

DYS/COURSE

DYSAUTONOMIA FOUNDATION

NEWS OF FAMILIAL DYSAUTONOMIA (FD) - SPRING 2018



WITH HUMANITARIAN VISA, 2ND FD PATIENT FROM MEXICO VISITS DYSAUTONOMIA CENTER

The Dysautonomia Foundation recently learned that a second of two young cousins from Mexico has been diagnosed with Familial Dysautonomia. It's particularly puzzling since neither of the girls has known Jewish ancestry. **Lucy Norcliffe-Kaufmann**, Associate Director of NYU Langone's Dysautonomia Center and an Assistant Professor of Neurology ponders, "Are they perhaps descended from Jews who fled persecution in Eastern Europe, from the Pale of Settlement, generations ago? Or do they represent a new manifestation of this rare genetic mutation and are there other cases in Mexico and elsewhere?"

A few years back, **Diana E.** and her mother visited the Center for a comprehensive evaluation. And this past fall, the Dysautonomia Foundation successfully arranged, through a humanitarian visa (not so easy in this political climate), for 6-year-old **Kamila L.**, and her mother, **Eva**, to come to New York from Aguascalientes, their small village in Mexico, where FD has been virtually unknown until now.

The Foundation and Dysautonomia Center welcomed the family with open arms, and facilitated their travel and three week stay in New York at the Ronald McDonald House. According to Professor Kaufmann, "We provided a comprehensive evaluation including monitoring Kamila's blood pressure, lung function, swallowing and lesions. We had a highly specialized team of neurologists, sleep doctors and nurse practitioners come together to analyze this mystery." The medical professionals at the Center also taught Eva how to care for her daughter's special needs and introduced her to other parents of FD children so she could learn from their experience. The Center is now communicating with Eva's local physician back home to help manage her care. Adds Kaufmann, "Kamila and her mother will remain members of the FD community, benefitting from our medical expertise and extended support system. We are quite confident, however, that we have learned something from their visit as well about how both Jews and genes travel over centuries and across borders."



Top: Kamila and her mom, Eva
Bottom: Dr. Horacio Kaufmann and Eva

PRESIDENT'S MESSAGE

Dear Friends,

I write with deep appreciation for your interest in the Dysautonomia Foundation as we sustain and expand our support for those challenged by the complexities of living with FD. Our foundation -- and the remarkable medical and scientific teams that we support -- have made enormous progress over the last few years. We now have more FD adults alive today than ever before. Please enjoy this edition of DYScourse, our first under the leadership of our dynamic new Executive Director, Lanie Etkind, who took on that position in September 2017. As you can see, we have had a lot going on with new research, fundraising, the accomplishments of our FD adults, care for new FD patients in Mexico, and the exciting activities of our emerging Next Gen supporters. Please accept our profound thanks for joining our efforts.

Faye Ginsburg

President of the Board of Directors



Faye Ginsburg

FD ART STUDENT COLLABORATES WITH NEUROSCIENTIST ON HER SENIOR ART EXHIBIT



Keshi presenting her beautiful artwork

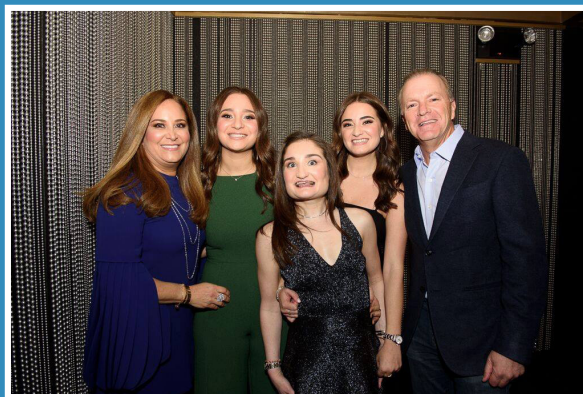
Keshi Taryan-Kigel is a very talented art student finishing her BFA at the School of Visual Arts in New York City. Her senior project, featured in the school's art show in December 2017, was a series of striking acrylic paintings inspired by her understanding of transgenic mice and their role in the medical research progress of FD, including her ambivalence about the use of animal testing. This past fall, Keshi met with neuroscientist **Frances Lefcort** at NYU Langone's Dysautonomia Center to glean more information about the topic. Dr. Lefcort, who teaches at Montana State University, has two cousins who died of FD and has focused the majority of her research on finding ways to alleviate many of the difficulties faced by people with FD. "We can mutate the same gene that causes FD in people in mice so that we have a medical system to test potential therapeutics," she explains. "We now have a mouse model for the disease. We are looking at why neurons die in the mice with FD and how to prevent the death of the neurons with this disease." After Keshi met with Lefcort, she created her vivid impressionistic paintings based on her sense of these unusual mice and their significance to biomedical research. Her exhibit also included a moving audio transcript of their conversation.

