

SPRING 2022

DYSCOURSE

NEWS FROM THE FAMILIAL DYSAUTONOMIA FOUNDATION



JOIN THE FD HANGOUTS!

**MEET SOME FD MOVERS
AND SHAKERS**

**NEW EQUIPMENT AT THE
DYSAUTONOMIA CENTER!**



**DYSAUTONOMIA
FOUNDATION, INC**

Justin Jacob

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

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On the Cover

"The King" This original painting by Justin Sachs was featured in the "The World Through My Eyes" art competition organized by the Dysautonomia Center as part of FD Day 2021. Inspiration for "The King" came from Justin's love of Disney's The Lion King, as well as the jungle mural his mother painted for him when he was a young boy.

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 Spring 2022

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



MESSAGE FROM THE PRESIDENT AND EXECUTIVE DIRECTOR

Dear Friends:

We write this message with a sense of optimism. For those of us living in colder climates, there is a hint of spring in the air, and we look forward to warm and sunny days ahead! We are also starting to see a light at the end of the tunnel regarding COVID. We are all eager to see an end to two years of isolation and, while remaining cautious, to begin to reconnect with friends and family and resume some sense of normalcy in our lives.

We are grateful to the **Stillman family** in Arizona, who hosted Peeper Pyper's Party, a fundraising and awareness event for FD in February. Read more about this unique and very successful event in this issue of the newsletter and check out the adorable photos online at www.familialdysautonomia.org/events/past-events/pyper-party. Also in February the Foundation observed **Rare Disease Day** by posting original artwork featuring the zebra—the international symbol for rare diseases. Follow the Foundation on [social media](#) so you'll never miss out on the latest news and updates.

The Foundation recently published its 67th annual **Journal**, raising close to \$170,000. If you did not receive a hard copy in the mail, you can view the digital version at www.familialdysautonomia.org/2022journal. Many thanks to all who participated.

Be sure to mark your calendars for the Foundation's traditional spring events: the **FD Golf Classic on Monday, May 23** and **FD Day on Sunday, June 12!** This year is the 25th Anniversary of the FD Golf Classic, an event chaired by **Paul Wexler, Steven Fass, Steven Kietz, and Rachel Schlau** that has raised millions of dollars over the years to fund the Foundation's work. We invite everyone to participate by registering to golf, by becoming a sponsor or by donating an item or experience for the silent auction (more info at www.birdease.com/FDgolf). FD Day will remain a virtual experience, enabling our friends from across the country and around the world to attend. We look forward to hearing the latest news and advances from the Dysautonomia Center team and from members of our esteemed Scientific Advisory Board. To register for FD Day visit www.familialdysautonomia.org/fdday2022.

Continuing with our theme of optimism, in this issue of DYS/COURSE, you will meet two **young adults with FD** who have recently started new business ventures. We are inspired by their creativity, tenacity as well as their willingness to give back.

Also in this issue you will meet social work student **Liza Freed**, who is facilitating our popular **virtual "hang-out" groups** for people with FD. If you are not participating in a "hang-out" group but would like to, or would like more information, please contact the Foundation at info@famdys.org.

We are always interested to hear your suggestions for articles and/or artwork for DYS/COURSE - please drop us a line at info@famdys.org.

Sincerely,



Faye Ginsburg
President



Lanie Etkind
Executive Director

FD HANGOUTS ARE BACK!

Since the start of the pandemic, the FD Foundation began offering “Hangouts,” an opportunity for people who have FD to meet and socialize with one another virtually. The objective was to gather people with FD from all over the world to share stories, play games and tell jokes. The groups went on hiatus last fall but started up again in January with new facilitator **Liza Freed**, a second-year social work student at Hunter College. Liza comes to the Foundation with a background providing group and individual support to adults with developmental and intellectual disabilities.

