

SPRING 2020

DYS/COURSE

NEWS OF FAMILIAL DYSAUTONOMIA (FD)

**FD FOUNDATION GOES
TO WASHINGTON
OCTOBER 19**

**FD HOPE JOINS
FORCES WITH THE FD
FOUNDATION**

**FD DAY GOES "VIRTUAL"
FOR 2020!**

**THE IMPORTANCE OF A
GOOD NIGHT'S SLEEP**



**FAMILIAL
DYSAUTONOMIA**
FOUNDATION, INC

FD DAY GOES “VIRTUAL” AND GLOBAL FOR 2020!

Every June, FD Day takes place at NYU’s Medical Center, where as many as 150 family members make the trip into Manhattan. This year, due to the worldwide coronavirus pandemic, the conference will be virtual, so that families can participate remotely. It’s something you definitely won’t want to miss.

FD Day 2020 is set for Sunday, June 7th and will encompass two sessions: one for clinical care and one for research progress. It will be a shorter FD Day than usual, starting at a time that makes it possible for people in Israel, Europe, and North America to participate. It’s the first time FD Day will be livestreamed, but it’s also the first time our clinical researchers will be able to reach members of the FD community all over the world at the same time.



Lucy Norcliffe-Kaufmann and Sue Slaughaupt speaking at FD Day 2019

Traditionally, FD Day is an annual event that brings doctors and scientists together with those with FD, their family and supporters, so they can learn about advances in medical treatment and future research plans. It’s a day when we all hear how improvements in care based on clinical studies can be incorporated into daily life. For many, it’s an opportunity to hear about new potential therapies and learn how to play an essential role in furthering crucial research. It’s also a time for those in the FD community to have a chance to catch up.

“The technology is here,” explains Dr. Lucy Norcliffe-Kaufmann. “Through virtual FD Day we actually have the opportunity to reach a greater number of patients while they remain in the safety of their own homes. We don’t want to delay and wait one year to show families how they can get involved. FD patients need advances in treatment today.”

Those with FD used to have limited options as to where they could go for care. Now patients have a choice. The Center has been working for a while on making a global FD network, and their approach to developing new treatments is shifting rapidly.



Steven Wexler, Pyper Stillman and Stephanie Stillman enjoying games during FD Day 2019

Adds Kaufmann, “Our virtual FD Day will keep families in the loop. We are collaborating with teams in Israel, London, and Mexico City. There are talented clinicians who have trained with us or have connections to our staff who see patients with FD at their local hospitals. We communicate and share ideas on patients. Those international networks were built with the plan of a global approach to developing new treatments.”

Of course, the staff at the Center will miss taking people with FD out for karaoke and pizza after the conference. But right now, the priority is keeping the research progress happening, while keeping people with FD safe in their own homes.

Notes Kaufmann, “It’s important to get families involved. We need to make sure that geographic boundaries are no longer a constraint for progress in rare diseases like FD.” Virtual FD Day 2020 is a time to sign up, get involved and be part of a global movement to find a cure.

35th Annual Conference

FD Day

Sunday, June 7, 2020

NOW VIRTUAL!

Register at:
www.famdys.org/fdday2020

A Day When Families, Researchers, and Doctors Come Together (Virtually)

FAMILIAL DYSAUTONOMIA FOUNDATION, INC.

Presented by Familial Dysautonomia Foundation in conjunction with NYU Dysautonomia Center

Registration is now open:
www.famdys.org/fdday2020

WE ARE KVELLING!

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



Dr. Horacio Kaufmann

Dr. Horacio Kaufmann was recognized with the Irwin Schatz Award from the American Academy of Neurology for his outstanding achievements in autonomic disorders research.

In January 2020, an article on FD and Baroreflex Dysfunction by **Horacio Kaufmann MD**, **Lucy Norcliffe-Kaufmann PhD** and **Jose-Alberto Palma MD PhD** was published in **The New England Journal of Medicine**, the top medical journal in the world. To learn more visit: <https://dysautonomiacenter.com/2020/03/10/review-on-dysautonomias-in-the-new-england-journal-of-medicine/>

In February 2020, **Lucy Norcliffe-Kaufmann** was a visiting professor at the Innsbruck Medical Hospital in Austria where she gave a lecture on FD. Additionally, she was featured in a published article in the alumni profiles of the British Heart Foundation about her work with FD. To read more, visit <https://alumni.bhf.org.uk/news/263153>.

