

Fall 2021

DYS/COURSE

NEWS FROM THE FAMILIAL DYSAUTONOMIA FOUNDATION

**FD FOUNDATION
TURNS 70**

**JOIN THE FD PARENTS
CHAT GROUP!**

**NEW FACES AT THE
FD FOUNDATION AND
THE DYSAUTONOMIA
CENTER**



**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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ARE WE CONNECTED?

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

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JOIN THE FD PARENTS CHAT GROUP!

Many years ago, **Barrie Rappaport**, mother of **Michelle**, created a chat group for FD parents and caregivers. This is a forum where parents can ask questions, share ideas and even simchas such as new jobs or accolades. According to Barrie, who lives in the Chicago area, "The FD chat group is a private site where families who are directly affected by FD can talk to each other and receive support from others in the same boat." With more than 60 members from all over the world, the group discusses what it's like having a child growing up with FD and imparts wisdom to parents with younger children today. While it's not active every day, some months there are many messages, depending on the subject. Adds Barrie, "There are lots of topics about preserving vision and how FD patients are handling the sclera contact lenses and getting fewer corneal abrasions. There are also plenty of conversations related to Covid vaccines, and if kids have had Covid, how they are doing. We really hope to cheer people up when they are having difficulties."

To join the group, go to: fdsupport+subscribe@groups.io.

GRATITUDE TO:

Barrie Rappaport, who worked with a board committee, sharing her marketing expertise to compile and analyze the results of the FD Family Survey. The information gathered was extremely helpful in identifying what is working well at the Center and areas that may need improvement.

Robin Landau, for helping to build community by setting up a Peloton group, #famdysriders for FD. The group welcomes anyone who has a Peloton at home or work or has access to one at the gym to join, so all can ride together and chat at the same time!

Perry Goldberger, for her volunteer efforts with the FD Foundation. Perry calls donors who contribute to the FD Foundation and thanks them for their support.

Mike Zucker, who participates in a bicycling event every year to raise funds and awareness for the Foundation in honor of his daughter, Sarah. This year, Mike flew past his fundraising goal, bringing in more than \$8,000 to support the FD mission.

Innovating Worthy Projects for its \$10,000 grant to the FD Foundation to support virtual medical kits and telemedicine visits at the NYU Treatment Center.



MESSAGE FROM THE PRESIDENT AND EXECUTIVE DIRECTOR

Dear Friends,

GRATITUDE

As we get closer to the holiday season, and with Thanksgiving just around the corner, we thought that GRATITUDE might be an appropriate theme to explore in our message for this issue.

The past 18 months have been challenging for all of us, including those responsible for keeping the Foundation on track. We are GRATEFUL to the many dedicated people who come together every day to ensure that the FD Foundation can continue its important work:

- **The team at the Dysautonomia Treatment Center**, who have helped guide us through the health challenges of the pandemic, developed and implemented a telemedicine program to ensure continuity of care, and who continue their efforts to keep our community as healthy as possible;
- **The Board of Directors**, whose leadership and vision has ensured the Foundation's stability, even during these uncertain times;
- **Our Scientific Advisory Board**, comprised of highly accomplished scientists, researchers, physicians and pharmaceutical executives, who despite their busy professional lives, make time to promote, participate in and encourage research to identify new treatments for FD;
- **The Foundation staff**, who keep the Foundation running on a day-to-day basis;
- **NextGen**, a dedicated group of siblings, cousins and friends of people with FD, who represent the future of the Foundation;
- **Volunteers**, who help in the office (and virtually) as well as assist at events, providing much-needed support to the Foundation team;
- **Donors**, whose philanthropic support makes it possible for the Foundation to invest in the highest quality medical care and cutting-edge research;
- And of course, **our Families**, the Foundation's raison d'être. Our families provide financial support, organize events and fundraise for the Foundation, help raise awareness for FD and give us helpful feedback to ensure that we can best meet their needs.

They say "it takes a village..."

We are GRATEFUL to all who are part of our "FD Village," and who contribute to our mission. We couldn't do it without YOU.