Born out of Covid and now here for good, the groups meet over Zoom every other week for an hour. According to Liza, “The hangouts are going really well. I think the younger participants are looking for more of a support group, since there is a sense of isolation as a teen. I’ve seen some moods completely turn around after a session and it’s great to be able to provide a happy space!” The smallest group has about 4 members and the largest group has 10 members. Adds Liza, “There is such a nice energy when we meet – this is a space where everyone knows what FD is and we don’t have to talk about it necessarily. Instead, we can focus on other topics that people want to discuss.”



Liza Freed

“I love participating in the FD Hangouts. It’s a great opportunity to reconnect with friends that you don’t see on a regular basis,” says participant **Rebecca Newman**. Adds **Zoey Schvan**, another hangout participant, “Having such a rare condition feels alienating sometimes, especially being the only one where I live. These meetups give me the feeling of belonging and acceptance that I’ve missed. I don’t have to explain myself and can feel at home.”

Liza is also excited to start hosting monthly, virtual social events, which will be planned by and for members of the FD community and may include programs such as movie nights, virtual games and karaoke. Watch for more information coming soon!



If you are not participating in the Hangouts but would like to, it’s not too late! Groups are organized by age and availability, so please contact the Foundation (212-279-1066 or info@famdys.org) and we will help you find the group that’s right for you!



Rabbi Larry, Rebecca and son Sam Sernovitz

WE ARE KVELLING!

Mazel Tov to the **Rabbi Larry and Rebecca Sernovitz** on the Bar Mitzvah of their son, **Sam Sernovitz**. Sam, who has FD, celebrated his Bar Mitzvah last September during Sukkot at Temple Kol Emeth in Marietta, Georgia. The Foundation also acknowledges the **Men’s Club at Temple Kol Emeth** for their generous donation of \$3,600 to the FD Foundation in honor of Sam’s special day.

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!

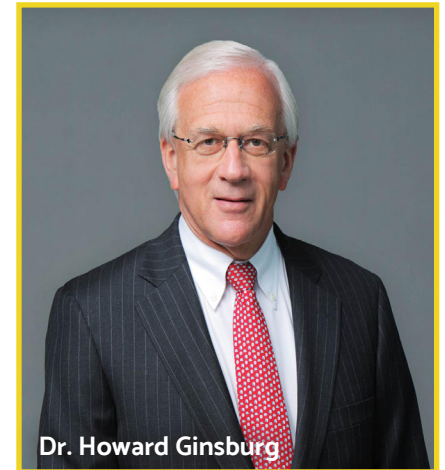
DR. HOWARD GINSBURG RETIRES FROM NYU LANGONE

After an extraordinary 41+ year career as a pediatric surgeon at NYU Langone, **Dr. Howard Ginsburg** retired in January. Dr. Ginsburg started working with FD patients at the Dysautonomia Center in 1983 and developed a wonderful relationship with the director there at the time, **Dr. Felicia Axelrod**. According to Dr. Axelrod, “Howard was more than a surgeon who went into an operating room to perform a surgery. He was truly innovative, and he developed deep relationships with our families.”

Dr. Axelrod explains that the way a mother usually relates to a child initially is through feeding “but in many situations we were taking that away when putting in tubes. Yet Dr. Ginsburg was able to connect with the families by using a life saving measure and explaining to families that they could still relate to children in other ways. It was important to have a surgeon who was on the same page as all of us at the Center.”

Notes Dr. Ginsburg, “Back in the ‘80s, I knew that FD patients had intense swallowing disorders and reflux which caused pulmonary problems, so we made a conscious effort to increase quality of life and life expectancy and decided to perform gastrostomies.” The tubes ultimately enabled patients to have enough hydration and over the course of 20 years, the life expectancy of these kids with FD increased significantly. He adds, “It was amazing to watch the kids accept their disabilities and strive to have as normal lives as possible. Much of that was due to Dr. Axelrod, who is a super human being with an incredible career. Her medical treatments were huge contributors to increasing life expectancy and I hope I played a small part of that as well.”

