

SPRING 2021

DYS/COURSE

NEWS FROM THE FAMILIAL DYSAUTONOMIA FOUNDATION

**FD DAY GOING VIRTUAL AND
GLOBAL ONCE AGAIN IN 2021**

**INTRODUCING NEW FACES AT
THE:**

- **DYSAUTONOMIA CENTER**
- **FOUNDATION BOARD &**
- **SCIENTIFIC ADVISORY
BOARD**

**FOUNDATION FÊTES DR.
FELICIA AXELROD ON HER
80TH BIRTHDAY**



**FAMILIAL
DYSAUTONOMIA**
FOUNDATION, INC.

FD Foundation Board of Directors

Faye Ginsburg, President
Steven S. Fass, Secretary
Allan Cohen, Treasurer
Ed Baranoff, VP
Jeffrey Goldberger, VP
Steven Kietz, VP
Laurent Landau, VP
Lisa Newman, VP
Paul Wexler, VP
Gerald Adler, Director
Daniel Landau, Director
Gregg Meyers, Director
Jennifer Sonenshein, Director
Brian E. Stillman, Director
Howard Weiser, Director

Staff

Lanie Etkind, Executive Director
Natasha Weinstein, Manager of
Development & Operations
Aaron Breen, Development Associate
Gabby Sadinoff, Intern

ON THE COVER

Original art created by **Mara Clawson** in commemoration of Rare Disease Day held on February 28, 2021. The zebra is the official symbol of rare diseases in the United States and is noted for its black and white stripes, which are central to its uniqueness. Everyone has his/her own stripes--characteristics that make each individual distinct.

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.

DYS/COURSE Spring 2021

Written by: Lisa Denburg
Edited by: Faye Ginsburg, Lanie Etkind and Natasha Weinstein



Faye Ginsburg



Lanie Etkind

MESSAGE FROM THE PRESIDENT AND EXECUTIVE DIRECTOR

Dear Families and Friends:

We write to you today with a new sense of optimism. Not only is spring upon us, and days are getting longer, but there seems to be a light at the end of the tunnel in terms of the pandemic. More and more of us are being inoculated against the COVID-19 virus, and slowly our world is starting to open up.

We feel fortunate that the FD community has emerged from the pandemic relatively unscathed. Our families took the threat of the virus very seriously and adopted the necessary precautions to keep safe. There were very few reports of COVID infections among people with FD, and no loss of life attributed to the virus in the US. Anecdotally, we are hearing that people with FD are tolerating the vaccine quite well.

That is not to say that this time has been without challenges. First, we must acknowledge that there have been an inordinate number of losses over the past year, including two since the last issue of the newsletter. Please see page 10 to view tributes to Chanie Profesorske and Gregory Brandt. As a community, we mourn every loss together. Most importantly, we come together as a community to comfort those who are grieving.

The Foundation has faced challenges during the pandemic as well. All of our 2020 in-person events were cancelled, resulting in significant loss of revenue. At the same time, the Foundation remains committed to maintaining the optimal level of staffing and care, including virtual check-ups, at the Dysautonomia Center at NYU and to continuing to offer services such as POC loans, virtual hangouts, mental health support and more. We are grateful that so many families and friends have continued to support the Foundation. Your generosity enables us to continue our important work.

While much of the world was on pause, the Foundation's intrepid Scientific Advisory Board has continued to foster the advancement of treatments to enhance and extend the lives of people with FD. To learn the latest updates on FD research and care, we encourage you to join us for FD Day 2021, to be offered virtually again this year, on Sunday, June 6. Check www.famdys.org/fdday2021 for more info and to register.

And finally, we look forward to welcoming Dr. Alejandra Gonzalez-Duarte to the team at the Dysautonomia Center at NYU. Dr. Gonzalez-Duarte trained at the Center in 2008-9, and she looks forward to relocating to New York from her native Mexico to continue her work in FD care and research. We will keep the community informed as her anticipated start date is confirmed.

We hope you enjoy reading this issue of DYS/Course and keeping up-to-date on the activities of the Foundation. We encourage you to join us for FD Day on June 6 to learn more!

All the best,

Faye Ginsburg

Lanie Etkind

WE ARE KVELLING!

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

Executive Director **Lanie Etkind** was recognized for her leadership at the FD Foundation by the National Organization for Rare Disorders in NORD's Head of the Herd column in October. To read the article, go to <https://rarediseases.org/head-of-the-herd-lanie-etkind-executive-director-familial-dysautonomia-foundation/>. Lanie was also invited to speak about fundraising strategies at a capacity building workshop for leaders in the rare disease community offered by NORD in December.

