Spring 2026

DYS/COURSE

NEWS FROM THE FAMILIAL DYSAUTONOMIA FOUNDATION

UPDATE ON THE IGALMI CLINICAL TRIAL

A HACK FOR DRY EYES

CONGRESS PASSES GIVE KIDS A CHANCE ACT

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

COVER ART BY PETER SONENSHEIN
"It is fun to watch the movie award shows and Pete picked up a moment of a surprise embrace by Adam Sandler with Timothy Chalamet in the audience. A great moment."

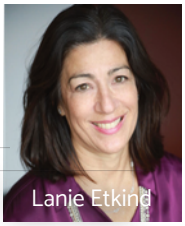
If you have an image you'd like to share for a future issue of DYS/COURSE, please send it to info@famdys.org

DYS/COURSE Spring 2026

Written by: Lanie Etkind, Alejandra Gonzalez-Duarte and Devorah Landau
Edited by: Faye Ginsburg and Lanie Etkind
Designed by: Nonprofit Ops Pro

MESSAGE FROM THE PRESIDENT AND EXECUTIVE DIRECTOR


Faye Ginsburg


Lanie Etkind

Dear Families, Friends and Supporters:

2026 year marks a remarkable milestone: 75 years since the establishment of the FD Foundation. What began as a small group of determined parents who came together in 1951 to support one another because they had nowhere else to turn has, over the years, evolved into a global force for progress, changing what's possible for those living with familial dysautonomia.

During the past seven and a half decades, the Foundation has taken a leading role in facilitating:

- **Specialized medical care** through the world's only dedicated FD treatment centers in New York and Israel,
- **Groundbreaking research**, including the discovery of the FD gene and ongoing therapeutic advancements,
- **Advocacy and education** that have transformed awareness, carrier screening, and clinical understanding, and
- **Support for families** navigating life with FD.

Every achievement was made possible by a committed community of donors, families, clinicians, and researchers who refused to give up hope.

Today, the Foundation is at an inflection point. For the first time, a treatment is currently in development that may not only slow deterioration but also restore aspects of function once believed to be permanently lost. At the same time, a population that is not growing (which is a good thing) means fewer impacted families to share the costs of sustaining the Foundation and its essential work. To quote Dr. Horacio Kaufmann, "This is a defining moment for our community. What generations hoped for is now within reach."

As we honor the FD Foundation's 75-year history, we invite you to join us in investing in our bright future. Suggests Dr. Kaufmann, "If our community stands together, united in purpose, we can change the course of FD."

Please stay tuned for more details about our 75th Anniversary Calendar of events.

Faye Ginsburg
President

Lanie Etkind
Executive Director

CONGRESS PASSES GIVE KIDS A CHANCE ACT

Thanks in large part to the advocacy efforts of our FD families and so many other rare disease communities, Congress finally passed the **Give Kids a Chance Act** in December 2025, and the President signed it into law in early 2026. A key provision of the Act is to renew the lapsed **Rare Pediatric Disease Priority Review Voucher (PRV) Program**, which incentivizes companies to develop treatments for children with rare conditions.


Dr. Frances Lefcort

Our readers may recall that **Tikun Therapeutics**, a public benefit corporation (PBC) wholly owned by the Foundation and under the leadership of **Adam Sachs** and **Frances Lefcort**, applied for and successfully secured **Rare Pediatric Disease** and **Orphan Drug Designations** for the small molecule therapy (under development at Harvard MGH through **Dr. Susan Slaugenhaupt**), and for the retinal gene therapy (first developed by Dr. Lefcort at Montana State University and now continuing under **Dr. Anil Chekuri** at Mass Eye and Ear). These two designations are required prerequisites for a future voucher request submission.


Adam Sachs

The PRV Program is a market-based incentive designed to encourage the development of new drugs for rare pediatric diseases. Established by the FDA in 2012, it aims to overcome the high costs and limited commercial incentives associated with developing treatments for small patient populations. A company such as Tikun that secures FDA approval for a drug targeting a rare pediatric disease such as FD may be awarded a (highly valuable) voucher, which then can be sold on the open market. This voucher can then be used by the holder to receive a priority review for a different drug application, speeding up the market entry of a potentially profitable product.

As Adam notes, "on behalf of the Tikun team we are thrilled that the PRV program is back in play. This opens up new potential funding pathways, particularly for parent-founder rare disease biotech companies like ours driving the development of multiple drug candidates."

