

SPRING 2019

DYS/COURSE

NEWS OF FAMILIAL DYSAUTONOMIA (FD)

**HOW YOU CAN HELP
ADVANCE FD RESEARCH**

**NEWS FROM THE
NYU DYSAUTONOMIA
CENTER**

**THE FD NATURAL
HISTORY STUDY**

**TEARLESS ART
EXHIBITION**



**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.

Introducing Our New Website!

New Look: New Name

We recently launched a **brand new website** -- check out our new look at **familialdysautonomia.org**. Please also note that the Dysautonomia Foundation is now going by a new name: The Familial Dysautonomia Foundation (or FD Foundation for short) to avoid confusion with other forms of dysautonomia.

FD Featured in 2019 Reelabilities Film Festival

On Saturday, April 6th and Monday, April 8th, the 12th ReelAbilities Film Festival, held annually at the Manhattan JCC, screened *Living Art*, a 32-minute documentary produced and directed by **David Rochkind**. The film features **Mara Clawson**, whose artistic work became her stunning and profound means of communication and livelihood. Through her story, we learn about what it's like to get FD diagnosed, to live with it, and understand the resilience of people with FD and their families. Mara is from Bethesda, MD and is a self-taught artist who uses pastels and iPad technology to convey her perception of the world. According to Mara, "Creating art makes me who I am and gives me lots of courage." The screening of the film was followed by a lively Q & A with Mara and filmmaker David Rochkind. To see a clip of the film, go to <https://reelabilities.org/newyork/guest/mara-clawson/>



Mara Clawson



Message from Lanie Etkind, Executive Director

The Foundation is in the midst of our busy season, with back-to-back events including TEARLESS (April 7), FLYWHEEL RIDE (April 28), LONG ISLAND GOLF (May 20), FD Day (June 2), and CHICAGO GOLF (July 29). With our tiny staff of three, the details can become overwhelming. Thank goodness for the many volunteers who help us with events and in the office:

- For TEARLESS, special thanks to event co-chairs **Robin Landau**, **Michelle Clawson**, **Gerard de Gunzburg** and curator **Kristina Hagman**.
- For FLYWHEEL, special thanks to **Adam Kietz** who organized the event.
- For LONG ISLAND GOLF, we couldn't do it without our hardworking committee: **Paul Wexler**, **Steve Fass**, **Steve Kietz** and **Rachel Schlau**.
- For FD DAY, we partner with our friends at the **NYU Dysautonomia Center** (not technically volunteers, but nevertheless deserving of recognition).
- For CHICAGO GOLF, we thank chairs **Gregg Meyers**, **Corrie DeLevitt** and **Joey Rosen**.
- The Foundation was fortunate to have two interns this semester: **Alexia Goussis** and **Elizabeth Tarakhovskaya**.
- And heartfelt appreciation to the volunteers who help throughout the year: **Perry Goldberger**, **Rachael Eisenson**, **Keshi Taryan-Kigel** and **Robin Landau**.

The Foundation is so fortunate to benefit from the time and talent of so many friends.

There's always room for more, so please contact us if you'd like to get involved.

What's Your Passion? Why Not Turn It Into A Fundraiser For FD?

Everyone has a passion. Some love biking. Others love walking. Many are avid runners. Do you love to bowl? Are you a mahjong maven? Or do you gravitate towards spinning or zumba? No matter what your passion is, why not organize a fundraising event for FD in your community? We can help you plan the event and provide fundraising tools. Give us a call at 212-279-1066 and tell us about your passion!



Dear Friends of the FD Foundation,

We are delighted that we can share so much good news in our latest issue of *Dys/Course*, with creativity evident on the scientific, medical, artistic, and activist fronts. In terms of science, we have started a generative new partnership with PTC pharmaceuticals, a group that has been working for several years with Dr. Sue Slaughaupt to develop Super-Kinetin, a promising treatment for people living with FD. With PTC's support, we have initiated a Natural History study of FD, a crucial approach being encouraged by the NIH for all orphan/rare diseases; the participation of those with FD is fundamental to its success. Dr. Alberto Palma, a key member of our medical team has been winning awards for his work. Our recent first-time art show, TEARLESS, not only featured the work of five extremely talented artists who have FD, but also raised over \$80K from supporters of this lively event. The same weekend of the show *Living Art*, a beautiful documentary by filmmaker David Rochkind on the life and work of FD artist Mara Clawson screened at the ReelAbilities Film Festival in Manhattan, giving audiences new to FD a sense of what it's like to live and flourish with this disorder. Finally, we are deeply grateful to ongoing activist projects: the NextGen's Flywheel event, the NY and Chicago golf outings, and many personal initiatives have all been crucial in helping us support the work of the Treatment Center.

