Fall 2022

DYSCOURSE

NEWS FROM THE FAMILIAL DYSAUTONOMIA FOUNDATION

FAMILIAL DYSAUTONOMIA FOUNDATION, INC

DYSAUTONOMIA CENTER WELCOMES NEW VISITING PROFESSOR

L'DOR V'DOR

TEAM FD RUNS THE NYC MARATHON!

ENTREPRENEUR WITH FD HELPS FELLOW DISABLED BUSINESS OWNERS

The FD newsletter was endowed with a gift in memory of Elaine Jamie Lipson, whose love of life will remain forever in our hearts.

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
Albulena Prelvukaj, Fundraising and Communications Manager
Julia Winer, Development Operations Associate
Artemio Leclerc-Jones, Intern

On the Cover

"Kalei-dye-scope World"
By Chana Perelstein z"l

The image on the cover features a tie-dye t-shirt designed by **Chana Perelstein** and submitted as her entry for the 2022 FD Day Art Competition: The World Through My Eyes. Sadly, Chana passed away in July 2022, but her legacy lives on through her loving family and friends and through the beautiful tie-dye art she created.

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

DYS/COURSE Fall 2022

Written by: **Lisa Denburg** and **Lanie Etkind**
Edited by: **Faye Ginsburg** and **Lanie Etkind**
Designed by: **Albulena Prelvukaj**

MESSAGE FROM THE EXECUTIVE DIRECTOR

ACKNOWLEDGING FAYE GINSBURG'S DECADE OF SERVICE AS FOUNDATION PRESIDENT

Lanie Etkind

Dear Friends:

Several weeks ago, I interviewed Faye about her decade-long tenure as President. Faye shared with me the history of her involvement with the FD Foundation, beginning with her daughter Samantha's diagnosis in 1989 and Faye's joining the board of directors in 2001.

Faye reflected on leading the Foundation through several significant transitions, including the passing of the Dysautonomia Center baton from Dr. Felicia Axelrod to Dr. Horacio Kaufmann, as well as the search for a new Executive Director after David Brenner's untimely passing. More recently, Faye, together with the rest of the Foundation leadership, helped ensure a smooth path during the uncertainties of the coronavirus pandemic. Faye observed, "There were some Titanic moments, where it felt like the ship was sinking, but together we turned it around and today the ship remains upright and on course."

Faye looked back with pride on some of the Foundation's additional accomplishments during her tenure including:

- Increased focus on excellent clinical care at the Dysautonomia Center at NYU Langone, including adding two Nurse Practitioners, Kaia Dalamo and Zenith Khan, to the team as well as Dr. Alejandra Gonzalez-Duarte;
- Reinvigorated Scientific Advisory Board, with Drs. Adrian Gilbert and Frances Lefcort at the helm, and many world-renowned scientists studying FD;
- Securing a $500,000 grant to fund translational research;
- Funding the Telemedicine program, which ensures access to care for people with FD;
- Pivoting FD Day to a virtual format, enabling participation from around the world;
- Creating new, life-enhancing programs for people living with FD, including virtual mental health counseling and facilitated virtual hangout groups;
- Adding a Social Work intern at the Center to support families with non-medical challenges;
- Strengthened relationships with the FD communities in Israel, Canada and the UK.

Thinking about the future of the FD Foundation, Faye observed that our success has become our challenge. Fewer babies born with FD, as a result of the Foundation's previous investment in research to identify the gene, means that our community is not growing. The cost of funding–and fundraising to support–medical care and research falls to a smaller group of families. Yet, we cannot afford to stop or slow down: with excellent medical care, people with FD are living longer and better quality of lives; and our researchers are close to breakthroughs that could change the course of the disease.

Faye concluded our conversation with a quote from anthropologist Margaret Mead: "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."