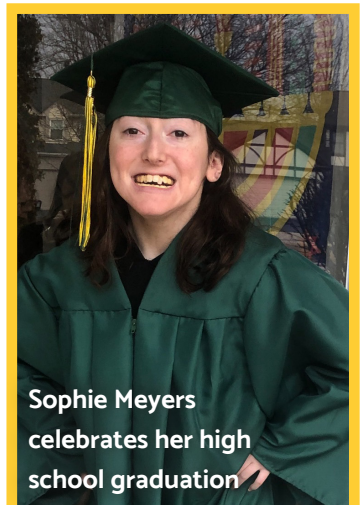
Rebecca Newman was featured in the December 2020 issue of the Pace Chronicle for graduating magna cum laude from Pace University. To read the full article, visit <https://pacechronicle.com/showcase/2020/12/02/17641/>.

Hofstra University recently renamed their prestigious Delta Alpha Phi Honor Society Award the 'Joshua David Field Award for Advocacy.' The award commemorates **Joshua Field Z"L**, beloved student, past society inductee and former staff member. The 2021 Award was presented by Houston Dougharty, Vice President of Student Affairs, who was a long-time mentor and friend of Joshua. To view the tribute, visit <https://www.facebook.com/HofstraStudents/videos/4597510413612294> (starting at 3:10).

Frances Lefcort, co-chair of the Foundation's Scientific Advisory Board, was invited to speak about FD research at a (virtual) US Congressional Neuroscience caucus meeting on neurological developmental disorders in March. The event was attended by congressmen/women and their staffers. Frances stressed the importance of supporting research on FD and discussed how difficult it is for a rare disease to attract pharmaceutical interest and drug development.

Foundation President **Faye Ginsburg** was a recipient of the 2021 NYU Martin Luther King Faculty Award on February 2nd. The event was sponsored by the Offices of the President and Provost, in partnership with the Office of Global Inclusion, Diversity, and Strategic Innovation. The awards recognize outstanding faculty who exemplify the spirit and work of Dr. Martin Luther King, Jr. through teaching excellence, leadership, social justice, activism, action, and community building.

Sophie Meyers graduated high school in December 2020, just a semester late, even after missing close to a year of classes midstream because of medical issues. Despite the pandemic, Sophie still managed to celebrate with a festive family dinner, as well as some drive-by visits from family and friends.



Sophie Meyers
celebrates her high
school graduation

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!

FOUNDATION CELEBRATES DR. FELICIA AXELROD ON HER 80TH BIRTHDAY



Dr. Felicia Axelrod

Who said you can't have a festive celebration during the pandemic? The FD Foundation's planning committee showed some creative chops when it came to commemorating **Dr. Felicia Axelrod's** 80th birthday. Not only did the FD Foundation feature a special section in the FD Journal (www.famdys.org/2021journal), but we also held a virtual Zoom birthday party on February 7th, attended by Dr. A's former patients, parents and members of the Dysautonomia Center's team. The party included live tributes by Faye Ginsburg, Dr. Horacio Kaufmann and former RN Jennifer Allison as well as a beautiful birthday montage with messages and birthday wishes from families across the globe (many thanks to Rebecca Newman for helping to assemble this). After a rousing group rendition of Happy Birthday, the party broke into two groups so that Dr. Axelrod could visit with her former patients while parents in the other group shared their favorite Dr. A. memories, which were recorded and sent to her afterwards. Dr. Axelrod also presented a gift to us—a video clip of her ballroom dancing that showcased her talent and grace. Hats off to the planning committee which included Faye Ginsburg, Lisa Newman, Robin Landau, Marsha Cohen, Lanie Etkind and Natasha Weinstein. To view footage from the party, go to <https://youtu.be/WgLg3OJrlcw>.

ALEXIA de GUNZBURG - A POSITIVE FORCE OF NATURE



Alexia de Gunzburg

Alexia de Gunzburg is a woman on a mission. Living with FD, Alexia is legally blind but always sees the bright side of everything. An outspoken advocate for the rights of the disabled, she has lived in Paris, London and New York. Currently residing in Naples, Florida near her parents and brother and sister-in-law, Alexia recently become godmother to her new baby niece! In March, Alexia turned 40 and her family put together a fabulous birthday tribute for her. More than 80 family members and friends from all over the world sent recorded messages in English and her native French to help her celebrate during the pandemic. To those who know her best, Alexia is a positive force of nature and a fearless warrior who inspires others with her determination to make the world a better place.

Alexia spends much of her life helping people, through her book, her art and as a motivational speaker. By sharing her unique and powerful story, she has become a role model for many individuals and groups around the world. In 2011, Alexia wrote and illustrated a trilogy of short books published together as, *Steps of Life, Exceeding Boundaries*, describing her 14 years living in London and the many obstacles she overcame. The book has since been studied in schools, where Alexia has been invited to speak about her experiences. She has also guest lectured with great audience response at various colleges and conferences. (To purchase a copy of her book,

go to the FD Store at www.famdys.org/store.) In 2019, Alexia participated in the TEARLESS exhibit at Allouche Gallery in New York City, showcasing her art along with other fellow artists living with FD. She sold nine paintings through the event and from subsequent commissions, raising more than \$50,000 for FD. To see some of Alexia's artwork, go to www.famdys.org/tearlessgallery or visit her personal website (see link below).

