

SPRING 2023

DYS/COURSE

NEWS FROM THE FAMILIAL DYSAUTONOMIA FOUNDATION

**SCIENTIFIC ADVISORY BOARD
MEETS IN PERSON IN NYC**

**TEAM FD RUNS THE NYC HALF
MARATHON**

**FD RESEARCH PUBLISHED IN
LEADING SCIENTIFIC JOURNAL**

**INTERNATIONAL FD CLINICAL
TEAMS MEET VIRTUALLY**



**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.

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On the Cover

Our cover image comes from the lab of **Frances Lefcort**, co-chair of the FD Scientific Advisory Board. Taken by grad student **Anastasia Schultz** (whose work is supported by a grant from the **Clare and Philip Wexler Research Fund**), this slide of a mouse retina merges images of ganglion cells (the cells that die progressively in the FD retina) in purple, and in green, the glial cells (which play good and bad roles in the retina).

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

DYS/COURSE

Spring 2023

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



We hope this finds you and yours well!

We want to thank everyone who participated in the **2023 FD Family Survey**. This was our second year inviting feedback from families on their experiences with the Foundation and the Center.

We are especially grateful to all those who took the time to speak with our surveyor and complete the questionnaire. While we know that there is always room for improvement, we were pleased to see evidence of progress on some of the pressure points reported during the first year. We want to assure you that the board takes this survey very seriously and is now developing a plan to address the issues and concerns that surfaced.

It is overwhelmingly clear from the survey that our families value the work of the Foundation and the funding it provides to the [Dysautonomia Center at NYU Langone](#). Nearly everyone reported depending on the Center for some level of care, including annual check-ups, telemedicine, 24/7 emergency support, consults with local medical team and/or clinical studies. We all know that it is impossible to find this level of specialized FD care anywhere else.

What concerns us is the dissonance between those who USE the Center and those who SUPPORT the Center.

The message we wish to impart here is two-fold:

- First, because we are such a small and rare community, EACH of us bears a responsibility to help ensure that the Foundation and the Center will continue to be there for ALL of us. To paraphrase the sage Hillel: **"If I am not for myself, who will be for me?"**
- Second, there are many ways to support the work of the Foundation. Going forward, it is imperative that EVERYONE contribute in some way towards sustaining the Foundation and the Dysautonomia Center, or we risk it not being there when we need it.

We are reminded of a message from Parshat Vayikra, read before Pesach, which details sacrifices to be brought into the newly-built Mishkan (tabernacle). Several of the stipulations in this parsha have to do with differences in wealth, ensuring that everyone gives according to their means. No one is expected to match that which their neighbor can afford, but no one is exempt from offering **something**.

In the spirit of *Parshat Vayikra*, we'd like to suggest that there are ways for each of us, no matter our resources, to help support the Foundation's work:

- Become a fundraiser for our annual Crowdfunding Campaign;
- Create a Facebook fundraiser in honor of your birthday or another milestone event;
- Join (or organize) a Team FD event (walk/run/bike ride/spin/etc.);
- Plan a fundraising event in your community – the Foundation will help support your efforts!
- If you're a sibling or cousin in your 20's or 30's, join NextGen;
- Encourage teens you know to support the Foundation as their mitzvah project;
- Help us collect amazing prizes for our auctions and raffles;
- Need a gift? Purchase it from the FD Store;
- Have another idea? We want to hear it!

For more information about these and other opportunities, please contact the Foundation at 212-279-1066 or letkind@famdys.org

Together we will ensure that the FD Foundation and the Dysautonomia Center will continue to provide excellent medical care, to support cutting-edge research and to offer life-enhancing services now and in the future.

Sincerely,

Faye Ginsburg

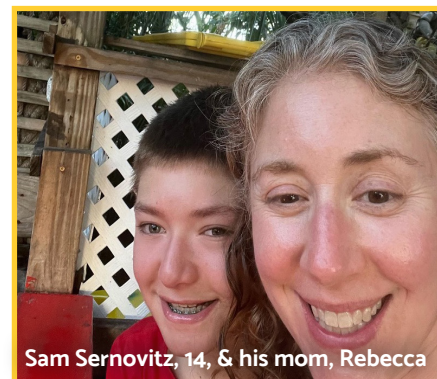
Lanie Etkind



FD BOARD OF DIRECTORS WELCOMES REBECCA SERNOVITZ

In December, the Foundation warmly welcomed **Rebecca Sernovitz** to the board. “We’ve been involved with FD since the get-go,” explains Becky. Just two years ago, Becky moved to Atlanta from outside of Philadelphia, with her husband **Larry**, who is a rabbi, their son, **Sam**, who is 14 and was born with FD, as well as their two younger daughters. “Sam was diagnosed at just four months old and he was an early adopter of carbidopa. We’ve been going to the Center for his annuals ever since and still try to go in person now that we’re down South, even during COVID.”