Enjoy this issue of *Dys/Course* and thanks as always for your interest!

Best wishes,
Faye Ginsburg, President

Board of Directors

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A special welcome to **Gregg Meyers**, our newest Board member from Chicago. Gregg is spearheading the 16th annual Chicago Golf Event slated for Monday, July 29 at Ravinia Green Country Club.

Gregg is married to **Laura Meyers**, and they are the parents of **Sophie**, age 17 who has FD and her brother **Zach**, 14.



Gregg Meyers and Sophie

Check Out Sue Slaughaupt's Podcast



Sue Slaughaupt, PhD, has spent her whole career at Mass General focused on understanding two rare diseases, including FD. She also tackled the challenges of building a thriving scientific career at the same time she was building her family. She is now working to change the culture of scientific research for the better.

She recently launched her podcast devoted to uncovering the stories of the relentless daily pursuit at Mass General to break boundaries and develop exceptional care: <https://www.massgeneral.org/charged/episodes/sue-slaughaupt.aspx>

American Autonomic Society Recognizes Our Own Dr. Palma

This past fall, **Dr. Jose-Alberto Palma**, Assistant Director of the NYU Dysautonomia Center, was the inaugural recipient of the Felicia Axelrod Investigator Award, presented by the American Autonomic Society. The award recognizes an outstanding scientist with a track record of significant contributions to the field of autonomic science at the Assistant Professor level. Further, the award acknowledges excellence in autonomic research for an individual poised to be the next leader in this field.

Dr. Palma's research identified that untreated sleep-disordered breathing is a risk factor of sudden death in patients with FD. His work demonstrates the value of nocturnal noninvasive ventilation such as BiPAP or CPAP in preventing such events; these simple technologies are now virtually universally used by people with FD. Such developments, along with potential disease-modifying therapies in the pipeline to be tested in forthcoming clinical trials, are key to extending the lives of those with FD.

The NYU Dysautonomia Center 24/7 On-Call Service

Patients with FD don't get sick just during office hours. That's why the NYU Dysautonomia Center offers a 24/7 on-call service for patients and their families to reach a doctor or nurse at the Center. This service is active after-hours, outside office regular hours (9AM to 5PM Mon-Fri). When patients/parents call the FD Center after office hours, the call will be redirected to the on-call service. An operator will process the message and notify the FD physician/nurse on call. The FD physician/nurse on-call will then call the patient/family back in a timely manner.

The on-call service is a good option, for urgent questions or circumstances that cannot wait until the next day when the office opens. Examples include uncontrollable dysautonomic crisis, high fever, low oxygen levels, new-onset severe diarrhea, or unexplained pain. On some occasions, after assessing the issue, the FD doctor or nurse on-call may recommend the patient/parent to call 911 and/or to directly go to the emergency room. Using the on-call service to let the FD providers know you are on your way to the NYU Emergency Room is also appropriate. If a doctor from a local hospital or emergency room wants to reach an FD provider after hours, the on-call service is a good way to do so.

For emergent issues (i.e., very serious problems, such as a severe bleeding that won't stop, or cardiac or respiratory arrest) it is better to call 911 and, after that, use the service to let the on-call FD provider know the situation.

For non-urgent questions or issues (e.g., medication refills, discussion of chronic problems, discussion of medication changes, scheduling appointments, referrals), the on-call service is not appropriate. It is definitely better to wait until the office is open again to discuss such routine matters.

Want To Be A Super Hero?