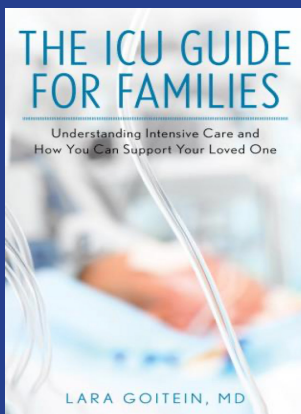
The two doctors worked closely together on many academic papers related to FD and Dr. Axelrod attributes much of the progress in the FD world to Dr. Ginsburg. “He understood that it was easier for kids to adjust psychologically if the tubes weren’t so visible, so we endeavored together to create small buttons that worked well on the gastrostomies. The important thing about him is that he was not just a technician but really related to patients and families.”



When asked what the most rewarding aspect of working with FD patients was for him, Dr. Ginsburg responded, “I was the primary pediatric surgeon for many of the kids for years. Once I started working with these kids as well as their families, I grew very close to them. Over the years, I probably treated about 40 kids with FD. Happily, with genetic testing we don’t see that volume anymore.” Dr. Ginsburg is especially proud to point out that many of the FD kids who became adults have contributed significantly to society.

Adds Dr. Ginsburg, “I am still in touch with Alexia de Gunzburg and her father to this day. I treated Scott Fass and am still friendly with his family and our continued relationship has been very important to me. I have played in the FD golf tournament every year to honor Scott and plan to continue to do so.”

Since his retirement, Dr. Ginsburg has been enjoying his free time by playing golf, reading, and taking it easy. He hopes to stay in touch with other surgeons and attend medical conferences and travel when it is safe to do so. “For so many years I got up at 4:30 a.m. to commute from New Jersey, but now I get to go back to sleep!”



HELPING FAMILIES IN THE ICU

A new book called *The ICU Guide For Families* offers guidance on how family members can support a critically ill loved one who is being cared for in the hospital’s intensive care unit. According to FD Foundation President **Faye Ginsburg**, “This book was written up in the *New York Times* and it’s a great resource. I highly recommend it to all our families.”

PEEPER PYPER'S PARTY RAISES FUNDS AND AWARENESS FOR FD

On Sunday, February 27, **Peeper Pyper's Party**, an event to raise funds and awareness took place at the Arizona Jewish Historical Society in Phoenix, Arizona. Hosted by **Stephanie and Brian Stillman** in honor of their daughter Pyper, who turned seven years old in December and has FD, Peeper Pyper's Party raised close to **\$140,000** to support the work of the FD Foundation. Chaired by close family friend **Hank Arens**, the event featured a Dr. Seuss theme including artwork by Pyper's ten-year-old sister **Zoey**. In addition to bidding on live and silent auction items, more than 125 attendees had the opportunity to enjoy a bouncy house and pony rides, participate in a zany scavenger hunt, enjoy treats from food trucks, dance to music from a live DJ and more. To see more photos from Peeper Pyper's Party and watch a video about Pyper and FD, visit <https://familialdysautonomia.org/events/past-events/pypers-party>.



Pyper Stillman



Hank Arens, Stephanie, Zoey, Pyper, and Brian Stillman, and Cat In The Hat - Joshua Fink



Hank Arens and Stephanie Stillman



Zoey Stillman (second from left) and her friends

FD MOVERS AND SHAKERS!

Meet **Carrie Baker**, a 25-year-old social media manager living with FD in Los Angeles. After graduating last year from Cal State Northridge with a major in art and an emphasis on photography, Carrie recently started an online cosmetics company called **Slash Em Beauty** that offers high-end makeup at a lower rate. Carrie has pledged to donate 15% of her company's profits back to the FD Foundation. According to Carrie, "I have been posting products on my Instagram **@slash.embeauty** and selling all different brands of makeup including Urban Decay, Stila, and Huda Beauty for less than retail as a way to give back to FD." After hiring an intern to help her get her business off the ground, Carrie is now in the process of creating a website. Adds Carrie, "Makeup can be very expensive and not everyone can afford it. I have access to great brands at a discount and I want to pay it forward. Check out my website www.slash-embeauty.com to support FD!"