Alexia is very grateful to the Dysautonomia Center for the accumulated years of research. "The Center has been instrumental in keeping my blood pressure stable and leading me to world renowned doctors to help me with my eyesight," she says. She has participated in many of the Center's clinical trials and typically travels to NYU Langone for her annual checkup and the FD Day conference. This year, she looks forward to attending the event virtually and learning about the latest in FD research and treatments.

During the pandemic, Alexia kept busy by enrolling in several virtual courses including music theory and the history of music. Alexia has made many friends within the FD community worldwide and keeps in touch with them by participating in the virtual hangouts hosted by the FD Foundation. If that wasn't enough, she kept up with her website, www.stepsofalexia.com. A published writer, passionate artist and advocate for people with special needs, Alexia says, "I see my condition as an inconvenience but not a disability. I want other people to see me that way too. I love my life and I am grateful to be alive!"

JCC CHICAGO FILM FESTIVAL SHOWCASES "LIVING ART"



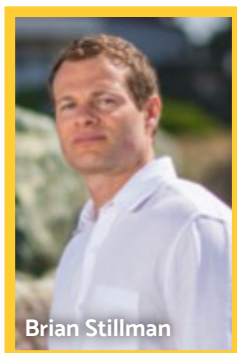
Still frame from "Living Art" featuring Mara Clawson

The FD Foundation, **JCC Chicago** and the **Sarnoff Center for Jewish Genetics** joined together on February 7th for a virtual screening and talkback of *Living Art*, a film by **David Rochkind** featuring **Mara Clawson**, an artist and young woman who has FD. The film documents the life of Mara as she prepares for the largest gallery show of her career. To learn more about the film, go to <https://ground.media/project/living-art/>.

FD FAMILY SATISFACTION SURVEY

In March we launched the 2021 FD Family Survey in order to gather data from FD families on their experience with the Foundation and Dysautonomia Treatment Center. Our goal is to facilitate an improved experience, as well as a better understanding of our families' relationships with the Center and the Foundation. More than 40 families participated in the survey by phone, and we are now in the process of tabulating the data. We anticipate that this feedback will help the Foundation and the Center adjust programs and services to better meet the needs of our community. Thanks to the many families who took the time to share their thoughts and suggestions. Please stay tuned for more news and updates.

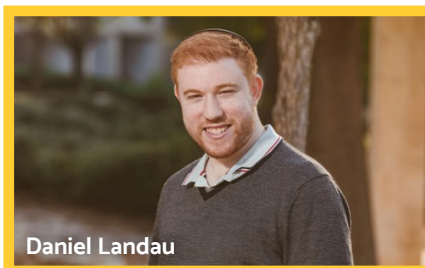
WELCOME TO THE FD BOARD OF DIRECTORS



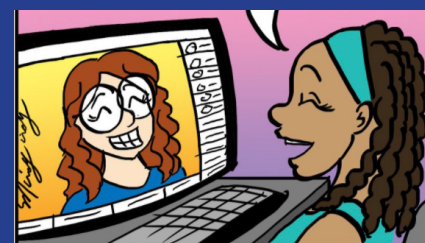
Brian Stillman

A warm welcome to **Brian Stillman** who joined the FD board of directors in January 2021. Brian lives in Phoenix, Arizona and works in commercial real estate development and brokerage services. According to Brian, "My wife Stephanie and I became actively involved with the FD Foundation right after Pyper's diagnosis when she was only 2 years old. We started with the annual crowdfunding campaign in September and have been participating in it ever since." Pyper is now six and because of the pandemic, is attending school remotely and receiving all of her therapies virtually as well. Brian hopes to help the board by offering his financial expertise, as well as by raising funds and awareness. Stephanie plans to spearhead two fundraisers this fall – a virtual scavenger hunt in the fall and a virtual birthday party for Pyper in December that will include an auction. "We want to be as involved as we can with the Foundation," adds Brian. "Being on the board is an opportunity to be in the know and to give back because there is nothing more important than our children."

Daniel Landau also joined the board in January 2021 after spearheading the successful UNIFIED concert in December which raised \$41,000 for FD. Daniel became involved with the FD Foundation after his son Rafi, was born with FD in February 2020. Born in NYC and raised on Long Island, Daniel and his wife Deena moved to Israel just three years ago. "We felt it was a good option for us since it's a very family-oriented country and the healthcare is very beneficial," adds Daniel. With a master's degree in non-profit management from Hebrew University in Jerusalem, Daniel hopes to bring new creative ideas to the table and help take the organization to the next level. He is involved in nonprofit consulting and is "thrilled to be the Israeli liaison to the FD Foundation." Daniel hopes to organize another virtual concert down the road since it helped raise awareness of FD and brought in many new donors.