FD Foundation board member **Paul Wexler**, Managing Director - Wealth Management at UBS, was named a 2020 “Best-in-State Wealth Advisor” for New York by SHOOK Research and Forbes for the third consecutive year.

Alexia de Gunzburg was named a Leader in the Capernaum Club, an organization in Naples, Florida that focuses on teens and young adults of all abilities with special needs.

Samantha Myers performed at the Daniel Music Foundation (<https://www.danielsmusic.org>) in November 2019, a non-profit organization dedicated to empowering individuals with disabilities through music.

Zenith Kahn, nurse practitioner at the FD Center, was married in Anaheim, California in March during a week-long festive celebration. Her husband, Faraz Khan, is an Emergency Medicine resident at SUNY Downstate. Her pink veil was made by fellow nurse practitioner Kaia Delamo and the mehndi on her hand depicts the Brooklyn Bridge.



Zenith and Faraz Kahn

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!

FD FOUNDATION GOES TO WASHINGTON OCTOBER 19

It's time to make the FDA aware of FD. Now that we have a number of potential pharmaceutical treatments for FD in the pipeline that will need FDA approval, it is critical that the FDA have a thorough understanding of the distinctive features of familial dysautonomia, its effects on the body, the varied range of impact on individual patients, and the particular challenges of conducting clinical research involving people with FD.

After submitting a Letter of Intent, the Foundation recently learned that the FDA has agreed that an **Externally-Led Patient Focused Drug Development (PFDD) meeting** would be of great value and interest to the patient community, patient advocates, researchers, drug developers, and the FDA. The PFDD meeting is confirmed to take place on **Monday, October 19** at the **College Park Marriott Hotel & Conference Center in Hyattsville, MD.**



The PFDD initiative aims to more systematically obtain the patient perspective on a specific disease and its treatment. The patient perspective is critical in helping the FDA understand the context in which regulatory decisions are made for new drugs. PFDD meetings give the FDA and other key stakeholders, including medical product developers, health care providers and federal partners, an important opportunity to hear directly from patients, their families, caregivers, and patient advocates. This input can inform the FDA's decisions and oversight during the drug development process.

The PFDD is an unparalleled opportunity for you to share your personal experience as a person with FD or their caregiver:

How does FD impact your daily life? What are the greatest challenges you face? What symptoms are most distressing to you? How has FD most affected you over time? What existing treatments work for you and what don't? What kind of studies are you willing to participate in?

There will be various opportunities for patients and families to participate in the PFDD—both in person and remotely—as panelists, as contributors to the live conversation, answering polling questions throughout the program, and more.

For information about attending and/or participating in the PFDD in Washington, D.C. on October 19, please contact PFDD@famdys.org or visit famdys.org/pfdd. Don't miss this opportunity to make a positive impact on your own life! (To learn more about the externally-led PFDD, visit www.fda.gov)

GRATITUDE TO:

The Morton H. Meyerson Family Foundation for its recent grant of \$18,000 to the FD Foundation. We are grateful to the Meyerson Foundation for investing in outreach and education efforts to raise visibility and awareness of FD.

The Joe Namath Foundation for their grant of \$5,000. The Joe Namath Foundation funds children's charities and neurological research.

Both of these grants resulted from a personal connection to the funder through a friend of the FD Foundation. Can YOU introduce us to a potential funder?

FD HOPE JOINS FORCES WITH THE FD FOUNDATION

The FD Foundation is honored to welcome friends and supporters of FD HOPE into our fold. FD HOPE was founded in 2001 to provide opportunities to fund additional scientific research areas that weren't being considered years ago.

In recognition of the diverse range of projects and research endeavors currently underway at the FD Foundation, in December the board of FD HOPE notified our Foundation that they had decided to disband and put their support behind our work.

It's an easy synergy, since both groups share similar objectives of advancing the scientific and medical understanding of the FD mutation, developing treatments to halt the progression of this devastating disorder and improving the lives of individuals with FD.