Meet **Peter Sonenshein**, a 37-year-old artist living with FD outside of Philadelphia. Peter participated in the TEARLESS art exhibit in 2019 in New York to benefit FD and continues to paint and experiment with new materials and styles. With almost 300 works of art featured on his website, Peter believes that painting and drawing help him deal with the uncertainty and anxiety that his condition causes, and he particularly enjoys cartooning and graffiti.

Recently, his mother Jennifer donated a pair of high-top converse sneakers with Peter's artwork imprinted on them for Peeper Pyper's Party, a recent FD benefit event in Arizona. They went over so well that he got another custom order as a result. Adds Jennifer, "Peter has always loved sneakers and sports and gets much of his inspiration from what's going on in the sports world. For a while he was even creating his own basketball and baseball trading cards!" Check out Peter's custom sneakers in the photo above and more of his works on his website www.petersonenshein.com.

ALL FOR A GOOD CAUSE

When Hunter College social work student **Liza Freed** resumed the FD Hangouts in January, she met **Alexia de Gunzburg**, who, while living with FD, is an author, artist, motivational speaker and advocate for the rights of the disabled. Alexia shared her website, www.stepsofalexia.com with Liza who then commissioned a piece of art from Alexia as an engagement gift for her sister and partner to commemorate the occasion. In lieu of payment, the de Gunzburg family invited Liza to donate to the **Tilsitt Fund**, which supports medical care and clinical research at the Dysautonomia Treatment Center at NYU Langone. Liza and Alexia have established a beautiful relationship and Alexia is always happy to give back to FD.



Casey Eisenreich and Madelyn Freed with Alexia's painting in the background

AN INSPIRING “FOREVER DEVOTED” STORY

When **Rochelle Solomon**, a retired elementary school teacher from Cleveland, Ohio had her first child **Benjamin** in 1976, she noticed he wasn't thriving. “He didn't have tears and I instinctively knew there was a problem.” After changing pediatricians many times and eventually receiving a diagnosis of FD, the Solomon family made their first trip to the Dysautonomia Center in New York and Ben became case #154 in the entire world. According to Rochelle, “The Center was a godsend. We developed a wonderful relationship with Dr. Axelrod. Since Ben couldn't fly, we would drive to New York twice a year for his check-ups. If it hadn't been for Dr. Axelrod, Ben would've died a million times. She was always there for us.”

The only person with FD in all of Ohio, Ben passed away in 1999 when he was 22 years old. Adds Rochelle, “Ben had the most engaging smile and he never complained. It was never about him, even if he was in the hospital.” Because she wanted to ensure Ben's legacy, Rochelle created a memorial quilt out of his baseball jerseys and hats. His high school even allowed students to wear baseball hats to class if they paid \$1, leading her to establish a scholarship fund in his name for a student who had beat adversity.

Notes Rochelle, “Since I'm getting older, I recently redid my will and while I'm leaving my estate to my younger son Adam, I also want to honor Benjamin and that's why I decided to include the FD Foundation in my plans. It's truly a wonderful foundation for such an orphan condition.”



Rochelle Solomon and her son Ben z"l

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

Now You Can Donate Cryptocurrency to the FD Foundation

The 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.

Donating crypto is safe, easy, and fast. For more information, visit: www.familialdysautonomia.org/donate-crypto or contact the Foundation at info@famdys.org.



NEW EQUIPMENT AT THE DYSAUTONOMIA CENTER!