TIKUN THERAPEUTICS

A "Hack" for Dry Eyes: Functional and Fashionable Dry Eye Eyewear


Jeremy Adler

Good news for dry eyes: No more wearing ugly goggles at the beach to protect against sand entering and irritating dry eyes. Ziena dry eyeglasses https://www.zienaeyewear.com feature a discrete, soft, latex-free silicone eyecup that creates a moisture chamber, retaining eye moisture and keeping eyes from drying out. The eyecup is designed to block airborne irritants such as dust, wind, sand, and pollen. Powerful micromagnets hold the eyecup in place and allow for easy removal to clean and replace. An optometrist can make prescription lenses to fit the frame.

Jeremy Adler, 38, of Melbourne, Australia has been wearing the glasses for several months and has found them helpful, and easy to clean. He uses a small damp cloth to clean the removable silicone shield. Then, after light cleaning, he wipes the lenses with a special anti-fog cloth that comes with the glasses. "Because the glasses retain moisture, they are prone to fogging up, so using the anti-fog cloth is important," explains **Suzanne Adler**, Jeremy's mother, who hopes getting the word out about the eyewear will help make an incremental difference for people with FD, whose eyes do not naturally produce tears.

UPDATES FROM THE DYSAUTONOMIA CENTER AT NYU LANGONE

A New Blood Test to Track Progress in Familial Dysautonomia

By Dr. Alejandra González-Duarte

We are making important progress in developing a simple blood test that can help better understand and monitor familial dysautonomia (FD).

FD is caused by changes in a gene called ELP1, which leads to lower levels of an important protein needed for normal nerve development and function. In animal studies, increasing ELP1 levels has been shown to improve many features of the disease, giving strong hope that treatments targeting this pathway could be effective in people. However, one of the main challenges has been the lack of a reliable way to measure ELP1 levels in patients over time.

In this study, we used a newly developed blood test to measure ELP1 protein levels in individuals with FD and in family members who carry the gene but do not have the disease. We found a very clear difference: people with FD had significantly lower levels of the ELP1 protein compared to carriers.

> "This type of biomarker will be essential as we move toward more targeted and effective treatments for familial dysautonomia."

Importantly, when we repeated the test in the same individuals, the results were highly consistent. In addition, when we measured levels again one year later, they remained stable, showing that this is a reliable marker over time.

We also identified a threshold level of ELP1 that strongly distinguishes individuals with FD from carriers. This means the test can help confirm the presence of the disease with a high degree of accuracy.

Why is this important? As new treatments are being developed to increase ELP1 protein levels—particularly gene-targeted therapies—we need a dependable way to measure whether these treatments are working in the body. This blood test provides a simple, objective, and minimally invasive tool to do just that. It allows us to directly assess whether a therapy is successfully increasing ELP1 levels, helping translate the promise seen in animal studies into meaningful progress for patients.

Overall, these findings represent an important step forward—not only for diagnosis, but also for monitoring response to emerging therapies. This type of biomarker will be essential as we move toward more targeted and effective treatments for familial dysautonomia.

This work has been published in Annals of Clinical and Translational Neurology, a peer-reviewed medical journal, making these findings available to the broader scientific and medical community. You can view it at https://onlinelibrary.wiley.com/doi/10.1002/acn3.70254

UPDATES FROM THE DYSAUTOMIA CENTER AT NYU LANGONE

Update on the IGALMI Clinical Trial

By Dr. Alejandra González-Duarte


Dr. Alejandra González-Duarte

We are pleased to share an update on the ongoing IGALMI clinical trial evaluating a sublingual form of dexmedetomidine for the treatment of autonomic crises in individuals with familial dysautonomia. This study is especially important because it compares the medication directly to placebo, which is required to obtain FDA approval for a treatment specifically indicated for autonomic crises in familial dysautonomia. At present, there are no approved medications for this purpose, and many patients rely on treatments such as benzodiazepines (e.g., diazepam), often at higher doses, to manage these episodes. The goal of this trial is to develop a safer, more targeted, and evidence-based option.

The use of dexmedetomidine for autonomic crises was initially inspired by prior clinical experience, using intranasal administration with encouraging results. However, intranasal dosing has limitations, particularly in terms of consistency and accurate dose delivery. The sublingual formulation being studied allows for more reliable and controlled dosing. Early findings from the trial are encouraging. When dexmedetomidine is given at the onset of a crisis, it reduced both heart rate and systolic blood pressure compared with placebo. In the early treatment group, systolic blood pressure decreased by an average of approximately 10 mmHg during the first two hours, whereas it increased in the placebo group. Heart rate also showed a markedly greater reduction with dexmedetomidine compared with placebo. Notably, patients receiving active treatment were more likely to settle, fall asleep, and come out of the crisis.