The Sernovitz family was involved in multiple bike races and walkathons for FD while they lived in Philly and attended FD Day in New York for many years. “I’ve connected to many FD moms who have kids near Sam’s age and even went to an FD peer’s Bat Mitzvah in Canada,” adds Becky. Working in recruiting at PwC, Rebecca hopes to bring her HR knowledge to the board. “We need more supporters and awareness of FD, especially down South. I think I can bring a new perspective to younger families. The biggest struggle for a lot of kids with FD is mental health, even more than medical issues, and we need to improve that. Where else can I better spend my time and efforts than bringing my passion to the FD board for the best future that Sam can have?”



Sam Sernovitz, 14, & his mom, Rebecca

SCIENTIFIC ADVISORY BOARD HOLDS FIRST IN-PERSON MEETING SINCE THE PANDEMIC

In November, the Scientific Advisory Board (SAB) held its first in-person meeting since the pandemic, welcoming members from Israel, France and across the U.S. The entire SAB board was present and according to **Frances Lefcort**, who is co-chair of the SAB, “It was the first time we were all in the same room with the two Israeli physicians and we got great insight from two retina/vision specialists as well. It was a terrific opportunity for us to establish smooth connections which will facilitate future productive working relationships.”

The group discussed the primary goals for treating FD, an update on gene therapy, research updates from the Dysautonomia Center and additional therapeutic approaches. The group plans to meet again virtually in April 2023, and will present their latest findings at FD Day in June.



Members of the SAB gathered for a fun evening before their November meeting

WE ARE KVELLING!

- **Alexia de Gunzburg's** story, “*Creativity - The Can-Do Attitude*” was featured as a chapter in the book, *The SHERO Mindset*, by Maria Luisa M. Carter (available on Amazon).
- In November 2022, **Dr. Alejandra Gonzalez-Duarte**, co-director of the Dysautonomia Center, was conferred the **Carl Seaman Family Chair** at NYU Langone and named as Clinical Associate Professor of Dysautonomia Treatment and Research.
- Mazel tov to long time board member **Howard Weiser** and his wife **Tova** on the Bat Mitzvah of their granddaughter in Silver Springs, MD in January 2023.
- In March, **Frances Lefcort**, co-chair of the FD SAB presented her paper, “What Elp1 Teaches Us About PNS Development” at the 2023 GRC Conference in Tuscany, Italy.

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!



TEAM FD RUNS THE 2023 UNITED AIRLINES NYC HALF MARATHON

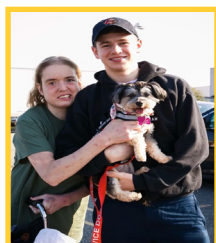


OFFICIAL CHARITY PARTNER



NYRR NEW YORK ROAD RUNNERS

Six dedicated members of [TeamFD](#) braved a chilly, windy day to run 13.1 miles through New York City on Sunday, March 19th, raising funds and awareness for FD. We are grateful to TeamFD, who together, brought in more than **\$15,000** for our cause!



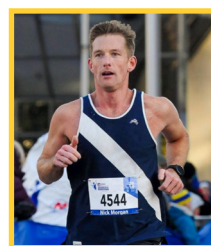
Jonathan Eisenson ran for his older sister **Rachael**, who has suffered from FD her entire life.



Sydnee Fried ran her first half marathon for her cousin **Morgan Asinowski**, who lives in Montreal. "I grew up in California, so we spent most of our lives visiting each other in our respective home cities." Morgan is the best person I know. He has the best attitude and the most loving heart. He is pure joy in a human being."



Madelyn Katz ran the 2023 United Airlines NYC Half Marathon to raise awareness and money for Familial Dysautonomia Foundation.