Wishing you a Happy Thanksgiving, Happy Chanukah and all the best during the coming holiday season.

Faye Ginsburg

Faye Ginsburg

Lanie Etkind

Lanie Etkind

WE ARE KVELLING!

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

Mazel tov to NextGen founder **Adam Kietz** and his wife **Elizabeth Shapiro** on the occasion of their wedding on August 21, 2021 at Engineers Country Club in Roslyn, NY, and to Adam's parents, FD Foundation board member **Steve Kietz** and his wife **Barbara**.

Congratulations to FD Foundation board member **Paul Wexler** and his wife **Karen**, who became grandparents for the second time when their grandson, **Leo Jaymes Berdia** was born on June 6. Best wishes also to proud parents **Stefani** and **Jay Berdia** of Rockville, MD and big sister **Ella**.

Adrian Krainer, an esteemed member of our Scientific Advisory Board, was awarded the 2021 Wolf Prize in Medicine. The Wolf Prize, a highly prestigious international award, is presented by the Wolf Foundation and the President of the State of Israel. Dr. Krainer is best known for his work on RNA splicing and the development of Spinraza, the first FDA-approved treatment for spinal muscular atrophy (SMA).

Mazel Tov to **Steve Kietz** who in August, was named CEO of Reliant Funding, a leading small business finance company. Steve, a vice president of the FD Foundation board, previously

served as the firm's Chief Marketing Officer.

Forbes magazine recently honored FD Foundation board member **Paul Wexler** as a 2021 Best in State Wealth Advisor for New York. As a managing director in wealth management at UBS, he was selected for going "above and beyond" for his clients.



Kudos to **Yehuda Blonder**, who has FD and participated in Bike4Chai, a 100-mile bike-athon in July, raising more than \$11,000 for Chai Lifeline and Camp Simcha in memory of his good friend, Yochi.

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



HOST A FACEBOOK FUNDRAISER TO BENEFIT FD

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

Thanks to everyone who held a Facebook fundraiser for us so far in 2021:

- | | | |
|---------------------|-----------------|-------------------------|
| Alyson Brenner | Kelly Brotman | Natalie Cohen |
| Andrew Sigman | Kim Finkel | Rebecca Newman |
| Barrie Rappaport | Lainie Roebuck | Robin Landau |
| Debbie Eisenson | Laurent Landau | Samantha Armzelga Brown |
| Faye Ginsburg | Lisa Kaplan | Sara-Ann Scherwin |
| Felix Frydberg | Lisa Newman | Stefani Wexler Berdia |
| Fred Meyers | Liz Kietz | Tee-Jay Anderson Cohen |
| Jeff Newman | Mara Clawson | Troy Heflin |
| Jennifer Sonenshein | Michelle Schwab | |
| Joe Greenberg | Mike Zucker | |

GOLF OUTING A SWINGING SUCCESS



On the links at the FD Classic (l to r): Kevin Shinnick. John Bretschneider, Dan Rackow and event chair Paul Wexler

After a one-year hiatus due to the COVID-19 pandemic, the FD Golf Classic reconvened for its 24th year. On June 21st, a record number of golfers enjoyed a glorious summer day on the links at the Glen Oaks Club in Old Westbury, NY. Many thanks to our sponsors and donors whose generous contributions support the FD Foundation's mission. We are especially grateful to Golf Chairs **Paul Wexler**, **Steve Fass**, **Steve Kietz** and **Rachel Schlau** for their ongoing efforts to create a successful and enjoyable event.

SAVE THE DATE
for the 25th Annual FD Golf
Classic, scheduled for **Monday,**
May 23 at Glen Oaks Club.

FD DAY 2021: A VIRTUAL GATHERING OF OUR INTERNATIONAL COMMUNITY

On Sunday, June 6, computers across the United States, Canada, Israel, Great Britain, Europe, South America and Australia were tuned in to FD Day 2021. While the coronavirus forced FD Day to go virtual in 2020, this year the Foundation made a conscious choice to continue the virtual format. Though we have enjoyed gathering in person in New York for past FD Days, we now realize that going virtual enables so many more members of the FD community to participate!