Just days after we spoke, Faye alerted me that her daughter Samantha had experienced a serious seizure. Tragically, Sam passed away a week later from cardiac arrest at age 33. The entire FD community, together with hundreds of family members, friends, and colleagues, as well as members of "Sam's Club" were deeply affected by Sam's passing and join Faye and Fred in mourning her loss.

This very well could have been the end of the story of Faye's leadership of the Foundation, but it is not. Faye now tells me that Sam's memory inspires her to remain steadfastly committed to the mission of the Foundation. As President of the FD Foundation, Faye will honor Sam daily as she continues to lead the Foundation towards accomplishing its mission of funding the Dysautonomia Center and supporting FD research, with the goal of ensuring the best quality and longest lives for people living with familial dysautonomia.

I know that we all send heartfelt condolences to Faye and Fred and to all those who knew and loved Samantha. At the same time, please join me and the entire board of directors in honoring Faye for ten years of service as President of the FD Foundation and in thanking her for her commitment to continue in this pivotal role as an eloquent tribute to the memory of her beloved daughter, Sam.

Sincerely,

Lanie Etkind

L to R: **Fred Myers, Samantha z"l & Faye Ginsburg**

FD GOLF CLASSIC CELEBRATES 25 YEARS

The weather on Monday, May 23 was perfect for the **25th Annual FD Golf Classic**, held at Glen Oaks Club in Old Westbury, New York. Thanks to the efforts of Golf Chairs **Paul Wexler, Steve Fass, Steve Kietz** and **Rachel Schlau,** this year's event drew 139 golfers and raised more than $285,000 to support the Foundation's work. During post-golf festivities, Paul Wexler and Steve Fass were honored for 25 years as chairs of this key fundraising event. We are grateful to all who contributed to the outing's success by golfing, sponsoring, donating, purchasing raffle tickets and/or bidding on silent auction items. **Save the Date for next year: Monday, May 21, 2023!**

L to R: **FD Classic Co-Chairs Paul Wexler, Steve Kietz, Rachel Schlau, Steve Fass.**

L to R: **Sydney, Perry & Cody Goldberger**

NIGHT OUT FOR FD

Many thanks to **Sydney** and **Cody Goldberger** for hosting a bar night event in May to benefit FD. The **Night Out for FD,** held at Nublu in NYC proved to be a wonderful tribute to their older sister **Perry**, who has FD. Not only did the sisters conceptualize the event, manage all the moving parts, and bring together all their friends for this very important cause, but they raised more than **$17,000**! These funds will help support the critical work of the FD Foundation. We are so grateful that the Goldberger sisters have taken an active role in ensuring the future viability of the FD Foundation by helping to educate and engage the next generation of supporters, and we hope that others will be inspired by their leadership.

L'DOR V'DOR

The FD Foundation's investment of millions of dollars to identify the FD gene continues to have an enormous impact on families–thousands of healthy babies have been born to carrier families–and now even 2nd generations of healthy babies have arrived to families who otherwise would not have been able to experience this joy. When FD Board member **Gerald Adler's** daughter Lauren was born in 1983 and passed away in 1989, there was no genetic test for FD. By 1994, when his son Joseph was born, one could test in utero using flanking markers - thanks to the Foundation's work. Gerald and his wife **Vivian** became grandparents for the second time to a healthy baby this past July when their first grandson was born. "I once again need to express my gratitude for all the work the Foundation does and to those who make it happen," Gerald adds.

L to R: **Gerald, Eliana, baby Sammy, Joseph, Vivian & Perry Adler**

A BEQUEST THAT WILL MAKE A TRUE DIFFERENCE

The FD Foundation gratefully acknowledges **Eric H. Arnold** who paid tribute to the memory of his beloved nephew, **Ben Solomon**, by planning a future bequest to the FD Foundation.

Ben, who lived in Cleveland, OH, passed away in 1999 when he was 22 years old. According to his uncle Eric, "I was motivated out of love for my nephew Ben and my sister, Rochelle, who is also a member of the Forever Devoted Legacy Society, to give back to FD. I want to make sure this small community is always at the forefront and I think it's important to do positive acts if I can."