Nick Morgan ran the 2023 United Airlines NYC Half Marathon to raise awareness and money for Familial Dysautonomia Foundation.



Stephanie Rippis ran in honor of **Jack Posnack**. "Despite spending his life in and out of hospitals, he continues to greet each day with a smile on his face and spread love and joy wherever he can. He and his whole family have inspired us all to be better people."



Lily Szajnberg ran in memory of her cousin, (who was more like a sister) **Samatha Myers (z"l)** who had FD. "Her unflappable optimism and resilience to life are an inspiration to channel into this year's run and many more dollars to help fund the invaluable research that can improve the lives of people like Sam."

We're looking for a few more good runners!

FD Foundation has secured five spots for the [2023 TCS NYC Marathon](#) on **November 5, 2023**. This is your chance to help someone you know and love who has FD by raising funds and awareness to support our work. To indicate interest, please email info@famdys.org or contact the office at 212 - 279 - 1066.



OFFICIAL CHARITY PARTNER

tcs
NEW YORK CITY
MARATHON

SUE SLAUGENHAUPT IS AWARDED PRESTIGIOUS NIH BLUEPRINT GRANT FOR FD RESEARCH



In March, Scientific Advisory Board member **Susan A. Slaughaupt**, Ph.D., who is the Scientific Director at Mass General Research Institute and a Professor of Neurology (Genetics) at Harvard Medical School, was awarded a coveted Blueprint Neurotherapeutic Network grant from NIH.

"This is a chance for us to get our drug that we created in 2018 in collaboration with PTC Therapeutics through to patients," explains Dr. Slaughaupt. "It corrects the mis-splicing defect in FD and increases ELP1 protein. The great thing about this therapy is that it's easy to administer. It can be administered orally and gets to all tissues in the body including the brain."

The NIH Blueprint Neurotherapeutics Network (BPN) is a collaborative framework that includes the NIH Office of the Director and eleven NIH Institutes and Centers that support research on the nervous system. The BPN was launched to enable neuroscientists in academia and biotechnology companies to develop new drugs for nervous system disorders. Through the BPN program, investigators, together with the NIH, build a team and leverage drug discovery and development experts who can help them advance their basic research into human testing.

The Slaughaupt Lab's early drug development work was also funded through the Blueprint Network, which led to the collaboration with PTC Therapeutics in 2015. PTC is no longer working on a clinical development program for FD, but they have made the drug available to the Slaughaupt Lab for further development. "It's so exciting that we will get to partner with NIH funded consultants with extensive expertise in toxicology work," adds Dr. Slaughaupt. "We had enough preliminary data to get a positive review from NIH, and now we will work with them to do the safety studies which will hopefully get us an IND (investigational new drug) from the FDA. The data generated during the milestone driven grant will be evaluated every six months to determine if the project can continue to move forward, with the goal of bringing the drug to a clinical trial within the next several years.

Dr. Slaughaupt will work collectively with members from her Mass General lab, spearheading the collaborative team built and funded through NIH, together with **Dr. Horacio Kaufmann** and **Dr. Alejandra Gonzalez-Duarte** from the Dysautonomia Center at NYU. "We have a kickoff meeting slated for May 3rd in Boston and I'm sure there will be encouraging developments going forward," concludes Dr. Slaughaupt.

STILLMAN FAMILY OPENS THEIR PHOENIX HOME TO BENEFIT FD

On November 12th, more than 900 people strolled through **Stephanie and Brian Stillman's** house in Phoenix, Arizona, as part of the annual *Phoenix Home and Garden* self-guided tour of spectacular private homes. The magazine showcases just ten homes per year and **Hank Arens**, who is a longtime FD supporter and the acclaimed interior designer of the Stillman home, submitted it for consideration.

Explains Stephanie, mom to daughter **Pyper**, who was born with FD and is now 8 years old, "We were thrilled to be selected for the house tour. We asked that the tour be a fundraiser for FD and placed ads in the magazine about FD and information on how to donate in the tour brochure as well." The Stillmans also held a silent auction for FD, which brought in \$20,000. Adds Stephanie, "We played a video on a loop all day long in our living room about Pyper's condition and I think it really raised awareness and brought in bids for the auction."