Daniel Landau



DO YOU WANT TO BE SOCIAL WITHOUT LEAVING THE HOUSE? JOIN AN FD HANGOUT GROUP!

Since the beginning of the pandemic and to keep isolation at bay, Natasha Weinstein, Manager, Development and Foundation Operations, has been hosting virtual "hangouts" for the FD community. Natasha has gathered people with FD from all over the United States, England, Israel and Brazil for bimonthly calls to share stories, play games and tell jokes.

If you would like to join an upcoming "hangout," please email Natasha at nweinstein@famdys.org.

MEET OUR NEW INTERN

Welcome to **Gabby Sadinoff** who joined the Foundation team in January as the new marketing and communications intern. Gabby is from White Plains, NY and is a



Gabby Sadinoff

sophomore at the NYU Gallatin School of Individualized Study. She is creating her own interdisciplinary concentration combining psychology, sociology, special education, and disability studies.

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 St., 15th Floor, New York, NY 10005).



project sunshine

PROJECT SUNSHINE BRINGS A BRIGHT LIGHT TO KIDS WITH FD

The FD Foundation has partnered with **Project Sunshine**, an international non-profit that brings free, interactive play and activities to families with children facing medical challenges. We learned about this special initiative through our shared board member, **Howard Weiser**.

In response to the pandemic, Project Sunshine introduced a new program last year, TelePlay, which features live, interactive activities and games led by highly trained volunteers. Families can choose from a variety of programs for children ages 5-9, 10-14 and 15-18, ranging from trivia, to Scattergories, to music to art.

Since the FD Foundation and Project Sunshine have aligned family-focused missions, a number of FD families have tried out the program and are enjoying the activities. Adds 15-year-old **Jack Posnack**, "My favorite is the Disney trivia. I play with the volunteers on Zoom and it's been great fun during the pandemic."

To join a game, click this [link](#) to be taken to a calendar of events. You can find the description of each game by clicking on the activity.

MEET THE NEWEST MEMBERS OF THE SCIENTIFIC ADVISORY BOARD

The Scientific Advisory Board recently welcomed two new members: **Adrian Krainer**, Professor at Cold Spring Harbor Laboratory and **Ralph Laufer**, Chief Scientific Officer at Lysogene. Both are giants in their respective fields (academia and industry) and bring a new perspective to FD.

Q: Where are you from originally?

Adrian: Uruguay. I came to the U.S. for my college studies.

Ralph: Vienna. I've moved around a lot and now live in Paris.

Q: What areas of research and drug development have you been involved with?

Adrian: RNA splicing and genetic diseases. I have researched spinal muscular atrophy and neuromuscular diseases and developed a drug called Spinraza, in collaboration with Ionis and Biogen, which was approved in 2016.

Ralph: Discovery and development. My main focus is antivirals, neurological disease and oncology.

Q: Where are you working now and what is your current focus of research?

Adrian: I work at Cold Spring Harbor Laboratory in Long Island. My current focus is RNA splicing, studying how defects in this process can cause cancer or contribute to genetic diseases.

Ralph: I work at Lysogene in Paris. I focus on gene therapy for neurological diseases.

Q: How did you become involved in FD research?

Adrian: I read Sue Slaugenhaupt's work with interest, specifically about mutations causing abnormal splicing of the FD gene. Since the FD mutation affects RNA splicing of the ELP1 gene, this was right up my alley. Recently, we have developed potential therapeutics to fix the defect in RNA splicing of the ELP1 gene. We have tested this in patient cells and mice and hope to go to clinical trials next.

Ralph: I was involved in FD research while working with Adrian Gilbert, who is also a member of the SAB, when we worked together at Teva Pharmaceuticals in Israel. We collaborated with a group at Tel Aviv University to investigate whether one of the Teva drugs had activity in cellular modules of FD.

Q: What motivates you to support FD Scientific research?

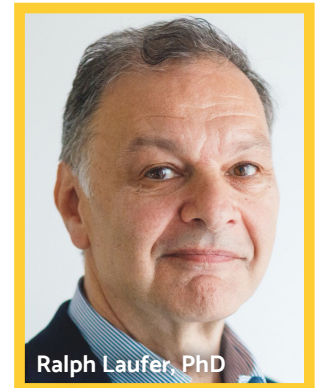
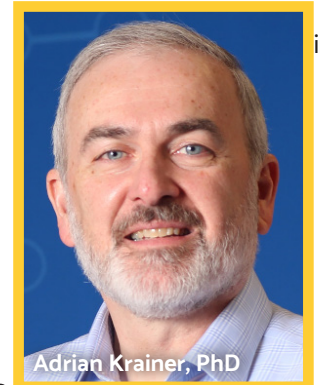
Adrian: I am very motivated to help find effective treatments for rare diseases. I think effective therapies are within reach.

Ralph: It's important to address any disease, no matter how rare it is. I also happen to know three parents who have children with FD so that motivates me as well.

Q: What do think is the most promising direction of research for FD?