He adds, "Ben and I shared an incredible devotion to Cleveland professional sports even though I live in Boston. Ben would constantly call into sports radio shows. His bedroom was completely decked out in Cleveland Indian's sports memorabilia. He was very sweet, always kind, and had a smile that could light up a room. My memory of him is that he had a great attitude despite the physical challenges and he was just a good guy and a beautiful soul."

Eric H. Arnold

A children's author and educator, Eric recently published his 19th children's book called **No Time for the Moon** under the auspices and in collaboration with the CDC. It's a new book for children with AFM, acute flaccid myelitis, that explores the story of four kids who have big dreams. "Interestingly, as I was researching and interviewing folks for this story, I took note of similarities between the AFM and FD communities,"

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

Forever Devoted

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. To join our Forever Devoted Legacy Society, please contact Lanie Etkind, Executive Director at 212-279-1066 or letkind@famdys.org.

FD FOUNDATION WELCOMES NEW TEAM MEMBER

Julia Winer

In November, the FD Foundation welcomes **Julia Winer** as the **Development Operations Associate**. Originally from Charlotte, NC, Julia graduated from Elon University with a degree in Public Health in May of 2020. It was there that her interests in disease prevention, healthcare accessibility, and population health were born. Julia moved to Manhattan in April 2021 to earn her Master's degree in Public Health from the NYU School of Global Public Health. During her program, Julia was a Communications Intern for the CDC in their Division of Nutrition, Physical Activity, and Obesity. She was responsible for developing social media content, responding to public inquiries, and revising the organization's website. Her passion for disease mitigation, social justice, and Judaism led her to the FD Foundation.

TEAM FD RUNS THE TCS NYC MARATHON ON NOVEMBER 6!

OFFICIAL CHARITY PARTNER

At press time, five intrepid runners were in the final stages of preparing to run the TCS NYC Marathon as members of Team FD. Not only will they run a grueling 26.2 miles, but each is raising funds and awareness in honor of a loved one with FD. The Foundation is organizing a cheering section to show our support on race day.

MEET TEAM FD 2022 TCS NYC MARATHON:

Brian Levine
Running for Josh Kletz

Chip Mechler
Running for Justin Sachs

Lily Szajnberg
Running for Samantha Myers z"l

Jacob Walker
Running for Josh Kletz

Kaia Dalamo
Running for all of her FD patients

It's not too late to support our runners and help them achieve their fundraising goals! To learn more and to contribute to Team FD, please go to www.familialdysautonomia.org/fdnycmarathon.

We're looking for a few more good runners!

2023 United Airlines NYC Half - March 19

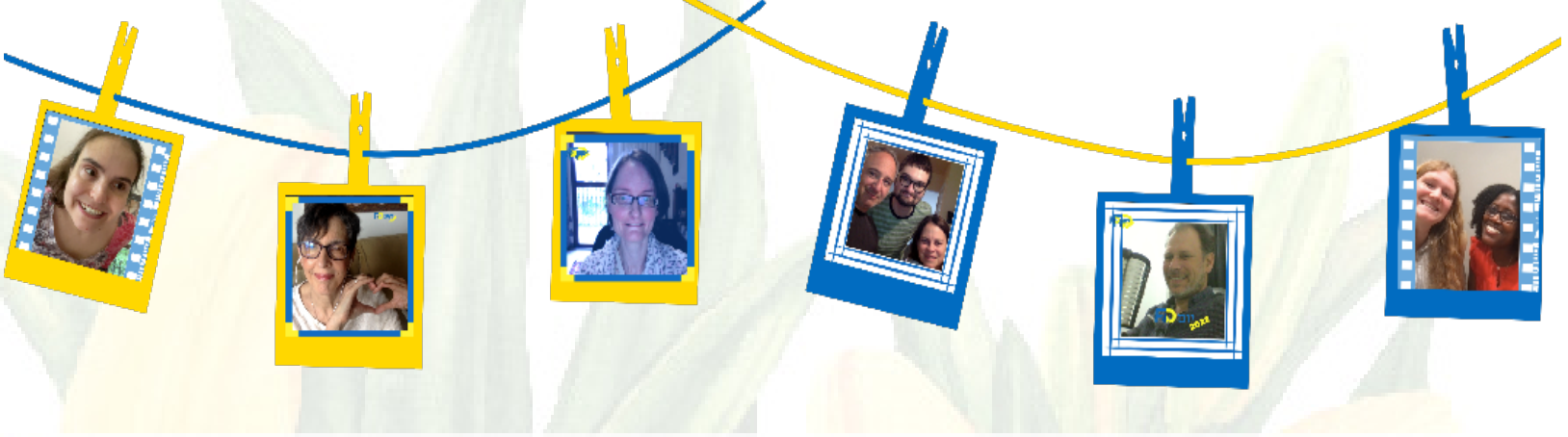
FD Foundation has secured five spots for the **2023 United Airlines NYC Half Marathon** on **March 19, 2023**.