FD FOUNDATION OBSERVES RARE DISEASE DAY ON FEBRUARY 28

The theme for this year's #RareDiseaseDay (Feb. 28th) was "Show Your Colors." In honor of this special day, the Foundation invited members of our community to share photos of themselves doing something they love. Check out these fun posts!

FD RESEARCH PUBLISHED IN LEADING SCIENTIFIC JOURNAL

In January, *Nature Communications*, a leading scientific journal, published a paper on [FD research](#) led by Scientific Advisory Board Cochair and [Montana State University](#) Professor **Frances Lefcort**. The work was conducted by a team that included graduate students and faculty from MSU's Department of Chemistry and Biochemistry and Department of Microbiology and Cell Biology in collaboration with researchers at the NYU Dysautonomia Center.

According to Dr. Lefcort, the paper investigated the impact of FD on the gut microbiomes and metabolisms of about 50 FD patients with findings that could lead to improved treatments that could mitigate symptoms and improve the overall quality of life for patients. "We learned so much from this research," explains Dr. Lefcort. "Over the last five years, it's become really clear to us that a person's neurological health is deeply affected by bacteria in the gut. Our team recognized that one strategy for improving human health in disease situations would be altering bacteria in the gut. People study this in common diseases like Alzheimer's and Parkinson's. But since we know the single gene cause of FD, we've got a cohesive population of people, all Ashkenazi Jews. We discovered that the only difference between the parent and the child is this one mutation. It's a powerful population to study to understand how gut bacteria could be affecting human health."



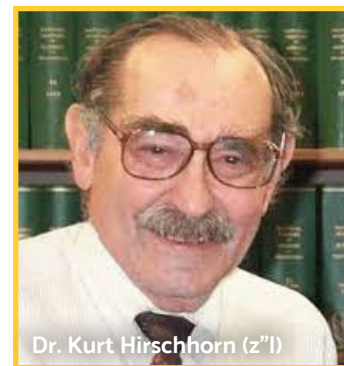
The team set out to find the connection between bacteria and the nervous system. "We know that most people with FD suffer from ulcers, diarrhea and constipation. They have problems with gut bacteria, get frequent infections and have to take antibiotics that alter their gut and metabolism. Since many people take probiotics, we thought maybe we could put together a great cocktail if we could figure it out so that's what we set out to do," notes Dr. Lefcort.

Collaborating with **Dr. Horacio Kaufmann** and **Lucy Norcliffe-Kaufmann** at the [NYU Dysautonomia Center](#), the research team collected stool and blood samples from patients and their relatives. Explains Dr. Lefcort, "We compared the bacteria in the gut and metabolism of those patients and their relatives and in both cases, we found they were altered in the patients. The parents were more similar to each other than to their children, showing how divergent the patients were. We know that certain bacteria are indicative of a healthy bacterial community but patients had lower levels of this. They are deficient in bacteria needed to have a healthy gut and metabolism." Another major finding was some of the metabolites like choline levels were altered in patients suggesting something wrong with choline metabolism. "With this information, we can potentially curate a diet that will correct choline levels to see if it will improve overall health," says Dr. Lefcort. "We could design probiotics or do some kind of stool transplant giving patients healthy bacteria. In fact, fecal transplants from parents to kids could help restore a normal bacterial community in patients." Dr. Lefcort hopes to conduct future trials and test whether correcting those imbalances would improve the health of patients. "We are extremely grateful to the patients and families for giving us samples. We could never have done this without all their help and support as well as from the clinicians at the Center. Hopefully a lot of good things are ahead," concludes Dr. Lefcort.

REMEMBERING DR. KURT HIRSCHHORN

Dr. Kurt Hirschhorn, a geneticist who worked at Mt. Sinai and had been a member of the FD Scientific Advisory Board (SAB) in the 1990s, passed away in November. Born in Vienna, Dr. Hirschhorn escaped the Holocaust and eventually became an important resource to the FD population.

According to **Dr. Susan Slaugenhaupt**, a current member of the SAB, “Dr. Hirschhorn was very involved when we were actively hunting for the gene. He kept us on our toes, pushing us to do better and keep searching. His depth of knowledge was tremendous.”



Adds **Dr. Felicia Axelrod**, who founded the Dysautonomia Center in 1969, “Kurt was a great guy. I took a year’s sabbatical from the Center to do a fellowship with him in 1975 because I wanted to work with him in genetics, knowing it was the future for FD.”