Adrian: There is a pressing need for therapeutics such as gene therapy, small molecules and ASOs (antisense oligonucleotides). Since I've already developed an ASO, Spinraza, I am optimistic because it has been very effective and has treated about 11,000 SMA patients so far. I really hope to repeat this success in the case of FD.

Ralph: Within the SAB, we are looking at a few different treatment modalities. I see several extremely promising ones including small molecules, gene therapy and antisense oligonucleotides.



Dysautonomia Center Latest News

For the latest news from the Dysautonomia Center at NYU Langone, check out their blog at www.dysautonomiacenter.com

COMING SOON TO THE FD CENTER

We are thrilled and delighted to announce the impending return of **Dr. Alejandra Gonzalez-Duarte** to the Dysautonomia Treatment Center. Many of you may remember Dr. Gonzalez-Duarte from the time she spent as an autonomic fellow at the Center in 2008-9. Upon approval of her visa, Dr. Gonzalez-Duarte will relocate from her native Mexico City to New York to join the Center team, where she looks forward to both providing hands-on patient care and conducting clinical research on FD and other autonomic disorders.

Dr. Gonzalez-Duarte first met Dr. Kaufmann while training in infectious diseases at Mount Sinai. They enjoyed working together, and when Dr. Kaufmann moved to NYU, he invited Dr. Gonzalez-Duarte to come along. When her visa expired, Dr. Gonzalez-Duarte returned to Mexico to practice medicine at the renowned Instituto Nacional de Ciencias Médicas y Nutrición Salvador Zubirán. At the time, there were no known FD cases in Mexico, but Dr. Gonzalez-Duarte retained a keen interest in FD and continued to keep in contact with the Dysautonomia Center. Fortunately, when four FD cases were later identified in Mexico, Dr. Gonzalez-Duarte had the knowledge and experience to oversee their care.



Dr. Gonzalez-Duarte's husband, a pilot with Aero Mexico, and her two children, now aged 14 and 5, plan to join her in New York full time next year, giving Dr. Gonzalez an opportunity to investigate schooling and housing options.

When she is not wearing her white coat, Dr. Gonzalez-Duarte likes to exercise (swim, jog or yoga), read, cook and learn about wine. How does she do all of this? Easy—very little sleep!

Meet Dr. Gonzalez-Duarte live (virtually) at FD Day on June 6 and stay tuned for an announcement of her official start date. Please join us in extending Dr. Gonzalez a warm re-welcome to our community!

SAB CONTINUES ITS MOMENTUM

The Scientific Advisory Board (SAB) held a truly global virtual meeting in January with scientists participating from France, Israel and Japan, and within the US from New York City, Montana, Boston, Washington D.C. and Cold Spring Harbor, NY. There was board representation including MD's, research scientists, academics, pharmaceutical industry executives, staff from the NYU treatment Center, FD families and Foundation staff. The SAB is currently tracking/monitoring as many as five prospective treatments in the research pipeline. Stay tuned for more exciting updates to come!

VACCINATION UPDATE

Good news on the COVID-19 front! Hopefully by now, many of you have received your first or second dose of the vaccine. There is finally a light at the end of the tunnel! To read more about the efficacy, side effects and where to get a vaccine, go to: <https://dysautonomiacenter.com/2021/03/04/covid-10/vaccines-and-where-to-find-them/>



GRATITUDE TO:

An **anonymous donor** for awarding us a \$36,000 challenge grant. Watch for challenge details to come at a later date.

The Herman Goldman Foundation for a grant of \$10,000 for general support.

The Applebaum Foundation for a grant of \$10,000 for general support.

The Ironman Foundation and **The Henry E. Niles Foundation** for each awarding grants of \$2,500 which helped fund our Virtual Medical Kits, essential for facilitating telemedicine check-ups during the pandemic.

Familial Dysautonomia United Kingdom (FDUK) for its contribution of \$2,000 to the FD Foundation. To learn more about their chapter, go to <https://familialdysautonomia.co.uk>.

WHAT THE CARES ACT MEANS FOR YOUR CHARITABLE GIVING IN 2021

On December 27, 2020, another stimulus package was signed into law to help combat the far-reaching impacts of COVID-19. Here's how the provisions may impact your charitable contributions in the 2021 tax year.

Are you itemizing deductions?

The adjusted gross income (AGI) limit for cash contributions to qualifying public charities (like the FD Foundation) remains increased for individual donors. For cash contributions made in 2021, you can elect to deduct up to 100 percent of your AGI (formerly 60 percent prior to the CARES Act).

Not itemizing?

The CARES Act allowed for an additional, "above-the-line" deduction for charitable gifts made in cash of up to \$300. This provision is extended into 2021 for taxpayers filing single/separately.

New in 2021 is an additional "above-the-line" deduction for those married filing jointly. Joint filers (who aren't itemizing) will be allowed to take an above-the-line deduction of up to \$600 in cash contributions to charity this year.