Do you want to Run for FD in Jerusalem?

We are considering forming a team to participate in the **Jerusalem Marathon** on Friday, **March 17, 2023**.

The event includes a marathon, a half-marathon, a 10K race, a 5K race and a family race. To learn more visit https://jerusalem-marathon.com/en.

To indicate potential interest, please email info@famdys.org.



FD DAY 2022:
A VIRTUAL GATHERING OF OUR INTERNATIONAL COMMUNITY

On Sunday, June 12, computers across the United States, Canada, Israel, Great Britain, Europe, South America and Australia were tuned in to **FD Day 2022**. This year's FD Day kicked off with a video segment called "We're watching from...," featuring recorded greetings from FD families around the world. We heard the latest news from the FD Foundation and from our international chapters in Canada, Great Britain and Israel.

During the Clinical Session, **Dr. Horacio Kaufmann** and his clinical team provided updates on the latest in FD care and treatment.

The Research Session highlighted encouraging advances on the research front and featured talks by our "super star" scientists, including **Sue Slaugenhaupt** (Mass General), **Frances Lefcort** (Montana State Univ.) and **Adrian Krainer** (Cold Spring Harbor Laboratory) and we also heard from our FD physician in Israel, **Dr. Bat-El Bar Aluma** (Sheba).

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

This year's Dystinguished Awards were presented to: **Morgan Asinowski**, **Mitchell Kofsky** and **Sarah Zucker**.

The **13th Annual FD Art Contest**, skillfully organized by nurse practitioner **Kaia Dalamo** showcased the incredible artistic talent of many people with FD. Prizes were awarded to **Simi Steiner**, **Justin Sachs** and **Mara Clawson**.

This year, we initiated a new FD Day tradition: the presentation of the FD Champion Award to honor someone from outside our immediate FD family who has gone over and above on behalf of the FD community. The inaugural award went to **Hank Arens,** who owns an interior design business in Phoenix, Arizona, and who co-chaired together, with FD mom **Stephanie Stillman**, the highly successful FD fundraiser "Peeper Pypers Party", held in Scottsdale in February.

View a recording of the full FD Day program or individual segments here: https://familialdysautonomia.org/fdday2022.