At Mt. Sinai, together they created long term lymphocyte lines on a number of FD patients. Axelrod adds, “I learned various genetic techniques with him mentoring me and asked my FD patients to come to Mt. Sinai to give blood. These lines lived for more than 20 years and eventually, Sue Slaugenhaupt was able to do family studies on them in her lab at Harvard. He was an innovative thinker and a wonderful mentor.”

In 1993, the location of the gene was identified and in 2001, scientists discovered the FD gene mutation, ushering in a new era of population screening and prenatal diagnosis. “Without those lines, I don’t think we could have identified the gene,” notes Dr. Axelrod. Adds **Faye Ginsburg**, Foundation President, “We have had so many amazing people helping us up the mountain. It’s so important to remember that legacy.”

PHD STUDENT WINS PRIZE FOR FD RESEARCH



In October, a Montana State University doctoral student received national recognition for her oral research presentation at the 2022 American Indian Science and Engineering Society conference in Palm Springs, California.

Stephanann Costello, a fifth-year Ph.D. student was awarded first place for her graduate research presentation describing the role of taurine metabolism in the development and progression of FD.

“My first year was a really life-changing experience,” said Costello, who explained that while she was growing up, her Aleut grandmother was hesitant to share or acknowledge the family’s cultural history. “Being part of the community of Native Americans in STEM at the conference was transformative for that part of my identity. I found a lot of support in who I am as a person and for the science I’m doing.”

Costello’s research is part of an MSU multidisciplinary study of FD. Three MSU professors are leading research on the disease: **Frances Lefcort**, research professor in the Department of Microbiology and Cell Biology in MSU’s College of Agriculture, who heads the neuroscience arm; **Seth Walk**, professor of microbiology and immunology, who is studying microbes in the digestive tracts of FD patients; and **Valerie Copié**, who is leading a large-scale study of patients’ metabolism by focusing on the small molecules known as metabolites that contribute to metabolic pathways.

2023 Calendar

May 22	26th Annual FD Golf Classic www.famdys.org/fdgolf23	Glen Oaks Club, Old Westbury, NY
June 11	FD Day www.famdys.org/fdday2023	Virtual
August 20	Stevie Schwartzberg Memorial Golf Outing	Edmonton, Alberta, CA
November 5	TCS New York City Marathon www.famdys.org/fdmarathon23	New York, NY

BITTY & BEAU'S IS SERVING UP COFFEE AND HOPE

Bitty & Beau's Coffee is more than just a place to grab a cup of coffee. The chain is named after Bitty and Beau, who both have Down syndrome. The mission-based shop was founded in Wilmington, North Carolina by their parents and is now a growing national franchise that proudly offers meaningful employment to people with intellectual and developmental disabilities. That's where **Frannie Cohen** comes in.



Born with FD, Frannie is now 28 years old. In addition to working at the JCC in her hometown of Charlotte, North Carolina, welcoming people at the fitness desk, Frannie has been working at her local Bitty & Beau's for more than a year, both at the cash register and making drinks for loyal customers. Explains **Marsha Cohen**, Frannie's mom, "Frannie just loves it. The shop is really busy with lines out the door. This place doesn't treat its employees like they have disabilities. It really brought out her confidence." Confirms Frannie, "I like working with my new friends and greeting the customers who come in, especially the regulars." While Frannie cannot drink anything by mouth, she is often asked what the best drink is at the local chain. "I tell them the vanilla latte is great. I try to be a good sport even though I don't get to take advantage of the employee perks like getting a free drink!"

Below, Frannie with **Larry Sprinkle**, the local weatherman, who did a story on her at work. To see the story, click here: <https://www.wncn.com/article/life/heartwarming/bitty-and-beaus-south-end-charlotte-north-carolina-coffee-shop/275-1e2c98e5-e7ca-4c54-af36-49832a91655f>