This year's FD Day program kicked off with a video segment called "We're watching from...", featuring recorded greetings submitted by FD families from around the world. We then heard updates from the FD Foundation and from our international chapters in Canada, Great Britain and Israel.

During the Clinical Session, **Dr. Horacio Kaufmann** and his excellent team provided the latest news on FD care and treatment, including the recently implemented telemedicine initiative; we met **Dr. Alejandra Gonzalez-Duarte**, the newest member to join the Center's team; and we heard from FD physicians in Israel, **Dr. Alex Gileles-Hillel** (Hadassah) and **Dr. Bat-El Bar Aluma** (Sheba).

This year's Distinguished Awards were presented to: **Kelly Brotman**, **Rebecca Newman**, **Ram Shalev** and **Avi Zimmels**.

New in 2021, the FD Art Contest, skillfully organized by nurse practitioner **Kaia Dalamo** and **Rick Guidotti** of Positive Exposure, showcased the incredible artistic talent of many people with FD. Prizes were awarded to: **Ivan Zelione** (drawing), **Peter Sonenshein** (painting) and **Sam Landau** (video). All participants received special recognition.

The Research Session highlighted new and encouraging advances on the scientific front and featured talks by "super star" members of the Foundation's Scientific Advisory Board: **Sue Slaughaupt** (Mass General), **Frances Lefcort** (Montana State Univ.) and **Adrian Krainer** (Cold Spring Harbor Laboratory).

Both the Clinical and Research sessions included an opportunity for participants to engage with the panelists for a live Q & A.

View a recording of the full FD Day program or individual segments here: <https://familialdysautonomia.org/events/upcoming-events/fd-day-2021>

In conjunction with FD Day, the NYU Treatment Center team prepared a comprehensive Research Booklet, which you can view here: https://familialdysautonomia.org/application/files/5216/2696/1813/Research_Booklet_2020-2021_PDF.pdf

We are grateful to financial supporters of FD Day 2021: **Faye Ginsburg & Fred Myers**; **Deena & Daniel Landau**; **Jennifer & David Sonenshein**; **Tova & Howard Weiser**; **Town Total Compounding Center**; and **JScreen.org**



Logo designed by Julia Newman

FD FOUNDATION, ESTABLISHED IN 1951, COMMEMORATES 70TH ANNIVERSARY

**A brief look back over the
Foundation's 70-year history...**

Seventy years ago, a caring and empathetic pediatrician named **Dr. Conrad Milton Riley**, who with his colleague, **Dr. Richard Lawrence Day**, had recently identified a rare hereditary syndrome, brought together the parents to form a support group, **one of the first parent support groups for a genetic disease in the United States**. While its genetic origins were still unknown, the fact that all the families were of Ashkenazi Jewish descent suggested that this group was at risk. With strength in numbers, the parents could compare symptoms, and explore and discuss treatments and care. That year, in **1951**, the small group of forward-thinking parents formed the Familial Dysautonomia (FD) Foundation.

Today, the FD Foundation works for the benefit of all people afflicted with FD, fewer than 800 ever diagnosed and 303 currently living worldwide, by supporting medical care and scientific research, as well as conducting social service and public awareness programs. The Foundation continues to be the main source of funding for the Dysautonomia Treatment Center at NYU Langone Medical Center in New York City, the only place in the US that provides clinical care for people with FD, and the model

for two treatment centers in Israel. The Foundation's support helps fund treatments that improve life expectancy and quality of life for people with FD, as well as research seeking a possible cure. In addition, the Foundation sponsors conferences for doctors and scientists to share their knowledge, and since 1985, has hosted FD Day, an annual symposium that brings together families and caregivers for a day of learning and connecting.