In conjunction with FD Day, the NYU Treatment Center team prepared a comprehensive Research Booklet, which you can view here: https://familialdysautonomia.org/application/files/4716/5592/9313/2022_RESEARCH_BOOKLET_COMPLETE-2.pdf

We are grateful to our sponsors of FD Day 2022:

PARTNER

PTC THERAPEUTICS
measured by moments

SUPPORTER

FAYE GINSBURG & FRED MYERS

HOWARD & TOVA WEISER

DEBBY SZAJNBERG (AUNT DEB)

FRIEND

TOWN TOTAL COMPOUNDING CENTER

DANIEL, DEENA & RAFI LANDAU

LAURA, TOM & BARBARA BALE

CONGRATS TO OUR 2022 DYSTINGUISHED AWARDEES

MORGAN ASINOWSKI

MITCHELL KOFSKY

SARAH ZUCKER

DYSAUTONOMIA CENTER WELCOMES NEW VISITING PROFESSOR

Dr. Maria Eugenia

For years, the FD Foundation has hosted a visiting professor at the Dysautonomia Center. The Center benefits from knowledge the visiting professor brings while the visiting professor takes back to his/her institution what he/she learns about FD. This tradition paused during Covid, but this past June, **Dr. María Eugenia Briseño Godínez** from Mexico City came to the Center, the first visiting professor since the program was reinstated. Her position is funded by proceeds raised through the 2019 TEARLESS art exhibition event.

Dr. Briseno worked at The National Institute of Neurology and Neurosurgery in Mexico City, spent two years in internal medicine and one year training in neuro-muscular disorders. She also specialized in autonomic disorders at the National Institute of Medical Science and Nutrition. Dr. Briseno previously worked in Mexico under the Center's current Co-Director, **Dr. Alejandra Gonzalez-Duarte**, and was inspired to follow her here. Living temporarily in Manhattan, Dr. Briseno will be working at the Center until December. According to Dr. Briseno, "So far it has been a great experience. I've been evaluating patients with FD and others with autonomic diagnoses and disorders, discussing clinical cases and treatment protocols with clinicians at the Center." She adds, "There is only one autonomic Center in my city but I want to build another so that there can be options. It's important to grow the field." Because some autonomic diseases are not common in Mexico, Dr. Briseno hopes to study more about them here and get involved with break-through research. According to Dr. Briseno, "Every mind is different and even though I have less experience in the autonomic field, I think I still bring a unique perspective to the table. I'm honored to learn from accomplished physicians like **Dr. Kaufmann** and Dr. Gonzalez-Duarte and eventually hope to build a lab in Mexico to bring my newfound knowledge there."

CROWDFUNDFUNDING CAMPAIGN #FDMATCH22 MAKES A SPLASH

For the 6th year in a row, the FD Foundation launched its annual crowdfunding campaign – **#FDMatch22**. This year we celebrated FD Stories, spotlighting individuals and families who are making tremendous strides towards–and benefiting from–the patient care, medical research, and life-enhancing programs and services provided by the Foundation and made possible by **YOUR** support. Thanks to the dedication of our fundraisers, the generosity of our matching donors and the particpation of many others, we are close to reaching our fundraising goal. With this support, we are able to fund vital FD programs and services such as virtual check-ups at NYU's Dysautonomia Center and critical treatment initiatives. Thank you to **Gerry** and **Vivian Adler, Gabi Jassi, Dr. Alejandra Gonzales-Duarte, Jason** and **Kevin Gross, Linda** and **Scott Kutner, Dr. Frances Lefcort** and **Stacey and Adam Sachs** for sharing their stories with us.

www.familialdysautonomia.org/fdmatch22

Many thanks to our 2022 Crowdfunding fundraisers/teams:

Alyson M Brenner
Allan Cohen
Natalie Cohen/ Team Cohen
Cheryl Furjanic/ NYU Loves Samantha Myers
Daniel Landau
Robin & Laurent Landau/ Landau Team
Susan LeVine/ Kelly and Susan
Lisa & Rebecca Newman/ Team Becca
Jennifer Sonenshein
Mike Zucker

DYSAUTONOMIA CENTER WELCOMES SOCIAL WORK INTERN

A great big welcome to **Matthew Hertzberg,** a social work grad student at Fordham University who joined the Dysautonomia Center in September as an intern, empowered to help families navigate the challenges of housing, and non medical issues, addressing relationships, death, and grieving. Currently living in Brooklyn, Matthew is thrilled to be at the Dysautonomia Center for his first field placement in his social work program, working closely with nurse practitioner **Zenith Khan**. He comes from a creative background and has worked in many different fields including film and television, hosting, bartending and was even a chef, but at the core, has always been a nurturer.