REMEMBERING BEN RAINER

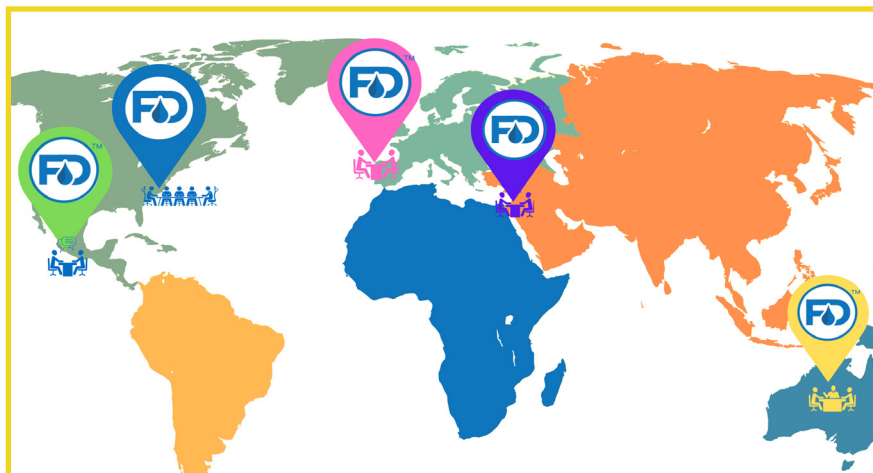
After 35-year-old **Ben Rainer** passed away from FD at the end of December, his family discovered he had a giant persona in the metaverse – complete with Marvel characters, chat groups and activity on various platforms. In fact, he knew thousands of people online, a virtual life consisting of people who didn't even know about his FD.

According to Ben's mom, Anne, who lives in L.A., "Ben was kind, funny and very bright, but locked in a broken body." She adds, "He loved Breaking Bad, going through a Walter White stage and was a Marvel comics fanatic." Ben worked at a TV production company for 11 years, making recommendations on pilots as to whether they should be made into shows. When he could no longer work, he joined Facebook chats to review movies, plots and characters. He then started a podcast called "Look Up in the Sky," a one-man show using his own voice to review sci fi and Comic con. "When the pandemic hit, he created a YouTube channel: The Multiverse of Geekdom. Since the whole world was home, this normalized his existence," adds Anne. "We heard him typing away with frenetic speed but we had no idea what he was doing. When I'd call him for dinner, he told me he couldn't come down because he had a show but I had no idea what that meant!" After his death, Ben's two younger brothers discovered many of his Twitter followers who created the "Ben-Verse" and put all of their shows under this title. Their intent was to unite the YouTube channels in his memory. At the end of each of these shows, they now feature his logo.



Adds Anne, "We learned that Ben had been their rock for years and came up with the idea to start shows, even teaching others how to do it. One boy from North Dakota had a stammer and later wrote to me saying, 'After watching Ben, I now have my own show and owe it all to him. He was the truest form of a friend to me.' Another from Israel said, 'I was at my lowest of lows and Ben showed up and taught me to create my own show.' The outpouring of support after he died was overwhelming and on January 5th, there was a memorial tribute on YouTube (<https://www.youtube.com/watch?v=HVxsESYVSRA>) for Ben, where his supporters organized a GoFundMe, raising \$5,300 for FD!

DYSAUTONOMIA CENTER FOSTERS INTERNATIONAL CLINICAL COLLABORATION



FD patients often present challenging medical issues that require unconventional solutions. The Dysautonomia Center has recently instituted virtual monthly meetings with an international team of clinicians from the US, UK, Israel, and Mexico. Established by Co-Director **Dr. Alejandra Gonzalez-Duarte**, these presentations create a space for practitioners to ask questions, challenge each other, and to discuss novel treatments for common complications. This group of clinicians brings a diverse set of experiences to the table, leading to important conversations regarding support for people with FD.

According to **Mecky Kuijpers**, Project Assistant at the NYU Center, “Our goal with this program is to foster a sense of community and collaboration between the members of the international FD medical community. Some countries, like the USA and Israel, are fortunate to have Centers dedicated to FD. Other countries with fewer FD patients often have just one or two doctors who see patients with FD, and who end up becoming a specialist for that patient. We hope that through these monthly sessions we can share cases that are interesting, challenging and unique, and we can ask our colleagues for advice. As we like to say, if you’ve seen one patient with FD then you’ve seen one patient with FD.”

Adds Mecky, “The first FD International Clinical Case Review was a huge success. **Dr. Bat-El Bar Aluma** from Israel presented a very interesting pulmonology case which stimulated conversations on different methods that are now being considered for treating patients at NYU. During our next meeting, **Dr. Alex Gileles** from Israel will be presenting one of his cases, which is sure to lead to more findings. Each of these meetings is stimulating and very helpful for the entire team.” Dr. Gonzalez-Duarte hopes to expand future sessions to include doctors treating FD in other countries such as Australia, Argentina, Belgium and Poland.