Alejandra Gonzalez-Duarte, MD, PhD who came to the Dysautonomia Center in July as Associate Director, is very excited about a vital new piece of equipment, the **TSA2 Thermosensory Stimulator**, which can be used to monitor the sensory nerves in people living with FD. Explains Dr. Gonzalez-Duarte, “I plan to use this with all our patients during their annual visits. It’s crucial to assess temperature and pain to see if our patients are perceiving stimulus the same as when they were younger, and I can compare my new findings to former data to see whether things are progressing.”

Acquired through a generous grant from the **J. Aron Foundation**, the TSA2 can assess the function of the small fibers which monitor temperature and pain. Explains Dr. Gonzalez-Duarte, “It’s very important to have an endpoint and markers. When analyzing the nerves, we look to see if the eyes are worsening and there is more vision impairment. If we notice that the sensibility is deteriorating, we need to create a plan and try certain stimuli to improve cognition.”

In the past, the Dysautonomia Center recognized that patients with FD have different thresholds to feel temperature and pain, and that in the first years of life, this capacity remains stable. Adds Dr. Gonzalez-Duarte, “The Center analyzed mental status, degree of muscle tone and gait impairment. Developmental deficits may be related to the absence of or decreased sensory information from the external world into the central nervous system.”

As the pandemic wanes and more patients start to return to the Center in person, the TSA2 will be incorporated into standard checkups. The thermode of the device can produce temperature changes from 0°C to 50°C in an organized sequential pattern, and it will register the threshold of cold, warm, heat and pain stimuli sensed by the patient. The stimuli can be applied to any surface of the body that needs to be tested and is fast and easily performed.



Notes Dr. Gonzalez-Duarte, “I am so pleased to be a part of the Center. We know that in adulthood, patients’ vision worsens due to atrophy of the optic nerves, and that difficulties with balance and walking increase. We aim to investigate if some of the long-term manifestations are a direct consequence of the poor survival of the sensory cell nerves, or if unresponsiveness and atrophy of the sensory centers in the brain are due to the diminished flux of sensory input. By understanding this relationship, new sensory rehabilitation therapies early in infancy could improve the quality of life and decrease some complications in adults with FD.”

GRATITUDE TO:

Miriam and Irving Borenstein (z”l) for a generous bequest from the estate of Miriam Borenstein.

The J. Aron Foundation for its \$30,000 grant enabling the FD Foundation to purchase a TSA2 Thermosensory Stimulator for the Dysautonomia Center at NYU Langone. This equipment is vital to monitor the sensory nerves in people living with FD and is critical to research underway at the Center by Dr. Alejandra Gonzalez-Duarte.

The Herman Goldman Foundation for providing a \$6,000 grant to the FD Foundation for general support.

The Joe Namath Foundation for its \$5,000 grant to the FD Foundation to support neurological research.

David and Jennifer Sonenshein for their letter writing campaign on behalf of the Foundation. To show their appreciation, the Sonenshein family invited contributors to select a piece of original artwork created by their son **Peter**, who has FD.

ARE YOU READY FOR FD DAY ON SUNDAY, JUNE 12?

The FD Foundation and the Dysautonomia Center at NYU Langone are hard at work planning our 37th annual **FD Day**, a virtual event scheduled for **Sunday, June 12, 2022**. You can anticipate hearing the latest updates on clinical care and scientific research from key members of the Dysautonomia Center team and leading scientists studying FD. You can also look forward to re-connecting (virtually, of course) with friends from the FD community worldwide. Programming details have yet to be confirmed as this newsletter goes to print, but we invite you to continue to check the FD Day site www.familialdysautonomia.org/fdday2022 for updates.

REGISTER:

- If you haven't yet registered to attend, please visit www.familialdysautonomia.org/fdday2022 to sign up today!

SPONSOR:

- The Foundation also seeks sponsorships to underwrite the cost of FD Day. To view sponsorship opportunities or to donate, please visit www.familialdysautonomia.org/fdday2022 or to learn more, contact Lanie Etkind at letkind@famdysorg.