We are grateful to the board of FD Hope for entrusting the FD Foundation with their reserve funds, which will be used to support medical research, and for encouraging their friends and supporters to join us as well.

Together we are even stronger and more resolute in our efforts to make every day better for those with FD and to move closer to finding a cure!



Lucy Norcliffe-Kaufmann and Kaia Dalamo run a “virtual” half marathon for FD

UNITED AIRLINES 2020 NYC HALF MARATHON: THE SHOW MUST GO ON...



Five dedicated friends of the Foundation joined Team FD to run the United Airlines NYC Half Marathon on March 15. For months in advance they prepared by fundraising for FD and training for the 13.1 mile race. Unfortunately, the coronavirus hit NYC in early March and forced organizers to cancel this year’s event.

Not to be deterred, **Lucy Norcliffe-Kaufmann**, Associate Director of the Dysautonomia Center, and **Kaia Dalamo**,

nurse practitioner at the Center, ran a virtual half marathon together (see photo above). Congrats to Lucy as our top fundraiser (\$6,641) this year and to both Lucy and Kaia for completing their first half marathon!

Participants **Alice Brownstein**, a physician whose father Mike is the former chair of the Foundation’s Scientific Advisory Board, and her husband **John Gerarden**, had planned to travel from Seattle to participate in the event. Together John and Alice have raised more than \$3,500 for FD. Alice and John have decided to run in the 2021 half marathon instead. Says John, “These resilient patients, and the chance to run with my wife, are the reasons why I will be participating in the United Airlines NYC Half Marathon next year.”

Brian Levine has also claimed his guaranteed spot for next year’s NYC Half; and he plans to continue to raise funds for FD. Explains Brian, “My cousin Josh Kietz and I were born just 10 days apart. Josh is one of the most loving guys around. He’s funny, smart, caring and loved so much by his family. Josh was diagnosed with FD at birth and I am running in his honor.”

Thanks to all for your enthusiastic participation and support! See you in 2021!

Interested in organizing or joining a TEAM FD event to run/bike/row/etc. for FD? Please contact the Foundation office for more information.

JOSE MARTINEZ CELEBRATES A DECADE AT THE DYSAUTONOMIA CENTER



This year marked a decade of service at the Dysautonomia Center for scientific researcher **Jose Martinez**. A certified clinical research coordinator with a master’s degree in physiology, Jose began his career at Columbia Medical Center followed by years of psychiatric practice at Mt. Sinai, where he first met Dr. Horacio Kaufmann. After Dr. Kaufmann moved to NYU, he contacted Jose to join his team.

Jose spends his time at the Center managing and conducting clinical trials for FD patients. “I have probably been involved in 15-20 studies during my tenure at the Center,” adds Jose. “Some of the studies last about a year, while others are ongoing for a few months. It’s particularly rewarding being at the forefront of discovering new drugs to help our patients.”

Jose currently lives in Bergen County, New Jersey with his wife; they have three grown sons. When asked about his favorite part of his role, Jose explained, “I particularly love working with bright people on the first stages of creating a new drug. It’s incredibly inspiring to see our patients respond to a study and it’s very motivating when we see the progress.” During the COVID-19 outbreak, Jose has been working from home, speaking with patients on the phone while assessing questionnaires related to the studies. The labs are conducted remotely as well with a partnership through Quest Diagnostics. “Thank goodness for telemedicine,” adds Jose.



Faye Ginsburg



Lanie Etkind

MESSAGE FROM THE PRESIDENT AND EXECUTIVE DIRECTOR

Dear Friends,

We have all been facing unimaginable challenges during the Coronavirus crisis. We are writing this message from our respective places of “social isolation.” We know that our FD families face even greater stress than most, ensuring that our loved ones stay safe, healthy and virus-free. Many of us have found comfort and support from within the FD community, commiserating and sharing helpful tips on keeping the virus at bay. It feels good to know we are all in this together.

We especially want to take this opportunity to acknowledge Dr. Horacio Kaufmann and his hard-working and dedicated team at the Dysautonomia Center at NYU. They are on the front lines of this health care crisis. Whether on-site at NYU or working remotely from home, they have been providing us with comprehensive and up-to-date information on the coronavirus as it relates to FD, and they continue to be available 24/7 to answer our questions and to ensure that our patients stay as safe and healthy as possible. Interestingly, they are relying more on telemedicine to connect with patients, which is a trend that will likely continue well beyond the current situation. We appreciate all they do for our community.