According to Matthew, "Seeing families grieve during Covid and training as an end of life doula, I met some social workers and realized there was an emotional intelligence I hadn't been using in all of my prior careers. I come from a background of grief and bereavement as my dad died from cancer when I was 15. My wife is a pediatric palliative care nurse practitioner at NYU Langone and is immunocompromised so I've acquired a caretaker role as well."

Matthew Hertzberg

Adds Matthew, "I hope to offer comfort to patients and families, to facilitate support groups and to advocate for improved quality of life. Patients rights and dignity are important to me. Coming from an Ashkenazi Jewish background, I deeply feel the connection to FD."

Matthew looks forward to meeting with patients and families conducting psycho-social assessments, offering support and advocacy, and discussing challenges outside of medical needs. He plans to provide connections to community wellness programs and offer mindfulness exercises, as well as talking people through living with a new diagnosis, coping with loss around independence, mobility, or social isolation. Notes Matthew, "I'm honored to be a part of the Center and offer my support in any way I can."

FD HANGOUTS AND VIRTUAL GAME NIGHTS

Social worker **Liza Freed** facilitates our popular **FD Hangouts** every other week on Zoom, providing an opportunity for people who have FD to meet and socialize with one another virtually. Liza has also kicked off a monthly game night! According to Liza, "We do all sorts of different activities, including Jackbox games, open mic nights, a murder mystery, as well as learning about arts and culture." Many thanks to the social committee participants who help plan the events: **Rebecca Newman, Gabi Jassie, Frannie Cohen,** and **Laura Bale**.

Game Nights are open to all - watch for notices for upcoming game nights, all at 7:30pm ET on:

2022

- 11/17
- 12/15

2023

- 1/19
- 2/16
- 3/16
- 4/20
- 5/18

If you are not currently participating in a **hangout group** and would like to learn more, please email Liza at lizafreed@gmail.com.

WE ARE KVELLING!

- U.S. News & World Report recently ranked **NYU Langone Health** #1 in New York State and #3 among the nation's "Best Hospitals." Additionally, their departments of neurology and neurosurgery are now ranked #1 in the country.
- In May, FD Foundation President **Faye Ginsburg**, who is also a professor and anthropologist at New York University, participated in grand rounds at Columbia University Medical Center, speaking about: An Unanticipated Life with Familial Dysautonomia: Caregiving in a Rare Disease Community. Faye is also the Director of the NYU Center for Disability Studies, and is currently completing a book, ***Disability Worlds***, with her colleague, medical anthropologist **Rayna Rapp**, which is rooted in her experiences parenting her daughter Samantha who lived with FD.
- Congrats to the Foundation's Fundraising and Communications Manager **Albulena Prelvukaj**, who married **Chris** on 5/10/22 in New York City.
- Mens Helpline, the non-profit support group for men struggling with the emotional challenges of miscarriage, infant loss, still birth and infertility, founded by FD board member **Daniel Landau**, recently achieved 501c3 status.
- Mazel tov to **Daniel and Deena Landau** on the birth of their son **Ezra**, in Israel on August 1. **Rafi** is delighted to be a big brother!
- Mazel tov to board member **Gerry Adler** and his wife **Vivian Kahn Adler** for becoming grandparents for a second time with the birth of their grandson **Sammy** on July 14.
- Mazel tov to board member **Allan Cohen** and his wife **Arielle** on the marriage of their daughter **Elizabeth Cohen** to **Michael Fagin** in Bronx, NY on August 22.
- Congratulations to **Mara Clawson** for her successful solo art show at Silo6776 in New Hope, PA. This exhibition, held over the summer, featured lots of Mara's early work, as well as pieces that were never for sale before. Thanks especially to Mara and her family for directing ten percent of sales to the FD Foundation!