In **1969**, **Dr. Joseph Dancis** was treating pediatric patients with rare diseases at Bellevue Hospital in New York City. He asked **Dr. Felicia Axelrod**, who had just completed her training at New York University (NYU) School of Medicine, to become the attending physician of record for six to 12 FD patients at University Hospital (today called Tisch Hospital and part of NYU Langone Medical Center). Having seen many of these patients and observed their crises during her training, Dr. Axelrod realized the need to collect and systematically organize information about the patients and their medical histories.

The following year, Dr. Axelrod established, and the FD Foundation began funding, the Dysautonomia Treatment Center at NYU Medical Center, which she directed until her retirement in 2015, when **Dr. Horacio Kaufmann** took over as Director of the Center. By the end of the first year, the Center had about 50 patients, many from outside New York. Today, the Center follows about 160 patients and is available to consult with doctors managing the care of those with FD in other locations such as the UK, Israel, Canada and Mexico. A multidisciplinary team of highly trained physicians, nurse practitioners and researchers manages daily patient care, performs annual physicals, handles patient emergencies 24/7 and oversees clinical research. Currently, 12 clinical studies are underway.

The work of our physicians and scientists has had a tremendous impact on prolonging lives. Today, there is a 50 percent chance that an FD patient will live to age 40; the largest number of adults are living with FD since the first diagnosis, the result of the substantially improved care that the Dysautonomia Treatment Center has pioneered over the last half century.

When patients began treatment at the Dysautonomia Center in the **1970s**, they completed medical history questionnaires. In the **1980s**, Dr. Axelrod took steps to digitize the FD database. Based on the robust data for over 650 patients, in 2017, the Center received a National Institutes of Health (NIH) grant for a natural history study that will help researchers better understand the progression of this disease and develop new therapeutic treatments to treat degenerative FD symptoms that affect older patients such as failing vision, spine curvature, unstable gait and impaired balance and coordination.

In **1990**, after consulting with scientists, the Board of Directors determined

that the Foundation should direct most of its funds towards research to locate the gene responsible for FD. The Foundation funded the prominent geneticist, **Dr. James Gusella**, of the Harvard School of Medicine. In **1991**, **Dr. Susan Slaugenhaupt** joined Gusella's lab as a post-doctoral fellow, bringing a strong background in gene mapping, the process of locating genes on chromosomes.

Thanks to the Foundation's support, collaboration with the Treatment Center, and further funding from the NIH, in **2001**, Dr. Slaugenhaupt discovered the FD gene mutation on Chromosome 9Q. Once the gene was located, potential parents could be tested before conceiving to determine if they carried the gene, and babies already conceived could be screened prenatally. The Foundation advocated for required screening for at-risk families through the American Academy of Obstetrics and Gynecology. FD was added to the Jewish Genetic Screening Panel and is

now a routine part of all prenatal carrier screening, resulting in dramatically fewer FD births worldwide.

Dr. Slaugenhaupt and her team identified the mutation as a gene-splicing error in Elongator complex protein 1 (ELP1, also known as IKBKAP); since then, Sue has dedicated her work to discovering how to repair the splicing defect as a route to a therapeutic intervention for those with FD. In **2016**, Dr. Slaugenhaupt's lab generated a phenotypic mouse model (mice with FD) and in **2019** was able to successfully correct the splicing defect in her mice, a treatment that has the potential to improve patients' sensory-motor coordination and intervene in the onset of spinal abnormalities.

The **2020s** are an exciting time for the FD Foundation:

- The work of its international Scientific Advisory Board and its support for research has accelerated the search

for treatments to slow or arrest FD's degenerative effects; Researchers have been approaching FD from all angles; several potential treatments are currently in the pipeline and could be ready for clinical trials by **2022**.

- The NYU Treatment Center is committed to expanding access for patients through annual checkups via telemedicine (begun during 2020's pandemic so that patients would not have to travel to New York) and will continue to build the natural history study for FD, crucial for providing essential knowledge to research on rare diseases, while proceeding with exciting, groundbreaking treatments.

This article is excerpted from a longer article written by Devorah Landau, communications professional and grandmother of a child with FD.