ENTER THE ART COMPETITION:

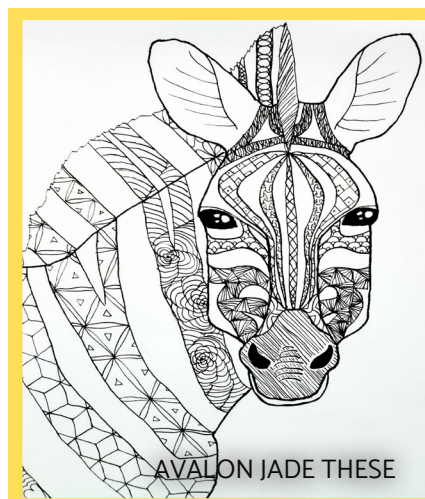
- We encourage everyone to participate in the FD Day art competition, **"The World Through My Eyes,"** sponsored by the team at the NYU Dysautonomia Center. Visit www.dysautonomiacenter.com/2022/02/18/the-world-through-my-eyes-the-mitzvah-year for more details. **Please send submissions to nyudysautonomiacenter@nyulangone.org.**

SEND IN YOUR VIDEO:

- We invite all families to send in a short video message telling us **"We're watching from..."** to be included as part of the FD Day program. Your video should be filmed in horizontal format, no longer than 15 seconds long. Feel free to be creative with backgrounds, props, etc! Please contact the Foundation for instructions on how to submit your video.

FOUNDATION OBSERVES RARE DISEASE DAY ON FEBRUARY 28, 2022

In honor of Rare Disease Day on Feb. 28th, 2022, the FD Foundation asked for art submissions of the zebra, the symbol of rare diseases. We subsequently showcased the artwork that we received from four artists on our social media platforms leading up to Rare Disease Day to raise awareness and generate positive action for the FD and rare disease community. This was the fourth year that 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! Many thanks to the four artists whose work is featured here.



HOST A FACEBOOK FUNDRAISER TO BENEFIT FD



If you're celebrating a birthday, anniversary or wedding, consider inviting friends and loved ones who would normally give you presents to make a donation to FD in your name instead, 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 Erin at the FD Foundation at eduddy@famdys.org for more information.

Many thanks to all who held Facebook Fundraisers in the last six months:

Freddie Baranoff

Andrew Cohen

Debbie Friedman

John Powers

Daniel J. Sernovitz

Carl Shotz

Diane Kandel Smolensky

Karal Taylor

Amy Teich

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>

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FD FOUNDATION AWARDS ITS FIRST GRANT FROM THE CLARE AND PHILIP WEXLER RESEARCH FUND



Dr. Frances Lefcort

Named in memory of the beloved grandparents of **Steven Wexler** and parents of Foundation board Vice President **Paul Wexler**, the **Clare and Philip Wexler Research Fund** was established in 2021 to support the Foundation's efforts to foster translational FD research, meaning moving research from the laboratory to the clinic, where it can directly impact people who have FD.

Based on the unanimous recommendation by the Foundation's Scientific Advisory Board, the Foundation board approved a request from esteemed FD researcher, **Dr. Frances Lefcort**, to support her cutting-edge gene therapy work at Montana State University. While currently testing AAV (adeno-associated virus) infection to express human ELP1 in the eyes of FD mice, with proof of concept, Dr. Lefcort anticipates eventually applying this therapy in FD patients to slow or stop the degeneration of the retinal nerve and preserve vision. The Foundation's grant will provide bridge funding for Dr. Lefcort to continue this critical work while she applies for a major NIH grant.



TEAM FD IS OFF TO THE RACES!

OFFICIAL CHARITY PARTNER



Where will YOU be on **Sunday, November 6th, 2022**? These five intrepid individuals will be braving the elements, the mean streets of New York City, and more than 30,000 fellow runners to complete the famed 26-mile **TCS New York City Marathon** while at the same time raising funds and awareness for FD. Each runner has a personal connection to FD and has committed to raising a minimum of \$2,500 to support the Foundation's mission.