For those who required a second dose, additional improvements were observed, including further reductions in heart rate and blood pressure, supporting the potential role of dexmedetomidine in stabilizing autonomic function once a crisis has begun. An important recent modification to the study protocol has been made to improve patient comfort and feasibility: video recording during crises is no longer required. This change was implemented to reduce the burden on patients and families while maintaining the integrity and safety monitoring of the study. Although these results are still preliminary, they represent an important step toward developing an FDA-approved treatment specifically for autonomic crises in familial dysautonomia—something that has not previously been available. Importantly, the medication continues to show a reassuring safety profile, and no serious events have been attributed to the study drug.

We are deeply grateful to the families and participants whose involvement is making this progress possible. The trial remains open, and we encourage individuals experiencing autonomic crises to consider participating, as this will help bring this much-needed treatment closer to FDA approval.

If you want to participate in the IGALMI Study, please contact the Dysautonomia Center at 212-263-7225 or NYUDysautonomiaCenter@nyulangone.org.

N-LOREM AND NANO-RARE GET NATIONAL ATTENTION

On March 3, **Stanley Crooke MD Ph.D.** (founder of n-Lorem) and **Amy Williford, Ph.D.** (Vice President, Foundation Development and External Relations at **n-Lorem**) participated in a one-of-a-kind event, the **CNBC Cures Summit**. CNBC Cures is a broad initiative by CNBC to focus attention on rare disease, genetic medicines and the barriers preventing treatment from reaching patients. The first CNBC Cures Summit, held in March in NYC, served as the centerpiece of this initiative. As tickets to attend were limited, the audience was handpicked (including Warren Buffett) to bring together key decision makers and investors. The half-day meeting consisted of discussions led by Squawk Box co-anchor and rare mom, Rebecca Quick, that focused on how to accelerate breakthroughs in rare disease research and bring innovative treatments to patients faster.

n-lorem FOUNDATION
eating a better future for ultra-rare, one patient at a time.

CNBC cures

According to CNBC, there were more than 8K views of the livestream and nearly 330K social media impressions with over 457K video views. The high engagement of this meeting demonstrates just how much visibility is on rare disease. Throughout the 'call to action' event, n-Lorem was highlighted and it was evident that n-Lorem's approach that is bringing treatment to patients today is a catalyst for innovation in the space. Below are two links that may be of particular interest to our community:

- **Stan's discussion: Redefining What's Possible with Dr. Anna Greka and Dr. Stan Crooke https://www.cnbc.com/video/2026/03/04/redefining-whats-possible-with-gene-editing-and-aso-therapies.html**
- **Chris Viehbacher Biogen CEO: From Science to Impact:https://www.cnbc.com/video/2026/03/04/from-science-to-impact-with-biogen-ceo-chris-viehbacher.html**

To learn more, visit https://www.cnbc.com/cures/

As a reminder, the n-lorem Foundation is partnering with the Dysautonomia Center team and the FD Foundation to provide a specialized anti-sense oligonucleotide treatment as part of an FD clinical trial currently underway at NYU Langone.

Meet our Summer Intern: Alexa Gelenter


Alexa Gelenter

The FD Foundation welcomes its newest intern this summer, **Alexa Gelenter**, a rising senior biology major at Binghamton University. No stranger to rare diseases, Alexa will serve next academic year as vice president of Binghamton's Students for Rare Diseases Organization. Under the auspices of the National Organization for Rare Diseases (NORD), the student organization raises awareness, educates the campus community, organizes fundraisers, and supports people with rare diseases. Alexa's interest in rare diseases stems from personal experience. She has been diagnosed with Axenfeld Rieger's Syndrome, a rare genetic disorder that affects the eyes and is managed with medicated eyedrops. Alexa became familiar with FD and the work of the FD Foundation because one of her cousins is living with FD. "I am looking forward to helping the FD Foundation in any way I can," she said. "In turn, I hope to learn about how the organization carries out its vital mission." Alexa has a deep interest in genetics and the connection between genetics and disease.
She is particularly interested in skin disorders such as acne, eczema, and psoriasis, and she dreams of using her scientific knowledge to ameliorate or eradicate these conditions. A natural leader from Kinnelon, NJ, Alexa serves as president of her sorority, Zeta Tau Alpha, speaks French, loves horseback riding, and has a second degree black belt in traditional Okinawan karate.

“I am Not My Diagnosis” Synagogue Presentations Spotlight Life With FD

“I am not my diagnosis. I am a person who lives with a rare genetic disorder.” This is the strong opening statement **Gabi Jassie**, 32, of Forest Hills, New York, made in presentations at two local synagogues during February, the Reform Jewish movement’s Jewish Disability Awareness, Acceptance, and Inclusion Month (JDAAIM).

Since FD affects so few people, most people are unfamiliar with how the disorder impacts the autonomic and sensory nervous systems. Gabi began her presentation by explaining how rare FD is. “There are approximately 730 known diagnosed cases worldwide, and only about 300 people are currently living with FD.” When she was diagnosed, just before turning two, Gabi said she was assigned patient number 475. “That’s 475 in the entire world’s population in 1996,” she announced.