Check out our new comic series FD Heroes IRL (that's "in real life" for those who don't know) on the Foundation's facebook page at <https://www.facebook.com/famdys/>. If you have FD and would like to be portrayed as a comic superhero, email Mindy at mindy@mindyindy.com

Subscribe to our Eblast List!

Don't forget to subscribe to our eblast list. If you have previously unsubscribed you will miss important information about medical care, research and Foundation events such as FD Day, so please be sure to get back on the list! **Please email us at info@famdys.org to subscribe.**

A New Mental Health Program At The Dysautonomia Center



Meet **Lily Armstrong**, who staffs a recently launched mental health program for people with FD. A licensed mental health counselor, Lily

lives in Portland, Oregon and offers psychotherapy sessions, via telephone, to FD patients all across North America. According to Lily, "I currently counsel seven to eight FD patients each week, ranging from 10 to 60 years old. We talk about issues of limited vision and mobility, possible resources they can connect with and I help them navigate their feelings about isolation. The goal is to help them reach a sense of fulfillment and meaning." The program is generously funded by a grant from the **Montreal Chapter of the Dysautonomia Foundation** made possible by the **Schwartzberg family** in loving memory of **Steven Schwartzberg**. Steven benefited greatly from the counseling services that Lily offered during her time as an intern at the Dysautonomia Center, and the Schwartzberg family has facilitated this gift to further enhance the lives of others with FD. Adds Lily, "I had such a great relationship with Stevie and this program is another way to extend his legacy." For more information about the program or to request a referral, please contact **Dr. Bhumika Balgobin** at the Dysautonomia Center at Bhumika.Balgobin@nyulangone.org or 212-263-7225.

How YOU Can Help Advance FD Research

Over the last decades, research supported by the FD Foundation has changed the way we treat FD and prolong life expectancy.

As you may be aware, **PTC Pharmaceuticals** is developing a drug which we hope will help compensate for the splicing defect caused by FD and improve the quality of life for people with FD as they age. Our community is small and the Food and Drug Administration offers groups with orphan diseases – those with very small affected populations – the opportunity to run clinical trials without the need for time-consuming and costly placebo or double blind studies IF the community affected has a comprehensive natural history study in place so that we can measure the effects of various treatments. Participating in this natural history project is crucial! The study expands every time you come in for your yearly evaluation, accelerating the possibility of new treatments becoming available for all of the FD community.

Participating in research is a crucial way you can help yourself, your loved one or your friends with FD to pave the way to treatments that will improve the quality of life for those with FD.

- **Sign up:** Most of our research studies simply require that you give permission to the FD Center staff to track your annual data over the years. This does not involve extra time at the Center. This “natural history” information is essential to our plan to create new therapies for people with FD and is now being used to speed up drug approvals for rare diseases in the US.
- **Show up:** In part, our research team is supported by grants that depend on people willing to participate. By signing up for a study, you are helping to support a dedicated research team that wakes up every morning with the single mission of improving the lives of people living with FD.
- **Speak up:** Tell us about your experience. Your story matters to us, to your doctors, to researchers and to potential funders.

Working together, we can make a difference for all.

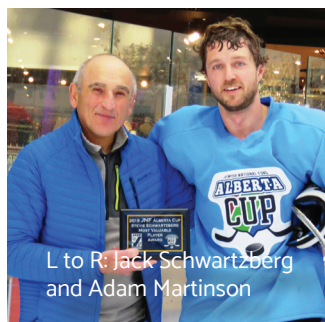
New Addition To Dysautonomia Center



Maria Cotrina (PhD) joined the Dysautonomia Center in November 2018 as clinical coordinator and research scientist for FD patients, focusing on the FD Natural History Project and the FD database. Maria holds a PhD in Cell Biology from New York Medical College and brings to the Center more than 20 years of expertise in biomedical research, mainly in neurobiology. She

transitioned to clinical research in 2014 when she joined the Department of Medicine at NYU and coordinated research projects for the Pulmonary Division with the patient survivors group for the World Trade Center Clinic at Bellevue Hospital. As part of her role, Maria was also in charge of data collection and database creation and maintenance for the diverse research projects, mostly on asthma and neuropathy. Maria is also personally involved with the rare disease community as a board member of the Propionic Acidemia Foundation, that promotes research on finding a cure for propionic acidemia, another ultra-rare disease that affects her oldest son Gabriel.