FD IN THE NEWS

- American television sports talk show host **Tony Kornheiser #thetonykornheisershow** recently did a podcast mentioning sports enthusiast **Peter Sonenshein**, who has FD. Pete wrote back to him and Kornheiser read part of Pete's letter on air, including how painting helps Pete cope with the uncertainties of FD. The podcast acknowledged FD and promoted Pete's artistic website on air and is now on Instagram along with Pete's paintings.
- Don't miss **Vivian Kahn Adler's** podcast www.buzzsprout.com/1962711/11038082 on Suffering Loss, Helping Children with Special Needs, and Choosing to Be Grateful Every Day. Vivian is the wife of board member **Gerald Adler** and is a speech pathologist who specializes in pediatric feeding disorders. After losing her daughter in 1989 to FD, Vivian was encouraged by well-meaning friends to shift away from working with children with special needs. Instead, Vivian leaned in, realizing that helping these children was her "raison d'etre." Vivian talks about showing up for others who are going through loss and how she lives a life of gratitude.
- The FD Foundation was spotlighted with a great article in the **knowrare** blog. Read all about it here https://knowrare.com/blog-v2/familial-dysautonomia-foundation.

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!

ENTREPRENEUR WITH FD HELPS OTHER DISABLED BUSINESS OWNERS

Zoey Schvan

Meet **Zoey Schvan**, a 33-year-old blogger with FD who lives in Ottawa, Canada. Zoey offers a unique online entrepreneurial course helping other disabled business founders break down prejudices, creating a more inclusive and accessible workforce.

Zoey helps fellow disabled/neurodivergent founders with their businesses and content. This all started four years ago when she began a personal blog as a hobby. After posting for a while, she discovered her hidden talent and gained a small following with requests to write for other blogs and websites. Explains Zoey, "It was great to start growing my little community and make some money doing what I love! After working a few more jobs, I decided to launch my own business, so I could really put my skills to use."

Zoey took courses to get certified as a business and entrepreneurship coach and then Incubator 13, a local nonprofit, hired her to give a complimentary course to help disabled entrepreneurs ages 16-30 kickstart their businesses. She started her business just a year ago and this Fall, she embarked on her 4th cohort with 10 hopeful entrepreneurs. Participants sign up on Instagram, Twitter, and Facebook and most come via word of mouth. Zoey's four week course meets weekly on Zoom for an hour, offering tips on how to start a business, outlining the benefits of being a business owner with a disability, and promising registrants they will leave with two concrete business ideas. Adds Zoey, "This is a great introduction to entrepreneurship for people who are toying with the idea of being a business owner. They come up with two different business ideas on their own and share ideas. It's very interactive. My favorite thing about it is showing other disabled people that they can do it too and I love giving them confidence." One of Zoey's former clients hopes to start a travel agency for disabled people, while another wants to launch an adaptive clothing line for people with disabilities.

"As a businesswoman with a disability, it's really important to help entrepreneurs like me turn their business ideas into realities," she explains. "Making a name for myself while living with FD has given me the know-how to overcome the challenges of doing business with a disability. Despite my unique situation, my disability doesn't stop me from succeeding, and I'm still able to do anything that a typical business owner would. Learning to navigate a conference with a walker, coping with the uncertainty of a chronic illness, and working on everyday skills (like speaking up for myself) has helped me understand what entrepreneurs of any ability deal with."

While coaching people with disabilities is her priority, Zoey is happy to work with anyone who needs assistance getting their business going. She adds, "I believe that anybody can start a business if they really want to, so I would be happy to provide my skills as a business consultant to whoever needs them." To learn more about the course or for more information, contact Zoey at z.schvan@outlook.com.