Gabi Jassie

To rapt audiences in three separate sessions for adults, grades K to 4, and grades 5 to 7 at Temple Tikvah in New Hyde Park and Temple Isaiah in Great Neck, NY, Gabi went on to describe how FD affects her eyes, her swallowing, her blood pressure, her ability to feel pain, and how she drinks and eats.

To make FD relatable, Gabi engaged the youngest students with thought-provoking questions. “Have you ever skinned your knee or broken a bone? Did it hurt? With FD, I don’t feel pain. I’ve fallen and not known that I broke a bone,” Gabi also spoke about avoiding sandy beaches, glitter, and eye make-up, drinking through a tube, staying away from extreme temperatures (missing a summer family trip to Greece), and needing to use oxygen before flights and during descent.

Gabi emphasized that her limitations have never prevented her from accomplishing. A graduate of Hunter College with honors in sociology, Gabi is a board-certified health and wellness coach. “I work, I create, I build relationships, and I contribute. I simply do so with accommodations that allow me to participate safely,” she said. She coaches virtually, uses a ride service, and employs a home health aide to assist with meal preparation, drinking, and hair styling.

Recognizing that many people shy away from people who are different from themselves, Gabi concluded her presentations with a request. “Don’t be afraid of FD, it’s not contagious. I want to be treated like everyone else. With respect. With kindness. With dignity. I’m just like you, but sometimes I do things a little differently.”

Rabbi Randy Sheinberg of Temple Tikvah, who has known Gabi since she was a teenager, said that Gabi was one of the most effective speakers the synagogue has ever invited to speak during JDAAIM. “Our young students can recognize pretense and falsehood,” she said. “They responded to Gabi because she is so genuine, so matter of fact, an inspiring model of integrity.”

Gabi encourages everyone affected by FD to share their stories. “If I can do it, anyone can,” she said, and added that promoting FD awareness has given her a sense of purpose. “I no longer ask, why me?” she said.

FAMILIAL DYSAUTONOMIA FOUNDATION, INC

FD FOUNDATION UPDATED MAILING ADDRESS AND PHONE NUMBER

719 2nd Ave #505
New York, NY
10016

212-279-1066

Update!

Gross Brothers Speak Out About FD

Kevin Gross, 43, and **Jason Gross**, 50, wanted their housemates and extended community to know more about FD and how the rare genetic disorder affects them and other people with FD. The brothers live in Hanover, New Hampshire in supported housing with ten other adults who have physical and developmental disabilities, but not FD.

Their 45-minute presentation began with video clips of people with FD and their parents discussing what it is like to live with FD, using the FRAME (Faces Reframing the Art of Medical Education) video about FD produced by Rick Guidotti at Positive Exposure, https://positiveexposure.org/frame/familial-dysautonomia/. Participants in the videos emphasized that although people with FD share symptoms and treatments, everyone affected has a unique medical journey. FD parent Laurent Landau likened the autonomic disorder to a car that does not respond to commands in the expected way. "If you turn on the switch to turn on your car, the windshield wipers go on. If you try to turn on the headlights, the seat goes down. So everything works a little differently. And actually, every FD kid works a little bit differently. So parents become technicians of their own kid," he said

Kevin and Jason Gross

The second video that Kevin and Jason shared featured a Hangouts meeting. Hangouts are weekly Zoom sessions that allow people with FD to socialize virtually, no matter where in the world they are located. In this recorded session, one person joined from Brazil, while others called in from the US. Participants compared their experiences, discussing how and when they were diagnosed, various interventions and treatments, and disease progression. They also spoke about how often they go out, and how they get around.

"With our helpers here [at our residence] we have more freedom to go out and spend time with friends and have a good time," Jason said. He explained that some outings are planned, while others occur spontaneously, such as a trip to the Apple store to fix a phone. The brothers mentioned that they often eat out, attend cultural and sports events, and participate in game nights and movie nights.

Direct Support Professional (DSP) Chris Murray, who attended the presentation, has worked with Kevin and Jason since 2024. He often accompanies the brothers on their errands and adventures. "Through my experiences with Kevin and Jason, I have come to know a lot about FD and the things they deal with on a regular basis." Chris said the presentation was "eye opening" for others who viewed the presentation and were previously unfamiliar with FD.

The third and final part of the presentation was nostalgic, showing Jason, Kevin and his twin sister, **Lisa**, during childhood trips to Universal Studios and Disney in Florida. The three siblings acted in an episode of Star Trek and a music video set on a beach. Lisa, who also had FD, passed away at age 36.