We also want you to know that the Foundation has not gone unscathed by the coronavirus outbreak. Our March events, the NYC Half Marathon and a showing of Living Art (a film about Mara Clawson who has FD) at the JCC Chicago Jewish Film Festival were both cancelled. Our Long Island Golf Outing, scheduled for May 18, has been postponed until May 24, 2021. The Chicago Ladies Lunch & Play, planned for July 27, has been cancelled, although we will encourage supporters to play virtually. Additionally, we have postponed a meeting of the Scientific Advisory Board planned for early June. And of course, FD Day will be virtual this year (visit www.famdys.org/fdday2020 for more details). Unfortunately, all of these postponements, together with the current economic crisis, has put further financial pressure on the Foundation, which has seen a considerable drop in revenue. We urge you to continue to support the FD Foundation to the extent you are able, and to help promote our mission to others who might be in the position to support us as well. Please contact the Foundation if you have questions or ideas.

Despite all of these challenges, we are optimistic that the road ahead for the Foundation is bright. We especially look forward to coming together as a community for FD Day on June 7. Since we will be virtual this year, we hope that friends from across the country and around the globe will join us to learn about the latest developments on both the medical and research fronts. Additionally, we eagerly await the opportunity to educate the FDA about FD during the externally-led Patient Focused Drug Development meeting (see article page 3) scheduled for October 19. We encourage you to join us (virtually or in person) for both of these very special events.

In the meantime, we hope you are all staying safe and healthy, and we hope that by the time this newsletter lands in your (very clean) hands, there has been better news on the coronavirus front.

Faye Ginsburg

Lanie Etkind

SCIENTIFIC ADVISORY BOARD ANNOUNCES NEW LEADERSHIP



Adrian Gilbert



Frances Lefcort

After many years, **Mike Brownstein, MD PhD** stepped down as chair of the Scientific Advisory Board (SAB). All of us at the FD Foundation are deeply grateful to Mike for his many years of invaluable leadership and guidance. At the same time, we are delighted to announce that **Adrian Gilbert, PhD** and **Frances Lefcort, PhD**, have accepted co-chairmanship of the SAB.

Adrian brings with him more than 26 years of experience in the pharmaceutical industry. He lives in Israel with his family, including his daughter Tamar, who has FD. Adrian and his wife Michelle are also active with the Israeli FD Organization. Adds Adrian, “As an FD parent who has

worked in drug development for the past 30 years, this is the most important, exciting and urgent challenge I could imagine. Frances is an outstanding scientist and I am truly optimistic that we can help bring new therapies to FD patients that change lives.”

Frances is a professor of cell biology and neuroscience at Montana State University. Frances’ passion for FD was developed close to home as she grew up with two cousins who lived with the disorder. Her lab has developed several mouse models for FD, and her goal is to identify therapeutics that could prevent neuron degeneration in both the retina and the parasympathetic nervous systems. According to Frances, “Thanks to the wisdom of the FD Foundation and the SAB, the expert and dedicated clinicians at the Center, and breakthroughs made by scientific researchers across the globe, we now have a deep understanding of how to treat FD. I am honored to co-direct the SAB with Adrian as we are poised to make some exciting advances in new therapeutics to help improve the quality of our patient’s lives.”

Additionally, in recent months, the SAB welcomed four new members including:



ADAM SACHS
father of Justin, and
Vice President, Program
Management and
Strategic Client Alliance
at Catalent Biologics/
Paragon Gene Therapy



ADRIAN KRAINER, PHD
professor at Cold Spring
Harbor Laboratory



RALPH LAUFER, PHD
CSO at Lysogene



BAT-EL BAR-ALUMA, MD PHD
Tel Hashomer Hospital, Israel

Other members of the SAB include: **Felicia B. Axelrod MD**, **James Gusella PhD**, **Horacio Kaufmann MD**, **Hilda Maibach Msc**, **Eric Schon PhD**, **Neal G. Simon PhD**, **Susan Slaughaupt PhD**, **Gail E. Sonenshein PhD**. All of these individuals bring talent, expertise and perspective to our dynamic and highly accomplished group of professionals.