2023 FD Hangouts



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

PLEASE JOIN FD HANGOUTS THROUGH THE 2023 YEAR:

- **ORANGE GROUP** (50S-60S) - EVERY OTHER TUESDAY AT 7PM EDT
- **BLUE GROUP** (TEENS) - EVERY OTHER THURSDAY AT 5:15PM EDT
- **YELLOW GROUP** (20S/30S)- EVERY OTHER TUESDAY AT 5:30PM EDT
- **GREEN GROUP** (30S)- EVERY OTHER THURSDAY FROM 5-6PM EDT

If you are interested in participating in a hangout group and would like to [register](#), please contact us at info@famdys.org.

2023 Virtual Game Nights

Hosted by the FD Social Committee

Join your FD peers for a **GAME NIGHT**. No registration needed.
Meet on this zoom link: <https://us02web.zoom.us/j/9270416820>

Game Night
7:30 PM ET

20
Apr

Game Night
7:30 PM ET

18
May

Game Night
7:30 PM ET

15
Jun

Game Night
7:30 PM ET

20
Jul

Game Night
7:30 PM ET

17
Aug

Game Night
7:30 PM ET

21
Sep

Game Night
7:30 PM ET

19
Oct

Game Night
7:30 PM ET

16
Nov

Game Night
7:30 PM ET

21
Dec

ARE YOU...



Join Forever Devoted to:

- Honor or remember a loved one
- Express your appreciation for the life-enhancing work of the FD Foundation
- Ensure continued funding for care and research to support those affected by FD
- Support a cause that is meaningful to you
- Demonstrate your values to those who will follow you

There are many steps you can take TODAY to ensure that the FD Foundation will continue to be here TOMORROW:

- Make a bequest through your will. You can specify a dollar amount or a percentage or designate the Foundation as a residuary.
- Name the FD Foundation as a beneficiary of your retirement plan such as an IRA or 401(k).
- Include the FD Foundation as a beneficiary of a trust or life insurance policy.

Did you know...If you're aged 70 ½ or older, you can make a tax-free charitable gift of up to \$100,000 per year directly from your IRA.

Join the many others who have already taken steps to ensure the future of the FD Foundation. For more information or to join Forever Devoted, please contact Lanie Etkind, Executive Director, or consult your attorney or financial advisor.

CAN YOU SAVE A LIFE?

A young member of our FD community is in desperate need of a kidney.

She was diagnosed with end-stage renal failure and has dialysis three times a week.

Her family is not compatible so they are seeking an altruistic donor.

CAN YOU HELP?

Donors usually return to their normal lifestyle within 2-4 weeks post-transplant.

Living kidney donation is performed laparoscopically with minimal scarring.

Donors do not need to take lifelong medication nor are they restricted with their diet.

TO LEARN MORE ABOUT KIDNEY DONATION OR TO SEE IF YOU ARE A MATCH

Email: R24462@Renewal.org
Call: 718-431-9831 ext. 209
www.Renewal.org

WAYS TO SUPPORT FD

DONATE YOUR VEHICLE



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www.familialdysautonomia.org/donate-vehicle

1.866.628.2277



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Just CALL and say "FD sent us ..."

Then K&E Travel gives you a great price, keeps track of your booking, and after your travels, K&E sends the FD Foundation a check equal to 50% of their commissions.

561-966-9808



Double the Donation
matching gifts made easy



YOUR DONATION + COMPANY MATCH = **DOUBLE THE IMPACT!**

It's the perfect opportunity to see if your employer will match your donation.



DONATE CRYPTO



FD Foundation now accepts donations in Bitcoin, Ethereum, and over 40 leading cryptocurrencies! Visit: www.familialdysautonomia.org/donate-crypto to learn more.



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 for more information.

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

Amber Brooke Conor
Ronit Frydberg-wells
Robin Lewitas
Kim Olin
Barrie Freeman Rappaport
Jane Archer Salat
Daryl Schwartzberg
Diane Kandel Smolensky
Keshi Taryan-Kigel
Ralph Wexler

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>

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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 2023-1

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38TH ANNUAL CONFERENCE

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