Jason and Kevin made the presentation available on Global Campus, an initiative Kevin has helped organize to bring classes to their house as well as to residents in two other supported houses. The entire presentation is available on YouTube. https://www.youtube.com/watch?v=FrcJDh2LZ0s&t=455s

A tax-wise tip for those aged 70 ½ and older: You can give up to $108,000 per calendar year to qualified charities (like the FD Foundation) directly from most IRA's (as can your spouse if you file jointly). The distribution counts towards your RMD, but the IRS does not treat it as income to you. Ask your financial advisor for details.

WE ARE KVELLING:


Anil Chekuri, Ph.D.

- We are delighted to share the news that **Anil Chekuri, Ph.D.**, principal investigator for the FD retinal gene therapy study, was honored with the **Bert M. Glaser MD Award for Innovative Retina Research**. View the full announcement at this link: https://www.newswise.com/articles/2026-bert-m-glaser-md-award-for-innovative-retina-research-announced
  Dr. Chekuri is also a 2025 recipient of an FD Foundation Young Investigator grant, funded through the **Clare and Philip Wexler Research Fund.**


Mara Clawson

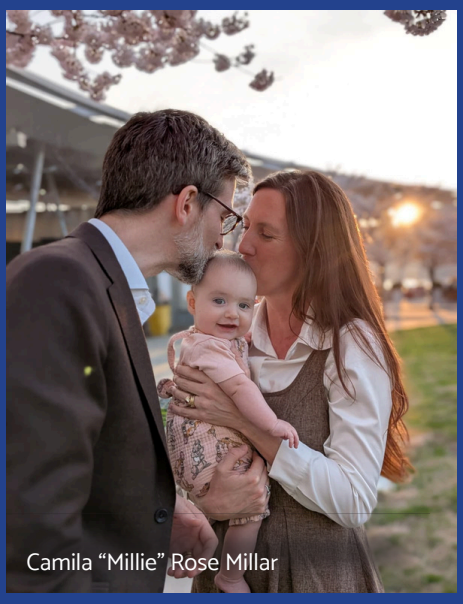
- We couldn't be prouder of **Mara Clawson**, who was selected to participate in the Artists-in-Residence Program at the acclaimed Byrdcliffe Arts Colony in Woodstock, NY last fall, an experience that Mara called "life changing."


Susan Slaugenhaupt, PhD

- **Susan A. Slaugenhaupt, Ph.D.**, Professor at Massachusetts General Hospital and Harvard Medical School and long-time FD investigator, is currently the President of the American Society of Human Genetics (ASHG). ASHG is the leading global organization for professionals in human genetics and genomics. ASHG envisions a future where people everywhere realize the benefits of human genetics and genomics research. The organization works to advance human genetics and genomics in science, health, and society through excellence in research, education, and advocacy.

Ruth Halle and family on her 100th birthday

- We wish a Happy (belated) 100th Birthday to FD parent, **Ruth Halle**. To celebrate, friends and family feted Ruth with cake and ice cream together with other residents at Ring House in Rockville, MD.

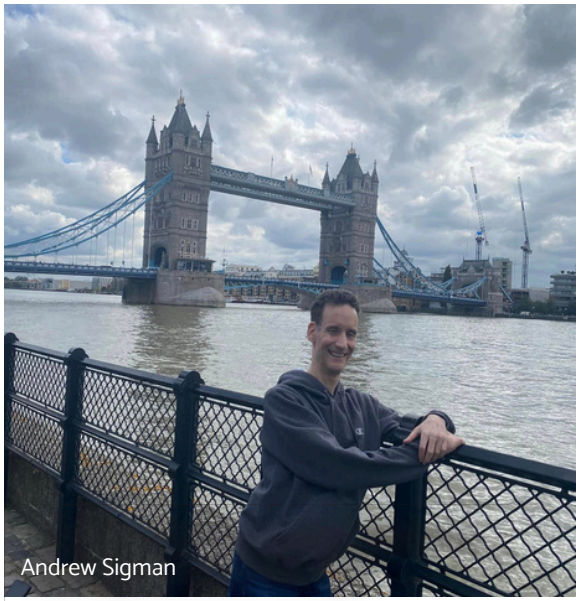

Camila "Millie" Rose Millar

- Mazel tov to **Kaia Dalamo**, Nurse Practitioner at the Dysautonomia Center, and **Patricio Millar**, MD, proud parents of baby girl Camila "Mille" Rose Millar, born November 3, 2025.


Faye Ginsburg

- Kudos to Foundation President **Faye Ginsburg** who, together with Dr. Rayna Rapp, was awarded the **Robert B. Textor and Family Prize for Excellence in Anticipatory Anthropology** for their book Disability Worlds by the American Anthropological Association.