Canadian Hockey Tournament Remembers a Special Fan



For the second consecutive year, the Jewish National Fund of Canada memorialized **Stevie Schwartzberg**, who passed away in December 2017, at its annual Alberta Cup Hockey Tournament. The tournament included one team from Calgary – the Girouxsalems – and three from

Edmonton – the Fighting Yids, the Oyveylers and the winning team, Chai Sticks. The teams played competitive hockey for two days and as you can tell from the names, the tournament was filled with good natured camaraderie as well as a sense of humor. It was also very meaningful that **Jack and Rowena Schwartzberg** attended the tournament to present a trophy named in memory of their son Stevie to Adam Martinson from Chai Sticks, who was the recipient of the Stevie Schwarzberg MVP Award.



L to R: Investigators in the Natural History Study - Carlos Mendoza, Alberto Palma and Lucy Norcliffe-Kaufmann

Introducing The FD Natural History Study

The **FD Natural History Study** -- part of a broad NIH initiative to better understand how rare disorders affect the life course -- is designed to collect clinical information from patients with FD over time in order to offer the best possible treatments as they age. According to **Maria Cotrina-Vidal**, a clinical research scientist who joined the Dysautonomia Center five months ago, "Well-organized natural history studies are very important for rare disease research." The project will unite specialists in FD care from around the globe to gather and organize information in a standardized way from all patients with FD regardless of where they live. All information is made anonymous and details that can identify individual patients are removed.

"It's really simple," explains **Dr. Norcliffe-Kaufmann**, Principal Investigator for the project. "When patients come to an FD clinic, they have the option to grant permission for us to take information from their clinical records. We collect this data to follow the function of each patient's lungs, heart, kidneys, eyes, gut, sleep patterns and bone formation. The natural history study enables us to display this information in real time. By putting together the data set from all patients with FD, we can evaluate which treatments we use in the clinic to actually improve survival and quality of life at different stages of the disease."

The FD Natural History Study is being carried out in partnership with longtime FD researcher **Dr. Susan Slaughenhaupt** at Mass General Hospital; the team includes **PTC Therapeutics**, a company that is working with Dr. Slaughenhaupt to develop new treatments for FD based on promising research with Kinetin. Patients are asked to give a small sample of blood to

be used to look at the FD genome and how the IKAP protein is expressed, which will ultimately help in assessing the efficacy of new versions of Kinetin, and our broader quest to find potential genetically-based treatments. However, in order for any therapy to succeed, "We must first know what our benchmarks for success are and how to best measure improvement," explains Dr. Kaufmann.

Study participants will have their retina scans stored in the database archives, so they can be retrieved and compared year-to-year. People with FD are at risk for progressive optic neuropathy; one of the Center's goals is to intervene in that process. Each year patients have their retina closely scrutinized as part of their clinical care. According to Dr. Kaufmann, "I see the retina as a window to follow cell loss and as a target for therapy. The eye gives us great insight into the effectiveness of any drug designed to alter the course of the disease."

Dr. Jose-Alberto Palma is leading the quest to better understand sleep in FD and look at the impact of therapies such as CPAP or BiPAP, initially created for people with sleep apnea. He adds, "Sleep is an important issue for patients with FD and we have an urgent need to understand this better. Following patients over time and carefully documenting their sleep patterns should help us treat sleep disorders to improve the quality of life in FD and avoid related problems."

The FD natural history study is an important way to speed up progress in medical care. Patients who participate in the project will not need to undergo any additional testing at their annual visits. The donation of blood for the bio-repository is optional. For more details, please contact the Center at 212-263-7225.



A Day at "PTC University"

Foundation Staff And Families Attend "PTC University"

On March 19th, a group of FD families went to PTC Therapeutics in South Plainfield, New Jersey to participate in "PTC University" in honor of National Rare Disease Day.