GOLDBERGER GALA FEATURING GAVIN DEGRAW SUPPORTS FD RESEARCH AND TREATMENT

An evening filled with great music, great food and great friends --- it was certainly a night to remember and a huge success. On November 8th, 2017, more than 650 people attended the lively Gavin Degraw concert and dinner at the Edison Ballroom in NYC. We are deeply grateful to **Laurie and Jeffrey Goldberger and family** for their incredible work on this event; the benefit brought in more than \$1 million for the Foundation.



Gavin Degraw - FD Benefit Concert



The Goldberger Family

ARE YOU "ABLE"? LEARN MORE ABOUT ABLE ACCOUNTS

An **ABLE (Achieving a Better Life Experience)** account is similar to a 529 College Savings plan for students, but for people with disabilities. After qualifying (which most people with FD should), anyone can contribute money to these accounts on behalf of their kids/family. The funds can be used for a variety of purposes including housing, tuition, etc. The best part is that these funds do NOT count against them for SSI and Medicaid benefits. (There are some limits, as one would expect.) Look into it and consult your personal financial advisor to determine if or how the ABLE account can fit into your family's financial plan. For more information, check out this website:

<http://www.ablenrc.org/about/what-are-able-accounts>

2017 GOLF OUTING A MAJOR SUCCESS

On September 11th, 140 golfers teed off for FD at the beautiful Glen Oaks Club in Old Westbury, NY. Although the original outing in May was rained out, the rescheduled event proved to be a big hit, bringing in a whopping \$260,000. Many thanks to Golf Chairs **Steve Fass, Steve Kietz** and **Paul Wexler** who are chairing this year's outing again on May 21st, along with **Rachel Schlau**.



SOCIAL MEDIA CAMPAIGN FOR FD RAISES \$178,000

This past fall, the Dysautonomia Foundation launched its first-ever fundraiser on a social media platform, Mobile Cause. Chaired by board member **Allan Cohen**, this new initiative brought in \$178,000 from more than 360 donors. Twenty FD family members and friends went above and beyond and reached out to their contacts on the platform, bringing in \$52,000 of the total raised. Special thanks to the highest personal fundraiser, **Laurent Landau**, who raised \$22,000 from his contacts alone.

LEAVE A LEGACY

What's your legacy? If you wish to continue supporting the mission of the Dysautonomia 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. Options include: bequests, trusts, gifts of life insurance and retirement funds.

We are in the process of forming a Society to recognize past, current and future legacy donors to the Dysautonomia Foundation. Please contact **Lanie Etkind**, Executive Director, at 212-279-1066 or letkind@famdys.org for more information or to inquire about joining our Society as a Charter Member. In this issue of DYS/Course the Foundation gratefully acknowledges 2017 Legacy gifts received from:

- **The Stanley and Estelle Rosenzweig Trust**
- **The Lou Bacon Trust**

FD WELCOMES NEW EXECUTIVE DIRECTOR

In September, the Dysautonomia Foundation welcomed Lanie Etkind as its new Executive Director. Lanie joins the foundation with a wealth of experience. She graduated cum laude from the Newcomb College of Tulane University in 1986 and started her career at the New York Philharmonic in PR and Development. From there, she joined Beth Israel Medical Center as the Associate Director of Development. After starting her family, she moved to Rockland County, New York, where she was the beloved Director of Development for United Hospice of Rockland for 21 years. There, she raised more than \$6 million to build the first ever Hospice Residence in Rockland County, NY. Recently an "empty-nester," Lanie returned to New York two years ago and became the Director of Major Gifts at The New Jewish Home before joining the Dysautonomia Foundation. We are so fortunate to have Lanie spearheading our foundation -- her expertise, knowledge and warmth are much appreciated throughout our FD community.