The World is His Oyster:
Next Stops London and Paris


Andrew Sigman

Andrew Sigman, 48, of Boynton Beach, FL does not let FD get in the way of his travel plans. A seasoned traveler to Europe and Israel, Andrew's next trip will be in June to London and Paris for two weeks. A close friend will accompany him.

While most tourists can just book a flight and a hotel, pack a suitcase and be on their way, travel is more complicated for people with FD, and requires detailed advance planning. Andrew has been making preparations since booking the trip through Costco Travel. "I always book an accessible hotel room. I need a shower entrance that is level with the bathroom floor, meaning no need to step up or into a bathtub," he said.

In addition to requesting an accessible hotel room, Andrew must arrange to borrow an oxygen tank from the FD Foundation. "When people with FD fly, we need oxygen an hour before the flight, and an hour before the plane lands," he explained. Both Virgin Atlantic and Air France allow passengers to arrange in advance to fly with oxygen tanks.

To accommodate his mobility issues, Andrew will bring a walker instead of his usual cane. He has also ordered a mobility scooter to be delivered to his hotel room upon arrival.

https://www.wheelchair-mobility-scooter-rental-london.com/

https://www.mobilityscooter.fr

Since touring can be tiring, Andrew has left space in the itinerary for rest, should he need it.

Although he visited London four years ago, there still are many more attractions Andrew would like to see. They include the Churchill War Rooms in the Imperial War Museum and taking in the sights on a Dr. Who walking tour. Andrew is looking forward to taking in the culture and the architecture of both London and Paris. He also hopes to learn more about British and French politics.

How is Andrew able to travel on his own? Andrew's mother, **Shelley Sigman**, said that she raised Andrew to be independent. "As a single mom, I needed to know Andrew could take care of himself," she said. "For example, I taught Andrew to do his own laundry at a very early age."

Shelley added that Andrew always has had a positive outlook. "No one knows how long Andrew will be able to continue doing the things he loves. Let him enjoy life and have a wonderful time."

To follow on Instagram...scan the QR code. You can also follow Andrew on TikTok.

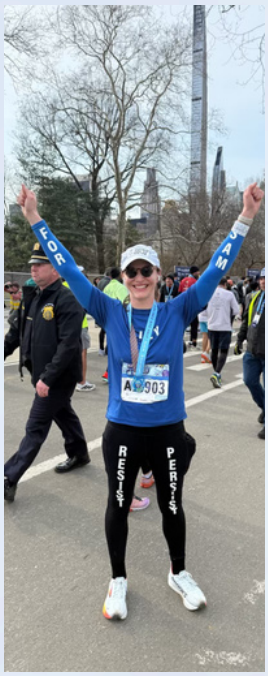
TeamFD RUNS 2026 UNITED AIRLINES NYC HALF MARATHON

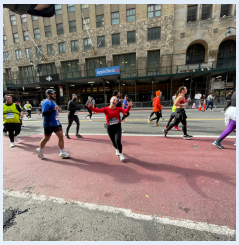
TO REMEMBER LOVED ONES AND RAISE FUNDS AND AWARENESS FOR FD

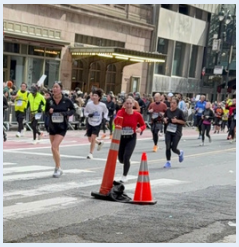
On Sunday, March 15, more than 30,000 runners finished the 2026 United Airlines NYC Half Marathon, hosted by New York Road Runners. Two of those runners represented TeamFD.

We are proud of and grateful to **Lily Szajnberg**, who completed her 4th Half Marathon (plus one Marathon) as a member of TeamFD in memory of her cousin **Sam Myers** and **Shani Sirota**, who completed her first Half Marathon as a member of TeamFD in memory of her cousin, **Scott Fass**.

Together Lily and Shani raised nearly $7000 to support the mission of the FD Foundation!







Mark your calendars for Sunday, November 1, to help us cheer on TeamFD running the 2026 TCS New York City Marathon!

Check out their fundraising pages at https://www.zeffy.com/en-US/peer-to-peer/2026-tcs-nyc-marathon and support our TeamFD runners today!

ARE YOU FOREVER DEVOTED?

LEARN HOW MICHELLE AND LANCE CLAWSON BALANCE THE DAUNTING CHALLENGE OF BOTH PLANNING FOR THE "G-D FORBID" AND SHOWING THEIR SUPPORT FOR THE FD FOUNDATION


Lance and Michelle Clawson

We look forward to welcoming FD parents and others as members of Forever Devoted.

Once you have included the Foundation in your estate plans, please let us know so we can acknowledge you as a member of our Forever Devoted Planned Giving Society.

Please contact the Foundation at 212-279-1066 or letkind@famdys.org for more information.