#BOXJUMPCHALLENGE #JUMPFORFD

In late October the FD Foundation launched the #BOXJUMPCHALLENGE to raise funds and awareness for FD. The brainchild of the Schwartzberg family of Edmonton, Canada, the campaign honors the memory of their son and brother Stevie Schwartzberg, who conquered the very challenging box jump as just one of the many hurdles he faced living with FD.

Modeled after the extremely successful Ice Bucket Challenge for ALS, the #BOXJUMPCHALLENGE invites all to:

- 1) Jump on a box (any raised surface will do)
- 2) Post your jump on your favorite social media and tag it **#BOXJUMPCHALLENGE** or **#JUMPFORFD**
- 3) Challenge 3 (or more) friends to do the same
- 4) Donate at <http://bit.ly/jumpford>

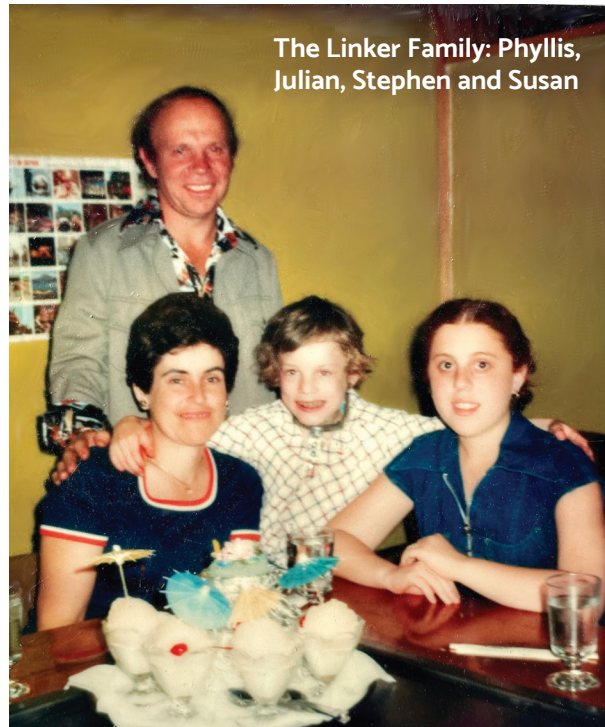
Will you help us make the #BOXJUMPCHALLENGE go viral?
JUMP TO IT!

Proceeds from the #BOXJUMPCHALLENGE fund the Mental Health Counseling program at the Dysautonomia Center, previously established in Stevie's name.



**STEVIE
SCHWARTZBERG
MEMORIAL FUND**

A BEQUEST THAT WILL MAKE A TRUE DIFFERENCE



The Linker Family: Phyllis, Julian, Stephen and Susan

The FD Foundation gratefully acknowledges a generous bequest from the estate of **Phyllis Linker**, the mother of **Stephen Linker**, who had FD and passed away in 1981 at the age of 17. Stephen had been seen by Dr. Axelrod early in her career and the family was most grateful for the ongoing care she provided.

Phyllis passed away this past March in Manhattan and had been involved with the FD Foundation for many years. According to her daughter Susan, who also lives in Manhattan, "My mom used to set up a gift shop for the holidays to benefit the FD Foundation. She worked with a wholesale distributor who helped nonprofits by giving them jewelry and housewares to sell. People from Long Island would purchase items and then, in turn, create their own gift shops throughout the area to sell to their friends in their homes."

While Phyllis knew that Stephen wasn't going to be a direct beneficiary in her will, she wanted to memorialize his legacy. Adds Susan, "Familial Dysautonomia played a large role in our family. A lot of my friends are siblings of children who had FD so we created a makeshift support group. My mom wanted to make sure that both of her children were somehow taken care of and this gift to the Foundation provided her the perfect outlet to do so."

All of us at the FD Foundation genuinely appreciate this generous legacy gift, as it will help our efforts to continue to make life better for those with FD.