Elie's car

Harry & Evan

GRATITUDE TO:

- **Mark F. Rockefeller** for recommending a $5,000 grant from **Rockefeller Philanthropy Advisors** in honor of **Jack Posnack.**
- **The Kay Family Foundation** for providing a $10,000 grant to the FD Foundation for general support.
- **Elie Eiger**, the first person to donate her car to the FD car donation program.
- **Hilary and David Kaufman** of Tenafly, NJ, proud parents of **Harrison**, who celebrated his Bar Mitzvah on October 29. As his mitzvah project, Harry raised funds and awareness for FD in honor of his cousin, **Evan Kaplan**.
- **Mike Zucker**, who once again this year organized a bike ride to raise funds and awarness for FD in honor of his daughter **Sarah.**

CHECK OUT THESE CREATIVE WAYS TO SUPPORT FD

DONATE YOUR VEHICLE TO FAMILIAL DYSAUTONOMIA FOUNDATION, INC

CARS // TRUCKS // MOTORCYCLES BOATS // RVS // CAMPERS

www.familialdysautonomia.org/donate-vehicle

1.866.628.2277

DOUBLE YOUR DONATION

WILL YOUR COMPANY MATCH YOUR DONATION?

FIND OUT INSTANTLY!

Tax ID / EIN: 13-5145280

Visit www.familialdysautonomia.org/double-donation to learn more.

DONATE CRYPTO

FD FOUNDATION NOW ACCEPTS DONATIONS IN BITCOIN, ETHEREUM, AND OVER 40 LEADING CRYPTOCURRENCIES!

Our partners The Giving Block and Gemini Trust Exchange, will process your crypto quickly and safely, send your charitable donation to the FD Foundation and provide you with all necessary tax documentation.

Visit: www.familialdysautonomia.org/donate-crypto

Support us with amazonsmile

You Shop. Amazon Gives.

This holiday season and throughout the year, you can shop on Amazon, and support the FD Foundation. It's easy:

- **Sign up at** www.smile.amazon.com
- **When prompted, choose Dysautonomia Foundation, Inc. as your charity.**

HOST A FACEBOOK FUNDRAISER TO BENEFIT FD

If you're celebrating a birthday, anniversary or wedding, consider inviting friends and loved ones to donate to FD in your name instead of giving a gift, or set up a campaign yourself on Facebook to collect donations. Whether you are tech savvy or new to Facebook, we are happy to help you set this up! Contact the FD Foundation at info@famdys.org for more information.

Thanks to everyone who held a Facebook Fundraiser for us recently:

Stefani Berdia
Kelly Brotman
Ellen Hattenbach
Sam Landau
Fred Myers
Fraida Perelstein
Ericka Sicilia Puglisi
Barrie Rappaport
Marc J. Shuldiner

JOIN THE FACEBOOK GROUP "FD ADVICE CORNER"!

Started by **Sophie Meyers** and **Gabi Jassie**, the group offers a safe and private space for people with FD to meet and socialize with one another. Says Sophie, "We're all in this together!"

To join, visit https://www.facebook.com/groups/353287232374518

FOLLOW US ON:

famdys.org
@Famdys
@famdys
@famdysfoundation
@FamDys
@FamDys

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

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).

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.

NORD 2022 MEMBER PLATINUM

Platinum Transparency 2022 Candid.

CHARITY NAVIGATOR ★★★★ Four Star Charity

DYS/COURSE 2022- 2

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

SILENT AUCTION *is back tonight!*

FAMILIAL DYSAUTONOMIA FOUNDATION, INC

BID TODAY

Virtual Bidding Accepted Until
Monday, November 14th, 2022, 6:00 PM MST

In honor of the daughter Pyper who lives with FD, the Stillman family is presenting a Silent Auction to raise funds for the FD Foundation during the Phoenix Home & Garden 2022 Home Tour on Nov. 12, 2022.

SCAN & BID NOW!

OVER 60 PACKAGES LISTED:

Experiences, Golf, Vacations & much more!

COMING THIS FALL!