Lanie Etkind, Executive Director

YESHIVA UNIVERSITY STUDENTS USE SOCIAL MEDIA TO SPREAD FD AWARENESS

Yeshiva University students **Shoshana Rozenberg, Chloe Levinson, Andrea Weiss** and **Hadassah Korn** used a creative approach to spread awareness about FD through their final project in their Social Media class. The four seniors, who are in the Sy Syms School of Business, are hoping for an "A" this semester. According to Rozenberg, "The assignment was to create an awareness campaign for a social issue and we selected FD." The group used FD's Instagram and Facebook accounts to target college students, touting the importance of genetic screening.

Explains Rozenberg, "We posted new, relevant content twice a week on both social media platforms, that focused on genetic screening. We also created a contest partnering with JScreen." Participants simply had to "like" the **Dysautonomia Foundation** and **JScreen** on Facebook and tag their friends. They also had to share the post with the hashtag #LetsFightDys, explaining the importance of getting screened. Adds Rozenberg, "JScreen agreed to donate a free screening kit to the winner of the contest. I hope we did a nice mitzvah!"

RUNNING A HALF MARATHON FOR FD AT “THE MOST MAGICAL PLACE ON EARTH”



**Hilary Mechler, Disney World
Half-Marathon Runner**

Many thanks to **Hilary Mechler**, who ran a half-marathon at Disney World in Florida on January 6th in honor of her nephew, **Justin Sachs**. Hilary raised \$4,500 for FD! Every year Disney holds this growing runDisney event, which includes the 5K Pluto, the 10K Minnie, the ½ marathon Donald and the full marathon Mickey. This was Hilary's second ½ marathon and her first fundraiser for FD. "I wasn't first, wasn't last, but had a blast," says Hilary, who ran from Epcott to Magic Kingdom and back, and was greeted by Disney characters all along the way. It was also a family affair for Hilary, who ran beside her husband **Chip** (who ran all four days and events!). Her 8-year-old daughter, **Jordin**, also participated in the kids Wizard Mickey race and her 22-year-old stepdaughter, **Lauren**, ran the 5k and the 10k with her dad.

"My original fundraising goal was \$2,000, but as a family, we doubled that, thanks to our friends, company matches and Facebook appeals," adds Hilary, who hopes to participate again next year.

INTRODUCING A NEW CHAT GROUP FOR THE FD COMMUNITY LED BY ALEXIA DE GUNZBURG

Alexia de Gunzburg is 37-years-old and lives in Naples, Florida. She is an abstract artist and a published author and has FD. In 2013, she wrote and illustrated *Steps of Life: Exceeding Boundaries*, a trilogy of short books outlining her adventures in exploring her newfound life after many years of not believing it was possible. In *First Steps to Freedom*, she conquers fear; in *Steps of Courage: Travelling with Confidence*, she embraces the world and in *Steps of Progress: My Years in London*, Alexia evolves into the person she was truly intended to be: an inspiration to all who know her, with or without disabilities.

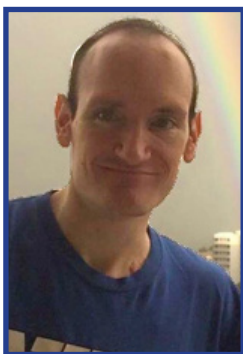
Now, Alexia would like to start a **chat group** for young adults with FD so they can share their experiences and discuss their problems. Adds Alexia, "It would be nice to have a monthly conference call where we could have the opportunity to talk to each other and discuss our quality of life, our obstacles and our solutions." To join the chat group, please email Alexia at biro781@googlemail.com and let her know that you are interested so that you can be part of the first call!