What about IRA Qualified Charitable Distributions (QCD)?

The CARES Act did not change the rules around the QCD, which allows individuals over 70½ years old to donate up to \$100,000 in IRA assets directly to charity annually, without taking the distribution into taxable income. However, remember that under the CARES Act an individual can elect to deduct 100 percent of their AGI for cash charitable contributions. This effectively affords individuals over 59½ years old the benefits similar to a QCD; they can take a cash distribution from their IRA, contribute the cash to charity, and may completely offset tax attributable to the distribution by taking a charitable deduction in an amount up to 100 percent of their AGI for the tax year.

If you're planning a large donation in 2021, this may be a smart strategy as long as you are between the ages of 59½ and 70½ and are not dependent on existing retirement funds.

For guidance on the tax implications of your personal charitable giving, we always recommend you consult your accountant or financial advisor or contact the FD Foundation at 212-279-1066 or letkind@famdys.org for more information.

UNIFIED CONCERT A HARMONIOUS SUCCESS



On December 6th, the Foundation hosted UNIFIED, a virtual concert, that not only raised awareness of FD and the importance of genetic testing, but also brought in \$41,000 for FD. The event, featuring five popular Israeli and Jewish pop performers including **Nissim Black, The Portnoy Brothers, Zusha, Lenny Solomon and Pey Dalid**, was emceed by **Eli Lebowicz** and included a special guest appearance by **Baruch Levine**. In case you missed the live event, go to <https://youtu.be/GeQHftUPLdE> to watch the entire

concert! Many thanks to **Daniel Landau** of Ramat Beit Shemesh in Israel, who conceived of and helped plan the event. Also, special thanks to our *Keyboard Sponsors* **Freddie & Eddie Baranoff** and **Audrey & Steve Shalom**, and our *Brass Section Sponsors* **Tova & Howard Weiser** and [Creating Memory](#).

Additionally, a shout out to our promotional partners:



RARE DISEASE DAY, FEBRUARY 28

Thank you for a successful rare disease day, held on February 28. The FD Foundation created the artwork (shown right) for our social media campaign, and the zebra was designed by **Mara Clawson**, an artist who has FD. The FD Foundation also posted rare disease facts on social media throughout the month.

This was the third year NORD celebrated Rare Disease Day with its popular "show your stripes" campaign, inviting supporters to embrace their stripes and show that rare is not just strong, but proud! With record virtual event turnout, extensive media coverage and robust chatter on social media platforms and beyond, the day was a resounding success! According to NORD, "Across social media we saw stripes! Thanks to thousands of posts from our rare community, Rare Disease Day made the top 10 trending list on February 28 and had posts trending on LinkedIn all weekend! Together, we estimate that **#RareDiseaseDay** and **#ShowYourStripes** posts reached millions of people in the US and were a huge part of making this big day a success across the world."



PROSE LENSES “LIFE CHANGING” FOR PATIENTS AND CAREGIVERS

Good news on the vision front for people with FD! Because most people with FD have reduced tears which are essential to ocular health and the corneas in particular, they sometimes endure corneal abrasions, that result in decreased vision. When the company BostonSight developed PROSE lenses (Prosthetic Replacement of the Ocular Surface Ecosystem), enabling saline solution to remain on the eye all day long, many people living with FD jumped on board. Fortunately, there are now satellite offices throughout the country, making it easier for people with FD to get fitted for these special lenses. According to [Dr. Jessica Ciralsky](#), a corneal specialist at Weill Cornell in New York City, “We have found that PROSE lenses have been a godsend for many in the FD community.” Dr. Ciralsky prescribes the customizable, hard

contact lenses for about 30 FD patients in her practice. She adds, “The lenses keep the surface of the eye moist and prevent corneal damage. Essentially, the eye is bathed in saline all day long.”

According to **Laurie Goldberger**, mother of **Perry**, who has worn these lenses for many years, “The lenses have been life changing. Instead of putting in artificial drops every few minutes, Perry’s eyes stay moist all day long. It has made Perry more independent and given her a much better quality of life. The lenses create a protective barrier and moisturize her eyes throughout the day and her vision is better as well.”

To learn more, check out bostonsight.org

FD DAY GOING VIRTUAL AND GLOBAL, THIS YEAR ON JUNE 6, 2021!

Every June, FD Day takes place at NYU’s Medical Center, where as many as 150 family members make the trip to New York City. Last year, while pandemic restrictions prevented us from gathering in person, the FD Foundation, in partnership with the Dysautonomia Center, brought FD directly to the homes of our families, friends, caregivers, medical teams and scientists. Thanks to modern technology, we were able to reach three times the usual number of people, with 250 households logging in from 9 different countries and 25 states.