Watch for more details coming soon on how you can encourage members of TEAM FD/NY Marathon 2022 and contribute to their fundraising efforts!



Jake Bergenfeld
New York, NY
Running for Jack Posnack



Chip Mechler
Ashland, MA
Running for Justin Sachs



Brian Levine
New York, NY
Running for Josh Kietz



Lily Szajnberg
Woodside, NY
Running for Samantha Myers



Jacob Walker
Charlotte, NC
Running for Josh Kietz

FD FOUNDATION WELCOMES NEW TEAM MEMBER



In November, the FD Foundation welcomed **Albulena Prelvukaj** as our new Fundraising and Communications Manager. Albulena has more than six years of experience leading partnership management, event coordination, and fundraising efforts for top-tier international non-profit organizations. As the Membership Manager for the G4 Alliance, Albulena gained significant experience with the inner workings of the international community while handling a variety of different clientele through various levels of communication, from Ambassadors, Ministers of Health, UN agencies, corporate partners and NGO delegates.

Albulena's experience also includes executing large-scale programs ranging from international conferences in Switzerland, Denmark, Peru, and Malawi to national advocacy events in New York City, Washington, DC, and Chicago. Outreach, event coordination and fundraising efforts.

Albulena graduated from the Australian National University with a master's degree in international affairs. Her passion to support critical global issues has exposed her to many different cultures and is the motivation that will demonstrate success in this role by providing fundraising and communications support and increasing the Foundation's visibility by leading social media outreach, event coordination and fundraising efforts.

VOLUNTEER HELPS BUILD FD NATURAL HISTORY DATABASE IN ISRAEL

Meet **Monique Ben-Am**, a volunteer at Sheba Medical Center in Tel Hashomer, which hosts one of two hospital-based FD clinics in Israel. Over the past year, Monique has entered the clinical data of nearly 50 Israeli FD patients into a web-based system that will ultimately be incorporated into the FD natural history database.

For many years, Monique worked for Teva Pharmaceuticals, heading up the operational department for global clinical trials. While there, she met Scientific Advisory Board co-chair and FD parent **Adrian Gilbert**, and they developed a great working rapport over the years. Knowing that Monique had recently retired,

Adrian reached out to her for assistance with this critical FD initiative. According to Monique, "Although I am no longer working in the pharmaceutical industry, I like to stay in touch with science and clinical trials. I am fascinated by developing drugs and I love giving hope to patients, so this is the perfect volunteer opportunity for me."

The FD Natural History Study, which tracks the progression of the disease in our patient population over time, forms the backbone of all research progress that is being made to cure FD. With a disorder as rare as FD, having a robust database is essential for clinical care and research. The Natural History database helps us plan for clinical trials and informs us whether new therapies that are introduced to the clinic prolong survival and improve symptoms so that patients can enjoy better quality of life.

Many thanks to Monique for her time and efforts!



Dr. Bat-El Bar Aluma and Monique Ben-Am



DOUBLE YOUR DONATION

Did you know that thousands of companies match donations made by their employees to organizations like ours? Visit <https://familialdysautonomia.org/donate/double-donation-matching-gift> to see if your employer will match your gift!

If you submit a matching request, kindly let us know at info@famdys.org.



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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.



DYS/COURSE 2022- 1

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

Monday
May 23, 2022



Glen Oaks Club
Old Westbury, N.Y.

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

REGISTER TODAY!

Presented by Familial Dysautonomia Foundation in partnership with NYU Dysautonomia Center

FD DAY

37TH ANNUAL CONFERENCE

SAVE THE DATE

SUNDAY • JUNE 12, 2022

JOIN US VIRTUALLY

A Day When Families, Healthcare Providers and Researchers Come Together

More info coming soon at:
www.famdys.org/fdday2022