Alexia de Gunzburg

IN LOVING MEMORY

We mourn the loss of three of our own FD adults:



Scott Fass
09/18/80-01/08/18



Lisa Gross
07/05/82-03/16/18



Steven Schwartzberg
10/29/82-12/26/17

MEET RACHAEL EISENSEN



Rachael Eisenenson,
Freelance Graphic Designer

Many thanks to **Rachael Eisenenson**, a member of our FD community, for sharing her talents with us. Rachael is 29 years-old, has a BFA in Graphic Design from Adelphi University and a Masters in Web and Multi-Media Design from Touro College. A freelance graphic designer, Rachael lives in Manhattan and graciously volunteered to design the 2018 FD Day “save the date” postcard, the 2018 Journal cover, and of course, the DYS/course Newsletter graphics. In her spare time, Rachael enjoys baking, hanging out with her dog, and all forms of art.

BROADWAY BENEFIT FOR FD – *CHILDREN OF A LESSER GOD*

Dr. Felicia Axelrod is the former director of the FD Center at NYU. Not only is she truly beloved amongst FD families, but she also has many hidden talents! After learning to Ballroom Dance in 2011, Dr. Axelrod started attending dance competitions a year later, specializing in smooth, standard and Latin styles. At these competitions, she met many Broadway producers and became interested in getting involved in the Broadway world herself. According to Dr. Axelrod, “One of my new friends from the dance competitions, who is also a Broadway producer, was forming an angel fund to produce seven Broadway shows and he invited me to participate. I have always loved the theater and was excited to become involved.” Dr. Axelrod was especially interested in *Children of a Lesser God*. “The play appeals to me on many levels. I knew the story and was sympathetic to the plight of an individual with a disability being fully accepted on her own merit.” Dr. Axelrod had seen the show this past summer in a summer stock production and was deeply moved by the performance. She adds, “The actors were compelling and beautiful. The story is so strong and universal. I am sure this Broadway run will be a hit.” We hope to see many FD family members and friends at the special Broadway FD benefit on June 5th.



Dr. Felicia Axelrod

INTRODUCING NEXT GEN

Adam Kietz, the older brother of **Josh Kietz**, is spearheading NEXT GEN, currently made up of 11 siblings and cousins of people with FD. Eight of these members, ranging from 20-30 years-old, reside in New York, while the others are based in North Carolina and Pennsylvania. According to Adam, “I had been thinking about doing something productive for the Foundation for a while. Back in 2015, I held a fundraising event for FD at Soul Cycle in Manhattan and raised \$10,000. This made me realize that it’s great to do good while also having some fun. With NEXT GEN, all of the members have a unique thing in common and it’s a good personal network for all of us.”

The group met in early January, and agreed to hold three events in 2018, with a \$15,000 fundraising goal. The first event kicked off in January, with a spinning class at Flywheel in Manhattan. About 70 people spun, sweated and sang their hearts out at the event that raised a whopping \$17,000. Adds Adam, “We have officially exceeded our goal for the year with our first event. There’s no stopping us now!” In February, the junior board met for a happy hour to brainstorm about upcoming fundraisers. The group is now planning a Spring Fling bar event in mid-May and a Fall walk-a-thon as well. Adam hopes that other millennials will join the group, whether they are related to someone with FD or not. Anyone is welcome to join the committee and even hold a satellite event in another city. For more information about upcoming events in 2018 or future board meetings, please email Adam at AdamKietz@gmail.com.



Adam and Josh Kietz

SPINNING, SWEATING AND SINGING FOR FD

The Flywheel event in January proved to be a huge success with more than 70 people coming out to spin, sweat and sing their hearts out for FD. The event brought in more than \$17,000! Many thanks to Adam and Josh’s cousin, **Brian Levine**, who taught the class. Special FD guests **Josh Kietz**, **Rebecca Newman** and **Sam Landau** were all in attendance to cheer for their spinning parents, **Steve and Barbara Kietz**, **Jeff Newman** and **Laurent Landau**.