If you wish to support the mission of the FD Foundation well into the future, you may want to consider a Planned Gift. Planned Giving offers options to make a contribution that may cost you little or nothing today, but will make a meaningful difference to FD tomorrow. In addition to supporting a cause that is important to you, there may be tax benefits for you or your estate. To learn more or to join our Forever Devoted Legacy Society, please contact **Lanie Etkind, Executive Director** at 212-279-1066 or letkind@famdys.org

THE VOICE OF FD

We are excited to announce the FD Foundation's newest initiative, the Voice of FD. VOFD represents the Foundation's efforts to move towards self-direction, meaning paying closer attention to and incorporating the voices and opinions of the folks directly impacted when determining the activities and priorities of the Foundation. Self-direction has become an area of increased focus within the disability community, and it is something potential funders are looking for as well. The Foundation's Voice of FD initiative kicked-off with a Virtual Town Hall Meeting on July 11 attended by several dozen people who have FD and some parents. Those present asked lots of great questions and expressed many excellent ideas. We look forward to collaborating and building this new program together, and we invite anyone interested to participate and contribute their suggestions. Please stay tuned for notice of the next (virtual) VOFD meeting.

Interested in participating in a future Voice of FD meeting? Contact Lanie Etkind at letkind@famdys.org.



Dr. Alejandra Gonzalez-Duarte

WELCOME DR. ALEJANDRA GONZALEZ-DUARTE

A great big welcome to **Dr. Alejandra Gonzalez-Duarte** who became the Assistant Director of the Dysautonomia Treatment Center in July. After serving as a Fellow at the Center in 2009, Dr. Gonzalez-Duarte returned to her native Mexico City to work at a clinic there until moving back to New York this summer. Dr. Gonzalez-Duarte is providing hands-on patient care while also conducting clinical research on FD. She adds, "Most of my former patients have grown up and it's great to see the same faces. It's very rewarding for me. I am most excited about making some changes after reviewing all the guidelines again and updating them." Dr. Gonzalez-Duarte was able to be a part of FD Day this year and enjoyed learning about all the new programs in place. "The virtual medical kits are great, and we are now updating them to include even more technology. They are extremely helpful for people who are not mobile." While the Center is providing both in person and telemedicine consultations, Dr. Gonzalez-Duarte notes that "since the Center is made up of staff from all around the world, it feels right that we are able to provide care to patients globally with our new telemedicine initiatives."



Erin Duddy

COMINGS AND GOINGS AT THE FOUNDATION OFFICE

We are pleased to welcome **Erin Duddy** who joined the Foundation team in September as Development Associate. A California native, Erin received her B.A. from the University of Michigan in Political Science with a minor in Gender, Race, and Nation in May 2021. She moved to Brooklyn in September and is most looking forward to "building a connection with the FD team and being able to contribute to a cause that has made so many great gains in recent history." Erin has always been passionate about getting involved in her community and fell in love with non-profit work during her time as a Development intern at GirlForward, a non-profit focused on enhancing opportunities for girls from refugee communities. Erin is delighted to join the FD Foundation's team to support and enhance the FD Foundation's mission. In her free time, Erin enjoys listening to and discovering new music, a passion she shares with her two siblings, and spending time reading and cooking.

Thanks and farewell to our colleagues **Aaron Breen**, who moved to Texas for a new venture, and to **Natasha Weinstein**, who has accepted a position at the Leukemia and Lymphoma Society.



CROWDFUNDING CAMPAIGN #FDMATCH 2021 MAKES AN IMPACT

For the 5th year in a row, the FD Foundation launched its annual crowdfunding campaign – #FDMatch2021. This year’s event celebrated and commemorated 70 years of trailblazing history, medical research and tremendous strides towards enhancing and extending the lives of people affected by this devastating and extremely rare genetic disorder. Thanks to the dedication of nearly 30 fundraisers and the support of well over 500 donors, we raised close to \$225,000 at press time, enabling us to fund vital FD programs and services such as virtual check-ups at NYU’s Dysautonomia Center and critical treatment initiatives.