What's Your Legacy?



How to support the FD Foundation without spending a dime today.

During these uncertain times brought about by the global pandemic, some of us may be more concerned than ever about our current financial situation. Did you know that there are ways to support your favorite charities (e.g. the FD Foundation) without spending a dime today? We are referring to planned giving—planning your giving for some time in the future. Examples include:

- Name the FD Foundation as a beneficiary, partial beneficiary or contingent beneficiary of your **trust** or **estate**.
- Name the FD Foundation as a beneficiary, partial beneficiary or contingent beneficiary of your **IRA, 401(k)** or other **retirement fund**.
- Name the FD Foundation as a beneficiary, partial beneficiary or contingent beneficiary of a **life insurance policy** or **bank account**.

You can make these arrangements today at little or no cost; and the Foundation will benefit from your generosity in the years to come. Let us know about your plans now, and we will be honored to welcome you as a member of *Forever Devoted*, the Foundation's Planned Giving donor recognition society. Contact your attorney or financial advisor or the FD Foundation for more information.

THE IMPORTANCE OF A GOOD NIGHT'S SLEEP

Dr. Alberto palma



Many of our patients are now sleeping with BiPAP or CPAP machines, according to **Dr. Alberto Palma**, Assistant Director of the Dysautonomia Center and an Associate Professor of Neurology at NYU who joined the Center in 2013, moving to New York from Spain.

“Sleep disorders are very common in the FD population. Almost all of our patients have some degree of sleep-disordered breathing and the use of a CPAP or BiPAP machine is the best treatment to avoid these type of problems,” explains Dr. Palma. While there is still reluctance among some to use these machines during sleep because of discomfort, more and more patients are getting on board. Says Dr. Palma, “In our studies, we have measured the levels of CO₂ in blood, and we saw that after using BiPAP, daytime CO₂ levels went down significantly. This is important because it shows the benefits of BiPAP extending into the daytime.”

He adds, “We understand that the pressure coming from a mask can be scary but the benefits far outweigh the inconvenience.” The team at the Center has conducted numerous studies on the machines and recommends some strategies to improve compliance, for instance, starting to use it for 30 minutes and then progressively increasing usage to longer periods of time so that patients gradually get accustomed. Dr. Palma goes on to explain, “There is a ramp setting on these machines that allows the power to increase as a patient sleeps and that is really helpful. Generally, patients wake up more refreshed and feel less drowsy during the day. Their cognitive abilities are better and that is very good for both the brain and the body. We can all agree that there is nothing better than a good night's sleep!”

FD FAMILY FUNDS VISITING PROFESSORSHIP

Dr. Joel Gutierrez



Funds raised by an FD family (who wish to remain anonymous) were recently designated to support an ongoing FD Family Visiting Professorship at the Dysautonomia Treatment Center at NYU Langone.

For years, distinguished physicians and researchers from around the world have traveled to New York to spend time at the Dysautonomia Center. They bring expertise from their particular discipline to share with our medical staff and to benefit our patient population. At the same time, these visiting professors learn in person about FD and FD patients, and bring that knowledge back to their home country (or institution).

In recent years, the Center has hosted **Dr. Joel Gutierrez**, an expert in neurophysiology from Cuba. During his residencies at the Dysautonomia Center, Dr. Gutierrez has spent time mapping reflex nerve pathways over time in patients with FD. His work has helped our doctors understand why patients with FD have difficulty swallowing, experience a dulled sense of pain, injure their corneas and struggle to work. This knowledge has helped the team develop programs specifically designed for the treatment of patients with FD. In 2019, Dr. Gutierrez received a prestigious award from the Cuban Academy of Sciences in recognition of his many research studies developed at the Center. Thanks to funding made possible by an FD family, we look forward to welcoming Dr. Gutierrez back at the Center again this year.

If your family is interested in making a meaningful impact on the work underway at the Dysautonomia Center, please contact the FD Foundation to learn about other funding opportunities.