While **Michelle and Lance Clawson** are among our more recently added members of Forever Devoted, the recognition society for those who have included the FD Foundation in their estate plans, their plans are not new. More than two decades ago, Michelle and Lance, parents of **Mara**, now age 34, understood that they needed to be ready for a "G-d forbid" situation.

Working with a trust and estate attorney, they developed a plan that would 1) ensure that there would be adequate resources in place to provide for Mara's needs in case of their absence, and 2) direct funds to the FD Foundation (among others) once no longer needed by their family. Said Lance, "Why include the FD Foundation in our estate plans? That's easy–because both the Foundation and the Dysautonomia Center at NYU have been pivotal in our lives, providing Mara with the care and services she has needed to enjoy her best possible quality of life." Michelle added, "Knowing that our plan is in place gives us peace of mind.

With this plan, we have achieved the dual objectives of providing for our family's needs and ensuring that that much-needed resources will eventually flow to the Foundation." Michelle and Lance want others to know that estate planning involving a special needs family member can be complicated, and that laws can vary by state, so they encourage parents to seek out professional guidance. You'll be glad you did.

Pledging a planned gift requires no outlay of cash today but asks you to consider how your funds will be disbursed at a future time. We invite you to:

- **Include a bequest to the Foundation in your will or trust:** You can specify an amount or a percentage, a residuary or a contingency, ensuring that your loved ones are provided for as well.
- **Name the Foundation as a beneficiary (or partial beneficiary) of a bank account or investment account; life insurance policy; or IRA, 401K or other retirement plan**: This can usually be done simply by completing a form and does not require an attorney.

Add YOUR NAME to the list of those who are investing in the future of FD care and research with a gift from their estate:

- Eric H. Arnold
- The Lou Bacon Share B Trust
- Birdie H. Blaine Living Trust in memory of Miriam Amy Blaine
- Miriam Borenstein (z'l) & Irving Borenstein (z'l)
- Gladys Heyman Brown Revocable Trust (Joan and Beth Susan Heyman Fund
- Lance Clawson & Michelle Marks
- Alvin Fishman
- David Gelley
- Faye Ginsburg & Fred Myers
- Estate and Trust of Sylvia Greenberg
- Beatrice Klier (z'l)
- Ann R. Laderman
- Phyllis Linker (z'l)
- Matzkin Family Trust
- Stanton B. Miller
- Lisa & Jeffrey Newman
- Faye Rabinowitz (z'l)
- Dena & Michael Raffler
- Eddie Ross Charitable Remainder Trust
- Sylvia Shandler (z'l)
- Samuel J. Silling (z'l)
- Rochelle Solomon
- Brian & Stephanie Stillman
- Karen & Paul Wexler
- Patricia Ann Young (z'l)
- Lucille Zolty (z'l)
- Anonymous Friends

FD FOUNDATION ACHIEVES HIGHEST RATINGS FOR 2026 FROM PROMINENT CHARITABLE OVERSIGHT GROUPS

Guidestar/Candid: Platinum Seal of Transparency

Platinum Transparency 2026

Candid.

A Platinum Seal of Transparency from Candid (formerly GuideStar) is the highest level of recognition for U.S. nonprofits, indicating a deep commitment to accountability and data sharing. Only a small fraction of charities achieve this top-tier seal.
https://app.candid.org/profile/6941929/familial-dysautonomia-fd-foundation-inc-13-6145280?keyword=famili

Charity Navigator: 4 stars and 100%

A 4-star rating from Charity Navigator signifies "Exceptional" status, indicating the nonprofit exceeds industry standards, operates with high financial efficiency, and maintains strong transparency and accountability. It is the highest rating, awarded to only about one-quarter of evaluated charities.
https://www.charitynavigator.org/portal/dashboard

Charity Navigator

FOUR-STAR

Can you help us secure prizes for the FD Golf Classic?

29TH ANNUAL FD 2026 GOLF CLASSIC

We invite members of our community to support our 29th Annual Golf Classic by contributing items to our raffle and live/silent auction—always one of the most exciting and impactful parts of the event. Your donation directly fuels our fundraising efforts, helping advance critical research and essential support for the FD Foundation. It's a meaningful way to showcase your generosity and your commitment to making a lasting difference in the lives of those affected by FD. We are seeking items such as:

- Foursomes at private golf courses in the NY Metro area or South Florida
- Broadway theater tickets
- Tickets to New York (or other) professional sports teams
- Vacation stays at exclusive resorts, spas, or destinations
- Dinners at upscale restaurants in the NY Metro area or South Florida

Matching Gifts:

Free Money? Too Good to Be True. Or Is It?

If someone told you that you might be able to double—or even triple the value of your gift to the FD Foundation, what would you say?

It's true! Many employers – perhaps even yours – will match their employees' (and sometimes retirees') gifts to charities, magnifying the impact of your contributions.