#GIVING TUESDAY™

Tuesday, November 30, 2021
<https://www.givingtuesday.org>

Mark your calendars! #GivingTuesday is held annually the Tuesday right after Thanksgiving, this year on November 30. The event was created in 2012 as a simple idea: a day that encourages people to do good. Over the past nine years, this mission has grown into a global movement that inspires hundreds of millions of people to give, collaborate, and celebrate generosity. Participating in GivingTuesday is about joining a movement. Whether you give your voice, goods, time, or money, being generous is a way to fight for the causes you care about and help people in need. Want to give back? Consider volunteering with or donating to the FD Foundation! Contact Erin Duddy at eduddy@famdys.org for more information.

“MIX IT UP” WITH NEXTGEN

What to do when you can’t host a live Happy Hour fundraiser in a bar because of the pandemic? Invite your friends to join you for a virtual mixology experience instead! That’s exactly what the FD Foundation’s NextGen Committee did. “Mix It Up” with NextGen, held in May, offered an interactive evening of cocktails and fun, all for a good cause. Attendees learned how to make two cocktails, including one that was custom designed especially for our group!

NextGen looks forward to organizing additional fundraising and awareness programming in the future.

If you’re a young professional (age 20’s & 30’s) who is a sibling/ cousin/friend of someone who has FD, we’d love for you to join our NextGen group. For more information contact info@famdys.org.

FD IN THE NEWS

Recently, our very own **Jack “Jack Attack” Posnack** was featured on ESPN via an interview with Matthew Berry. Check out the clip here: <https://www.youtube.com/watch?v=TXx4WHT7nx4>

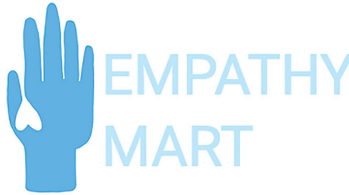
Scientific Advisory Board Member **Sue Slaughaupt** was featured in a blog published by the Mass General Research Institute about her life as a scientist. Read the article here: <https://mgriblog.org/2021/03/26/voices-of-women-in-science-susan-slaughaupt-phd/>

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AmazonSmile has raised more than \$215 million for charity since its debut in 2013. Check out smile.amazon.com – This holiday season and throughout the year, you can shop on Amazon, and support the FD Foundation. It’s easy:

1. Sign up at smile.amazon.com
2. When prompted, choose **Dysautonomia Foundation, Inc.** as your charity.
3. Do all your Amazon shopping at smile.amazon.com and support a great cause!



A GREAT WAY TO SUPPORT THE FD COMMUNITY

Have you tried Empathy Mart? It’s a great way to support the FD Foundation simply by shopping or donating from the comfort of home! EM will send you a pre-paid parcel to ship your item(s). When your item(s) sell(s), the FD Foundation receives a portion of the proceeds.

It’s simple :

- Select items to donate
- Choose FD Foundation as your charity
- Follow shipping instructions

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

Save the Date

Giving Tuesday

Tuesday, November 30, 2021
<https://www.givingtuesday.org>

Champions for Charity

Thursday, December 2 - Saturday, December 4
Americana Manhasset (also available for virtual shopping)
championsforcharity.org

PLEASE JOIN US IN 2022:

Peeper Pyper’s Un-Birthday Party

Sunday, February 27, Arizona Jewish Historical Society, Phoenix, AZ

25th Annual FD Golf Classic

Monday, May 23, Glen Oaks Club, Old Westbury, NY

37th Annual FD Day

Sunday, June 12, Virtual

13th Annual Chicago Ladies Lunch & Play

Monday, July 25, Ravinia Green Country Club, Riverwoods, IL

FD Newsletter Fall 2021

Written by: Lisa Denburg
Edited by: Lanie Etkind and Faye Ginsburg

ON THE COVER

Samantha Myers and **Michelle Schwab**, her support person, collaborated on this photo, taken two weeks after Samantha’s second vaccination. They encountered this wonderful mural by Jeff Rose King on Bleecker Street in Greenwich Village, NY, where Sam lives, and got inspired to give Samantha wings.

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

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

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



**FAMILIAL
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DYS/COURSE 2021-2

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encouraged!*

SHOP

December 2-4

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for **curbside pick-up.**

*Store appointments
encouraged!*

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