Participants included Executive Director **Lanie Etkind**; Development Assistant **Danny Carlisto**; **Robin, Sam** and **Laurent Landau**; **Laurie** and **Perry Goldberger**; **Lisa, Mark** and **Mitchell Joseph**; **Keshi Taryan-Kigel** and **Adena Lebeau**, (mother of **Ezra Kress**). According to Lanie, "PTC wanted to put a human face to the disease to inspire the researchers who are developing a drug for FD." The day included a panel discussion with Q&A (attended in person by more than 150 people and remotely by even more), a tour of the lab and the innovative equipment, as well as a conversation with the CEO and COO of PTC, **Stuart Peltz** and **Marcio Souza**. Adds Lanie, "It was a truly moving day for all of us as the leadership of the PTC discussed their research and exciting plans for the future treatment of FD." According to Laurent, "The kids all spoke beautifully and it was the perfect balance of showing how badly FD acts on its victims and the humor we have all developed in order to deal with it."

Rare Disease Video Wins Honorable Mention

Last fall, the National Center for Advancing Translational Services (NCATS), a division of NIH, launched the Rare Diseases Are Not Rare! Challenge, seeking ways to educate people about rare diseases through social media or art. Out of nearly 50 submissions, including posters, videos, and poems, our very own **Samantha Myers** and her group, the Fearless

Theater Company, run by NYU School of the Arts Faculty **Lynne McVeigh** and **Louise Tiranoff** were selected for an Honorable Mention for their video, "Rare Diseases? They Aren't That Rare". All entries were on display at Rare Disease Day at NIH on February 28, 2019 in Bethesda, MD. Check out the video and all the winners at <https://ncats.nih.gov/funding/open/rare-diseases-challenge/winners>.

PTC Therapeutics Announces Potential Drug Candidate To Treat FD

Encouraging news in the FD drug research world: Building on years of investigation by **Sue Slaughaupt** and her team at Massachusetts General Hospital, PTC Therapeutics recently announced exciting progress in its efforts to identify a drug to treat FD.

This drug candidate for super-Kinetin—called PTC-808—which was previously in the discovery phase, has now progressed to pre-clinical investigation. This will involve IND enabling studies throughout the year, and hopefully move on to Phase 1 clinical trials for patients as soon as 2020.

We are grateful to Sue and her lab, our team at the NYU Dysautonomia Treatment Center, as well as PTC Therapeutics for their collaborative work towards enhancing and prolonging the lives of those affected by FD. We look forward to continuing to bring you good news on the research front.



Columbia Business School Flywheel Fundraiser for FD

Spinning for FD

On December 2nd, NEXTGEN founder **Adam Kietz** spearheaded a FLYWHEEL fundraiser in honor of his brother **Josh Kietz**, to benefit FD with his Columbia Business School class. Many thanks to Adam and Josh's cousin, **Brian Levine**, who taught the class. Twenty-eight spinners attended the event, bringing in \$1740 for FD.

Recent Grants

Many thanks to the **Hittman Family Foundation** and **Zack Gober** for the very generous \$5,000 grant to FD in November. Zack, who represents the Hittman Family Foundation, met **NEXTGEN** founder **Adam Kietz** at Columbia Business School and jumped on board to support the FD Foundation.

Keep Up With Dr. Lucy Norcliffe- Kaufmann's Blog About The NYU Dysautonomia Center

<https://dysautonomiacenter.com/category/lab-news/>

In Loving Memory

Jessica Shore 1/19/81-3/8/19

Her memory inspires us in the ongoing battle to support and improve the lives of those living with FD.



Jessica Shore



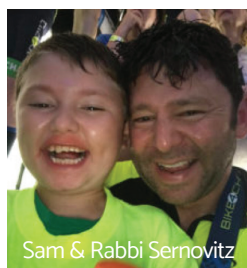
A Birthday Celebration For Dr. Axelrod

On February 3, FD board member **Laurent Landau** and his wife **Robin**, hosted a get together at their home in honor of **Dr. Felicia Axelrod's** birthday. Eleven FD patients attended the gathering and seven others participated via Facetime to help Dr. Axelrod celebrate!

Facetime participants included **Frannie Cohen, Sarah Zucker, Alexia de Gunzburg, Veronica Segal, Lindsay Ross, Jamie Goldblatt** and **Andrew Sigman**.