FOUNDATION OFFERS VIRTUAL MEET-UPS TO COMBAT COVID-19 ISOLATION



Quarantine rules resulting from the COVID-19 outbreak have made social isolation worse for everyone, but especially for people with FD, who have to be especially vigilant to avoid exposure to the coronavirus. To combat feelings of loneliness, the FD Foundation recently began offering weekly Virtual Meet-ups via Zoom. At press time, nearly 30 adults and young adults with FD were signed up to participate. If beneficial, these meet-ups could well continue past the COVID-19 crisis and become part of the Foundation's regular programming. If you haven't yet signed up, but would like to participate in the Virtual Meet-Ups, it's not too late!

To register, visit <https://bit.ly/fdsupportgroup>

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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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LESS SOCIALIZING = MORE ON-LINE SHOPPING?

If, during these crazy COVID-19 days you find yourself shopping online more often, don't forget to use AmazonSmile. AmazonSmile will direct 0.5% of your eligible purchase to the FD Foundation.

amazonsmile
You shop. Amazon gives.

POSITIVE EXPOSURE PHOTO SHOOT

Many of the beautiful photos that have graced the FD Foundation website, fundraising mailings and social media posts were taken by **Rick Guidotti** of **Positive Exposure** (PE). PE celebrates the beauty of human diversity and promotes a more inclusive global society through educational programs, lectures, photography, film and multi media exhibitions. Rick recently offered his time and talent to take a new round of photos. We look forward to showcasing our new photos in future Foundation communications. Thank you, Rick!



Rick Guidotti sets up a photo featuring L to R: Michael Baranoff, Perry Goldberger, Steven Wexler, Dr. Horacio Kaufmann, Lucy Norcliffe-Kaufmann

RARE DISEASE DAY 2020



On February 29, 2020—Leap Day—the world observed Rare Disease Day. Locally, familial dysautonomia was one of a number of rare diseases featured as part of Celebrate RARE 2020, an event hosted at Positive Exposure 109 gallery. The day

included screenings of FRAME films, discussion and other fun activities. We were thrilled to have a great showing from the FD community at this event including members of the Dysautonomia Center Team: **Lee-Ann Lugg, Kaia Dalamo, Zenith Khan, Miguel Perez and Patricio Millar**; as well as the **Ginsburg-Myers, Landau, Newman, Jassie-Pepkin, and Taryan-Kigel** families. To view the FRAME film about FD, visit <https://positiveexposure.org/frame/familial-dysautonomia/> and to learn more about Positive Exposure, visit their website at www.positiveexposure.org.



IN LOVING MEMORY JAMIE ERICA GOLDBLAT

6/4/90 – 3/27/20

Born in 1990, Jamie was a 2008 graduate of Jonathan Dayton High School. She was the beloved daughter of Robert and Elise Goldblat; the dearly loved sister of Jessica Cohen and her husband, Matthew, of Bridgewater, and the adored aunt of Leah and Emma Cohen. Jamie was writing a book and loved animals, especially her cat, Chloe, arts and crafts, tv shows, and her family and friends. Her optimistic spirit and ever-present smile will be missed by all who knew her.



Want to host a fundraiser on Facebook in honor of your birthday or another special occasion? Many people have successfully raised hundreds or even thousands of dollars for the FD Foundation on their personal FaceBook page. Whether you are tech savvy or new to FaceBook, we are happy to help you set this up! Contact Natasha at the FD Foundation at nweinstein@famdys.org for more details.

Save the Date

24th Annual FD Golf Outing

Monday, May 18th

Postponed to May 24, 2021

35th Annual FD Day (VIRTUAL)

Sunday, June 7

On-line registration is OPEN! www.famdys.org/fdday2020

2020 FD Ladies Lunch & Play

Monday, July 27, Chicago, IL

Now “virtual” for 2020; see you in 2021!

Externally-Led Patient Focused Drug Development Meeting with the FDA

College Park, MD

Monday, October 19

FD Newsletter Spring 2020

Written by: Lisa Denburg

Edited by: Lanie Etkind, Natasha Weinstein and Faye Ginsburg

ON THE COVER

The cover of this issue of DYS/COURSE features artwork done in acrylics by Pete Sonenshein. Do you recognize Adam Duritz, lead singer of Counting Crows?

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

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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35th Annual Conference

FD Day

Sunday, June 7, 2020

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A Day When Families, Researchers, and
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REGISTER TODAY!

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