honorable Mention for the Lifetime Achievement Award in the 2023 Invest in Others ("IIO") Awards. This also resulted in a \$2000 grant from IIO to the FD Foundation.

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](mailto:info@famdys.org) so that we may include your news in our next KVELLING section!



We are delighted to welcome Dena and Michael Raffler as the newest members of Forever Devoted, the FD Foundation's planned gift recognition society. If you have included the Foundation in your estate plans, please notify us so we can acknowledge you and add your name to our ever-growing list of members.

## HOW TO LEAVE A LEGACY

You can act today to ensure that your favorite charities will be supported in the future:

Name the FD Foundation as a beneficiary (or contingent beneficiary) by specifying an amount or percentage of your:

- **Will or trust**
- **Retirement plan**
- **Life insurance policy or**
- **Bank account**

Did you know? If you are age 70 ½ or above, you can make a charitable contribution directly from your IRA, which counts towards your RMD.

Consult your financial advisor or contact the Foundation for more information about how to include the FD Foundation in your estate plans.



# TEAM FD ROCKS THE NYC MARATHON

On Sunday, November 5, members of TEAM FD joined more than 50,000 runners to participate in the 2023 TCS New York City Marathon. Congratulations to Team members **Kyra Bronfman**, **Sydnee Fried** and **Robin Stairman**, who participated for the first time, and to veteran **Brian Levine**, who completed the race in an impressive 3:17. Together TEAM FD raised close to \$28,000 for FD.

## MEET TEAM FD



**KYRA BRONFMAN**  
RUNNING FOR  
NAOMI TSIPORA WALKER



**MARGO FINK**  
RUNNING FOR  
PYPER STILLMAN



**SYDNEE FRIED**  
RUNNING FOR  
MORGAN ASINOWSKI



**BRIAN LEVINE**  
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JOSH KIETZ



**ROBIN STAIRMAN**  
RUNNING FOR  
EVAN WHITE



## WE'RE LOOKING FOR A FEW MORE GOOD RUNNERS!

### 2024 United Airlines NYC Half - March 17

FD Foundation has secured five spots for the **2024 United Airlines NYC Half Marathon** on **March 17, 2024**. To secure a spot please contact us at [info@famdys.org](mailto:info@famdys.org)



## FD FEATURED ON RARE DISEASE PODCAST

Foundation Executive Director **Lanie Etkind**, along with **Keshi Taryan-Kigel** and her mom **Rita Taryan**, were invited to participate on **It Happened to Me**, a podcast about rare diseases and medical challenges. The trio were interviewed by patient advocates **Cathy Gildenhorn** and **Beth Glassman**, who also live with rare diseases. Keshi spoke about FD from the perspective of someone who lives with the disorder, and Rita shared some of the knowledge and experience she has gained over more than three decades of managing FD as a parent. Lanie contributed relevant facts and figures to complete the story. To listen to the podcast, visit <https://tinyurl.com/fdepisode>



Rita Taryan and Keshi Taryan-Kigel

## GRATITUDE TO:

- **Old Westbury Club**, which held their annual charity day on August 19. Due to the fabulous play of **Paul Wexler** and friends as well as the generosity of the club, the Foundation received a check for **\$6,784.71**.
- **Michael Zucker and friends** for raising more than **\$8600** through their annual bike ride to benefit the FD Foundation, breaking the record for dollars raised that they set just two years ago! [See accompanying photo]
- NYC-based activewear brand **Terez** for hosting a shopping day in July to benefit the FD Foundation.



L to R: Mike Zuker, Bill Donahue & Mike Pomerantz

# FOUNDATION LAUNCHES NEW PILOT PEER MENTORSHIP PROGRAM

**Michelle Schwab**, who coordinates both the FD Hangouts and Game Nights, is also piloting a new Peer Mentorship Program, that connects younger people living with FD with more mature FD folks. Says Executive Director of the FD Foundation **Lanie Etkind**, “We are very excited about this program and the potential it has to bring our community even closer and to foster personal growth.”

Inspired by a Hangout participant who didn’t want to share a personal issue with the larger group, Michelle had an epiphany. “I thought it would be cool to set up people from different age groups over Zoom to help them navigate life.” Michelle is now facilitating the conversations, and they have been very meaningful for the pilot duo. She adds, “During Hangouts, sometimes group members are more reserved and it can be intimidating to bring up a negative aspect of having FD. No one wants to bring the group down with a serious issue. I thought this peer mentorship program would be an opportunity for a younger person to discuss issues like dating or mobility with an older person who has already gone through these same challenges.”

Explains Michelle, “Ideally it would be great if I could pair up a 16-year-old with a 25-year-old in a more private setting than a Hangout group. Since I don’t have the same struggles, I can’t always speak to their experience.” Says Lanie, “We encourage others to volunteer to participate either as mentors or mentees in this pilot program.” For more information, please email Michelle at [michelle61096@gmail.com](mailto:michelle61096@gmail.com).

## HOST A FACEBOOK FUNDRAISER TO BENEFIT FD



If you’re celebrating a birthday, anniversary or wedding, consider inviting friends and loved ones to donate to FD in your name instead of giving a gift, 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 the FD Foundation at [info@famdys.org](mailto:info@famdys.org) for more information.

Thanks to everyone who held a Facebook Fundraiser for us recently:

**Michael Zucker**  
**Norbert N Steiner**  
**Joyce Sanders**  
**Gabby Stenzel**  
**Arlene Gannet**  
**Addy Krantzler**  
**Andrew Sigman**  
**Stephanie Gruber Ripps**

## OUT AND ABOUT



Rick Guidotti photo session with FD families



Perry and Jeff Goldberger at Rick Guidotti photo session



Sernovitz and Landu families meet up in Israel  
L to R: Daniel and Deena Landau; Larry, Sam, Daniella, Becky and Eden Sernovitz



Newman family welcomes the Cohens to town  
Top row: Frannie Cohen, Gabi Jassie; Bottom row: Josh Kietz, Becca Newman

## JOIN THE FACEBOOK GROUP “FD ADVICE CORNER”!

Started by **Sophie Meyers** and **Gabi Jassie**, the group offers a safe and private space for people with FD to meet and socialize with one another. Says Sophie, “We’re all in this together!”

To join, visit <https://www.facebook.com/groups/353287232374518>

## NEXTGEN SEEKS YOUNG PROFESSIONALS TO RAISE FUNDS AND AWARENESS FOR FD

- Are you in your 20’s or 30’s?
- Do you have a sibling, cousin or friend who is living with FD?
- Would you like to work with other young people to raise funds and awareness for FD?
- Do you have some ideas for programs or events?
- Are you curious to learn more?

If you answered “yes” to any of these questions, please contact us at [info@famdys.org](mailto:info@famdys.org) to let us know that you’re interested to learn more about NEXTGEN. We’ll be back in touch with more details after the first of the year.

## FOLLOW US ON:

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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).

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.



**DYS/COURSE** 2023- 2

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

2024 ANNUAL JOURNAL



PLEASE REPLY BY JANUARY 15, 2024

We invite you to participate in the 2024 FD Journal by placing an ad or making a donation.

Visit <https://familialdysautonomia.org/2024journal>



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