Flywheel Fundraiser 2018

FOR FURTHER READING, CHECK OUT THESE ARTICLES OF INTEREST

An interesting article from **Redbook** about parents of disabled children:
<https://www.redbookmag.com/life/mom-kids/a13149944/parents-of-disabled-children-can-develop-ptsd/>

An interesting article from the **New York Times** about gene therapy:
<https://www.nytimes.com/2017/10/05/health/gene-therapy-brain-disease.html>

INSIGHT TIMER -- A MEDITATION APP THAT MAY PROVE BENEFICIAL FOR FD PATIENTS



Kelly Brotman

Kelly Brotman is a very busy 32-year-old woman, living with FD. Kelly resides in Santa Barbara, California and volunteers at the Jewish Federation. She loves ceramics, kickboxing and writing and is currently working on a Young Adult novel. About a year ago, she discovered "Insight Timer," a free meditation app that helps her manage her stress. "I haven't had a crisis for over a year," adds Kelly. "The app helps me sleep and takes away a lot of my problems. I think it will change lives

for young FD adults!" Kelly uses the app about five times a week and there are many different variations of meditation on it including guided meditation, a self timer and music tracks to sing along to. The Insight Timer app contains more than 3,000 lively discussion groups. Topics range from community support to buddhism and mindful eating to stress relief. Check out the app at <https://insighttimer.com> or feel free to email Kelly at kellybrotman@gmail.com for more information.

RESEARCH UPDATE: NEW DRUG IN DEVELOPMENT TO HELP FD PATIENTS IN CRISIS



Dr. Michael Brownstein

Meet **Dr. Michael Brownstein**, aka "Mike", Chair of the Foundation's Scientific Advisory Board (SAB), who is working on developing a new drug designed to prevent or reduce the severity of crises in FD patients. Dr. Brownstein plans to meet with the FDA shortly and hopes to launch a clinical trial this year to get this drug into the FD community. Explains Dr. Brownstein, "We are looking for trial participants who have three or more crises per week. The about six people, half of them between the ages of 12-16 years old."

Adds Dr. Brownstein, "When we ask FD families what we can do to help, they always answer that the most important thing is to get their crises under control, and I think this drug will help do that." Currently there are active clinical trials being run at the Center that target the crises, but according to Dr. Brownstein, "As the trials are still on-going, we don't know whether they will help all people or be fully effective. Having more treatment options available and being able to use more than one drug seems like the best solution. We want to let families know that we hear you and we are working on ways to make a difference."

Another way that the SAB and the Center are hoping to make a difference is by deploying a free **iPhone app** called **FDConnect** that will be used in tandem with the study (and future studies). According to SAB member **Hilda Maibach**, who collaborated with Dr. Brownstein on the app, "Several of the FD community members have provided key input to shape both the original app design and the current modifications." The team is in the final phase of updating the app and it should be available for download soon.

Working closely with **Drs. Kaufmann** and **Norcliffe-Kaufman**, Dr. Brownstein and the FDconnect app team will identify trials in which the app and its features will be valuable. Adds Maibach, "Among other things, the app is intended to supplement telemedicine visits and make trial participation more feasible and less burdensome for the patients and family." Look for upcoming information about the app on the FD Community website, or contact help.fdconnect@gmail.com. We will be sure to let you know when the trial is approved and open to new patients.

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ARE WE CONNECTED?

If you are not receiving email communications from the Foundation, we may not have your email address. If you'd like to add or update your email address, **please send an email to info@famdys.org**. In the subject line, include your full name and the words "add my email"

WE LOOK FORWARD TO CONNECTING!

SAVE THE DATE



Monday, May 21: New York Golf, Glen Oaks Club, 'Westbury, NY



Monday, July 23: Chicago Golf, Ravinia Green Country Club, Riverwoods, IL



Sunday, June 3: FD Day, NYU Langone, New York, NY

For more information about any of these events
email dcarlito@famdys.org

YOUR SUPPORT MEANS A LOT TO US.
PLEASE DON'T FORGET TO USE
THE ENCLOSED ENVELOPE!



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THE 2018 JOURNAL IS NOW LIVE!

The 2018 FD Journal has been published!
Please visit <http://www.familialdysautonomia.org/papers/2018-journal.pdf> to view the Journal on line. Thanks to all who supported this important fundraising initiative.



The 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.

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