This year we will be holding FD Day virtually once again and it will be scheduled at a convenient time for people all over the world to participate. This is 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 potential new therapies and learn how to play an essential role in furthering crucial research. To register, go to www.famdys.org/fdday2021



JAKE TAKES THE (4X4X48) CHALLENGE

Meet TEAM FD’s newest member, **Jake Walker**. Jake recently took on the David Goggins 4x4x48 Challenge – running 4 miles every 4 hours for 48 hours, totaling 48 miles upon completion. Taking this challenge to the next level, Jake knew he had run for a cause close to his heart, and what better organization than the FD Foundation. According to Jake, “My wife’s cousin Josh Kietz, is the [most] enthusiastic, loving and all-around great individual who happens to live with FD. This is why my family and I hope to do our part to raise awareness...” Jake’s Challenge raised more than \$4,600. Read

more about Jake’s story by going to: <https://secure.givelively.org/donate/familial-dysautonomia-foundation-inc/jake-runs-for-fd>

Interested in joining TEAM FD and hosting your own peer-to-peer fundraiser like Jake? Reach out to Natasha at the FD Foundation to learn more: nweinstein@famdys.org

A NIGHT AT THE (VIRTUAL) MOVIES

Last fall, the FD Foundation hosted its first movie night for individuals with FD. Meeting together on Zoom, FD folks of all ages gathered to watch Night at the Museum. The event was so popular that it has become a quarterly happening! A second successful movie night followed, and plans for future virtual events to gather and connect the FD population are in the works.

Interested in joining a future movie night or have a movie suggestion? Let us know by emailing Natasha at nweinstein@famdys.org

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 join our mailing list. We look forward to connecting!

FOLLOW US ON:

- [famdys.org](https://www.facebook.com/famdys.org)
- [@Famdys](https://twitter.com/famdys)
- [@famdys](https://www.instagram.com/famdys)
- [@FamDys](https://www.youtube.com/famdys)

SHOP FOR FD

Go to www.AmazonSmile.com or www.EmpathyMart.com to

support FD while you shop! Eligible portions of your purchase(s) will go to the FD Foundation.

amazon
smile
You shop. Amazon gives.



THANKS TO OUR FACEBOOK FUNDRAISERS

The FD Foundation appreciates everyone who helps raise funds on our behalf. If you'd like to learn more about ways to fundraise for the Foundation, including during our traditional fall Crowdfunding campaign, please contact the Foundation at 212-279-1066 or email Natasha at nweinstein@famdys.org

Thanks to everyone who held a Facebook fundraiser for us in 2020:

Andrew Sigman

Cammy Stein

Robin Posnack

Keshi Taryan-Kigel

Jeri Burkow

Pamela Alfant Dubson

Stephanie Stillman

Naa Asheley

Jessica Goldblat Cohen

Chava White

Robin Landau

Liz Shapiro

Kevin Gross

Barbara Ross

Jonathan Eisenson

Cryssie Rose Sutton

Rebekah Lieberman

Coming September 2021

FD Foundation's 5th
Annual Crowdfunding
Campaign -
#FDMATCH2021

Get ready to Fundraise
for FD!

To sign up, contact
nweinstein@famdys.org

TELL US YOUR *Forever* DEVOTED STORY....

You may have read in past issues of DYS/Course about family members of people with FD who have made arrangements to include the Foundation in their estate plans. These individuals wish to ensure that the FD Foundation will have the resources it needs to continue its mission well into the future.

We cannot emphasize enough the important role these gifts play in the Foundation's ongoing ability to meet its objectives. For example, during the pandemic when fundraising revenue was down, income from planned gifts helped keep the Foundation on sound financial footing. We are grateful for planned gifts received during 2020 from:

***The Birdie H. Blaine Living Trust *Helen Strauss IRA
*Helen Strauss Revocable Trust *Estate of Samuel J. Silling
*Estate of Patricia Ann Young**

Have you included the FD Foundation in your estate plans? We want to hear YOUR story--perhaps it will inspire others to do so as well.

What is a Planned Gift?

A planned gift is defined as a gift that is arranged in advance and made at a time in the future when you no longer need the assets (most often at end of life).

There are many ways to make a planned gift:

- ◇ Include a **bequest** to the Foundation in your will (you can designate a specific amount, a percentage or a residuary amount)
- ◇ Designate the Foundation as a beneficiary of your **401K, IRA or other retirement plan** (full, partial or contingent).
- ◇ Name the Foundation as a beneficiary of a **life insurance policy** (full, partial or contingent).
- ◇ Name the Foundation as a beneficiary of a **bank account**.

For more information, contact Lanie Etkind, Executive Director, at 212-279-1066 or letkind@famdys.org or consult your attorney or financial advisor.