Top Row L to R: **Evan Kaplan, Rebecca Newman, Rachael Eisenson, Keshi Taryan-Kigel, Simi Steiner, Michael Brenner, Mitchell Joseph**

Bottom Row L to R: **Sam Landau, Dr. Felicia Axelrod, Gabi Jassie, Perry Goldberger**, Not pictured: **Sam Myers**



Sam & Rabbi Sernovitz

Father To Bike 180 Miles In Honor Of His Son With FD

This coming August, for the second consecutive year, **Rabbi Larry Sernovitz** of Cherry Hill, New Jersey, will bike for "Team Sammy" as part of the Bike4Chai event run by Chai Lifeline. Stopping only to eat and sleep, the Rabbi, biking along with 500 other men, will combat over 6,000 feet of elevation over the course of two straight days. His aim is to mimic the feeling of living with FD, to try to understand how **Sam**, his ten-year-old son, feels every day. The finish line ends at Camp Simcha in Glen Spey, N.Y., where Sam will once again be a camper.

"Last year, Sam told me he wished he wasn't different from his school friends," said Sernovitz. "Thankfully, he doesn't have those worries at camp." There, among children with similar disabilities, Sammy walks around without fear of judgment. "Three years ago we learned about this amazing camp that takes kids with chronic illness for two weeks and gives them the world. They each have a specific counselor assigned to them. There are ziplines and helicopter rides. And it's free. And for Jewish camps to be free," Sernovitz laughs, "that's something!"

All the money raised from the ride goes to the camp. Last year, the ride brought in \$9 million. Adds Sernovitz, "This ride is a walk in the park. It teaches us a little about perseverance and intensity and what these kids go through."



Tearless Art Exhibition a Smashing Success

The TEARLESS art exhibition on April 7th at the beautiful **Allouche Gallery** in Manhattan, proved to be a resounding success across the board. Featuring five artists with FD, including **Mara Clawson, Alexia de Gunzburg, Rachael Eisenson, Keshi Taryan-Kigel** and **Peter Sonenshein**, and curated by **Kristina Hagman**, herself an accomplished artist, the event raised more than \$85,000 for FD with more than 200 people coming to view and purchase the stunning works. Many, many thanks to all our sponsors, committee members and volunteers who truly helped make the day complete.

L to R: TEARLESS artists **Alexia de Gunzburg, Rachael Eisenson, Peter Sonenshein, curator Kristina Hagman, Mara Clawson** and **Keshi Taryan-Kigel**

To view our sponsor list and see more photos from TEARLESS visit <https://familialdysautonomia.org/events/past-events/tearless>



Beth Sue Heyman

A Bequest That Will Make A True Difference To The FD Foundation

In this issue of DYS/Course the FD Foundation gratefully acknowledges a generous bequest, received from the **Gladys Heyman Brown Revocable Trust**. Mrs. Heyman Brown was the mother of two daughters with FD.

Joan Heyman was born circa 1940 and died in 1961. At that time, she was the oldest known person living with FD. Her sister Beth Sue was born several years later. Gladys and Harry were advised by their physicians and others that there was a million-in-one chance that Beth Sue would also have FD (this was of course before genetic testing became available). Obviously, they had received misinformation and Beth Sue died at approximately six or seven years old in the mid-1950s.

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

If you wish to continue supporting 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. 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 FD 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.



Joan Heyman



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

Coming Events

23rd Annual FD Golf Outing

Monday, May 20
Glen Oaks Club, Old Westbury, NY

Chicago Golf Event to Benefit FD

Monday, July 29
Ravinia Green Country Club, Riverwoods, IL

FD FOUNDATION

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Lanie Etkind, Executive Director

FD NEWSLETTER SPRING 2019

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

COVER NOTES

Father **Adam Sachs** and son **Justin** enjoy time together searching for shells on a Florida beach. If you have a photo you'd like to share for a future issue of DYS/COURSE, please send it to letkind@famdys.org.

SAVE
THE
DATE

6.2.19
FD DAY

RSVP

RSVP by May 25th at <https://familialdysautonomia.org/events> or call us at 212-279-1066 to register.

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)