How can you find out if your employer has a matching gift program? Just ask!

You may also need to submit some paperwork—we are happy to help you with that.

Bottom line? Don't leave "free money" on the table! Put your –and your employer's philanthropic dollars to work to help further the mission of the FD Foundation!

To learn more about Matching Gifts, ask your employer or visit https://familialdysautonomia.org/double-donation to learn more.

Hangouts

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

- ORANGE GROUP (40S-60S) - MONDAYS WEEKLY AT 7:00PM ET
- GREEN GROUP (30S)- MONDAYS BIWEEKLY AT 8:00PM ET
- YELLOW GROUP (20S)- MONDAYS BIWEEKLY AT 6:00PM ET
- BLUE GROUP (TEENS) - MONDAYS WEEKLY ALTERNATING BETWEEN 6:00PM & 8:00PM ET

If you are interested in participating in a hangout group and would like to register, please contact Michelle at info@famdys.org.

Virtual Game Nights

Hosted on Zoom by the FD Social Committee

Game Nights are open to all. No registration is needed.

If you are interested in participating please contact Michelle at info@famdys.org to receive a zoom invitation.

Game Night 7:00 PM ET — 18 May

Game Night 7:00 PM ET — 29 Jun

Game Night 7:00 PM ET — 27 Jul

Game Night 7:00 PM ET — 24 Aug

More 2026 Dates Coming Soon!

Virtual Hangouts Connect Peers With FD

If you are looking for ways to meet and socialize virtually with others your age who have FD, Hangouts could be for you. Four age-specific Hangout groups are held weekly or biweekly for one hour on Zoom, for teens, people in their 20's and 30's, and those 40 years and up. If you are more interested in playing games than conversing, there also is a fun-filled monthly virtual Game Night for all ages.

"Hangouts are a great way for participants who might live far away from each other, to get to know one another, and to share common experiences as well as resources," said **Michelle Schwab**, who for the past two years has facilitated both Hangouts and Game Night. Michelle explained that the conversations in Hangouts usually flow freely and naturally, she is there to guide when difficult topics come up, or when there is a lull in the conversation. For teens, to stimulate conversation, she sometimes engages participants with a game, such as Would You Rather.

No stranger to FD, Michelle worked four and a half years as a caregiver to a person with FD. She recently received a Masters in Clinical Mental Health Counseling and currently is pursuing a PhD at Montclair State. "It is so rewarding to see friendships develop and flourish, and community created among people who have so much in common but might not ordinarily meet," she said.

To learn more about Hangouts and Game Nights, please email Michelle at michelle61096@gmail.com.

Gratitude to:

Carla Rosenberg

Deborah McGlynn

Sarah Wilson Sorensen

For hosting FaceBook fundraisers to benefit the FD Foundation

&

Jason Joseph

For hosting his second YouTube fundraiser in memory of his brother, **Mitchell**.

If you have an idea for a fundraising and/or awareness campaign for FD, we'd love to help you launch it! Please contact the FD Foundation team at info@famdys.org or 212-279-1066.

FOLLOW US ON:

- famdys.org
- @Famdys
- @famdys
- @famdysfoundation
- @FamDys
- @FamDys

WAYS TO SUPPORT THE FD FOUNDATION

WAYS TO SUPPORT

FAMILIAL DYSAUTONOMIA FOUNDATION, INC

01.

BECOME A MONTHLY FD FOUNDATION DONOR

Did you know you could pre-set monthly donations to the FD Foundation by credit card or ACH bank payments? Visit the donation form to get started!

www.famdys.org/donate

02.

DONATE YOUR VEHICLE

If you have an old vehicle and don't want to deal with it just donate it to the Foundation. The process is simple. Cars, Trucks, RVs, Boats, Motorcycles are accepted.

www.famdys.org/donate-vehicle

03.

DOUBLE YOUR DONATION

Many employers will match charitable gifts made by their employees. Check to see if your employer participates!

www.famdys.org/double-donation

04.

DONATE APPRECIATED STOCK

This is an excellent tax strategy, as the IRS allows you to deduct the current value of the stock rather than its original cost. Please contact the Foundation for more info.

www.famdys.org/donate/stock

05.

PLAN YOUR TRIP WITH K&E TRAVEL

www.ketravel.com

Just call and say "FD sent us" ... Get 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!

FAMILIAL DYSAUTONOMIA FOUNDATION, INC

719 2nd Ave, #505
New York, New York 10016

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A copy of our latest annual report may be obtained from the FD Foundation 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.

NORD 2026 MEMBER PLATINUM

Platinum Transparency 2026 Candid.

Charity Navigator FOUR-STAR

DYS/COURSE 2026- 1

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