FD IN THE NEWS

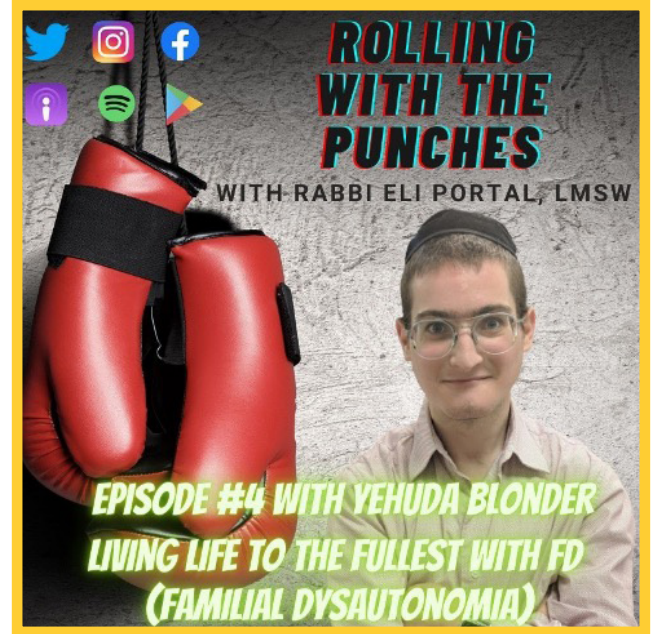
The BBC aired a segment about the vagus nerve in *CrowdScience* in March, entitled “How does my mind talk to my body?” The program includes a conversation with an expert in the field, **Lucy Norcliffe-Kaufmann**, former Associate Director of the Dysautonomia Treatment Center. To hear the podcast go to <https://www.bbc.co.uk/sounds/play/w3cszv75>.

In conjunction with the Foundation’s virtual concert event UNIFIED, in December The *Arizona Jewish News* featured a story about **Pyper Stillman**, a young girl with FD living in Arizona. To read the full article, go to https://www.jewishaz.com/community/local-family-advocates-for-genetic-testing/article_od9122a8-2dc2-11eb-9116-d7f11b34b5a.html

Check out **Rabbi Eli Portal’s** podcast series, “Rolling with the Punches.” A recent episode focuses on the experience of living with FD and highlights how one’s perspective on life makes all the difference. When Rabbi Portal interviewed **Yehuda Blonder**, about how he lives his life knowing that FD has a decreased life expectancy associated with the illness, Yehuda said, “It is what it is and I can’t change that, but I made a decision that I am going to live life to the fullest. As long as I am given that opportunity, that’s what I am going to do.”

You can find the episode on all major streaming platforms.

Spotify: <https://open.spotify.com/episode/OHvC8Cu8eg9Bm-6FwKc8FW2?si=121269b3fde84186&nd=1>



IN LOVING MEMORY



Gregory Brandt

5/16/91 - 2/24/21

Gregory had a great personality and sense of humor. He could light up a room. Gregory graduated Marlboro High School and Brookdale Community College and even took classes at Rutgers University. He loved his car and watching sports. He was a tv buff, watching all of the most popular shows and giving

recommendations. He loved reading and listening to music. Gregory made the best of every situation. For someone who dealt with health issues and limitations his entire life, he never complained. He was kindhearted and selfless--always more concerned about others worrying about him than he was about himself. Gregory’s friends and family meant the world to him. In turn, he was their hero, and he taught them a great deal. Gregory was so loved and will be missed beyond words.

Chanie Profesorske

3/28/92- 10/29/2020

Chanie was born and raised in Brooklyn, NY. She was loved tremendously by her dear parents and had a very close and special bond with her sister, Devorah. Chanie had a sweet and caring demeanor as well as a genuine and infectious smile. Chanie was incredibly brave and never missed

a chance to go on a scary rollercoaster. She didn’t let her illness stop her from enjoying life. She would look forward to attending summer camp at Camp Simcha and going on Kids of Courage trips to California, Florida and Texas. Her favorite hobbies were shopping, coloring, crafts, and playing on her iPad. She had a true love for animals and her favorites were dogs, birds and rabbits. Chanie’s favorite holiday was Purim and she loved dressing up in amazing costumes with her sister. Chanie will be forever missed by her family and friends. May her memory be a blessing.





**FAMILIAL
DYSAUTONOMIA**
FOUNDATION, INC

315 WEST 39TH STREET, #701
NEW YORK, NEW YORK 10018

ADDRESS SERVICE REQUESTED

NON PROFIT
US POSTAGE
PAID
WHITE PLAINS, NY
PERMIT NO 825

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



DYS/COURSE 2021-1

Registration Open!

36th Annual Conference

FD Day

JOIN US VIRTUALLY

Sunday, June 6, 2021

Program begins at 11am (EDT)



**FAMILIAL
DYSAUTONOMIA**
FOUNDATION, INC

Presented by Familial Dysautonomia Foundation
in partnership with NYU Dysautonomia Center

Register at:

www.famdys.org/fdday2021

A Day When Families, Healthcare Providers
and Researchers Come Together

REGISTER TODAY!

**Monday
June 21, 2021**



Glen Oaks Club
Old Westbury, N.Y.

212-279-1066 • info@famdys.org • www.famdys.org