JOURNAL

2023

FAMILIAL DYSAUTONOMIA FOUNDATION, INC


FAMILIAL
DYSAUTONOMIA
FOUNDATION, INC

JOURNAL

2023

Familial Dysautonomia Foundation
315 West 39th Street, Suite 701
New York, New York 10018

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

Dear FD Families, Friends and Allies -

Our annual journal is an amazing expression of support for the FD community. Thank you all for your generous contributions to this effort, not only for the wonderful thoughts and photos in this journal, but especially for your work on behalf of our loved ones with FD. The messages expressed in the following pages are full of love and memories; they also contribute to the future, supporting our ongoing efforts to help those with FD live the best lives possible thanks to expert medical care, social and mental health support, and essential research.

It has been a particularly difficult year for me and for a number of others who lost their beloved FD family members. Our wonderful daughter Samantha (Z"L), an activist on behalf of those with FD, passed away on Sunday September 25/ Elul 29, the last day of 5782, at age 33. She experienced cardiac arrest while singing one of her favorite songs on her exercise bike. Fortunately, Sam experienced no pain. She left us singing her heart out; the words to the song she was singing, The Climb, were a clear expression of what her days often felt like:

There's always gonna be another mountain
I'm always gonna wanna make it move
Always gonna be an uphill battle
Sometimes I'm gonna have to lose
Ain't about how fast I get there
Ain't about what's waiting on the other side
It's the climb

Like most FD parents, we were with Sam on every step of that climb. When Sam was born in 1989, her life expectancy was 10; we never expected that we would have the gift of seeing her grow into a beautiful adult. While my husband Fred Myers and I are overwhelmed with grief with her loss, we are also so deeply grateful that she made it into her fourth decade because of the exceptional medical care and ground-breaking research that the foundation's work has made possible. Due to the dedication of our doctors and scientists who are constantly searching for ways to improve FD lives, Sam led an extraordinary life full of friends, joy, love, quirky passions, and an unflagging commitment to telling the world about FD, always encouraging people to support the efforts of the FD Foundation and the NYU Dysautonomia Center

I am heading into my 11th year as President of the Foundation with a renewed dedication to our work. Losing a child is a terrible loss, but it in no way diminishes my commitment to carrying on the visionary efforts that a small group of intrepid parents started over seventy years ago. Along with our dedicated Foundation staff and Board, I want to thank every one of you for generously joining us on this climb.

With gratitude,

Faye Ginsburg

President, Familial Dysautonomia Foundation

BOARD OF DIRECTORS

PRESIDENT
Faye Ginsburg

EXECUTIVE DIRECTOR
Lanie Etkind

VICE PRESIDENTS
Ed Baranoff
Jeffery A. Goldberger
Laurent Landau
Steven Kietz
Lisa Newman
Paul B. Wexler

SECRETARY
Steven S. Fass

TREASURER
Allan Cohen

DIRECTORS
Gerald Adler
Daniel Landau
Gregg Meyers
Rebecca Sernovitz
Jennifer Sonenshein
Brian E. Stillman
Howard Weiser

The FD Foundation Thanks

Its Wonderful Staff

ALBULENA PRELVUKAJ

and

JULIA WINER

Volunteers

PERRY GOLDBERGER

ROBIN LANDAU

Your Efforts Make All
Our Good Work Possible.
Thank You!

WHAT IS FD

Familial Dysautonomia (FD) – pronounced “dys-auto-NO-mia” – is a devastating neurological disease that occurs almost exclusively in people with Ashkenazi Jewish heritage. FD is inherited in an autosomal recessive manner, when both otherwise healthy parents pass on their copy of a mutated IKAP gene to their unborn child. The misread DNA “blueprint” profoundly disrupts the normal development of the sensory and autonomic nervous systems. Infants are born unable to sense information coming from inside their own bodies.

All the normal bodily functions we take for granted are gone awry in people with FD. As people with FD are insensitive to pain, they lack an essential protective mechanism and often severely burn or injure themselves. Blood pressure swings from dangerously high to extremely low. People with FD also face problems with feeding, breathing and walking and confront an uncertain future with kidney failure and blindness looming at a young age.

Crying without tears is a signature feature of FD, hence the teardrop in our “FD” logo. A world without pain and tears exists, but it is far from a carefree existence.

People with FD face unimaginable daily struggles. They must survive frequent bouts of pneumonia, uncontrollable vomiting attacks triggered by their own emotions, and there are times when the drive to take another breath fails while sleeping.

FD is a devastating disorder that causes severe physical, emotional and social problems. Nearly every major bodily function is impaired. Living with FD is a daily challenge for those who are affected as well as their families.

Features of FD include:

- Infants born with poor suck & feeding problems
- Malnutrition & failure to thrive
- Poor muscle tone (hypotonia)
- Aspiration pneumonias
- Delays in milestones like walking & talking
- Unexplained high fevers & very low temperatures
- Almost no reaction to pain
- Inability to taste
- Episodic vomiting
- Drenching sweats
- Uncontrollable flushing of the skin
- Abnormal spine curvature
- Learning disabilities
- Kidney failure
- Sleep apnea
- Walking & coordination problems
- Blindness

OUR MISSION & HISTORY

The Familial Dysautonomia Foundation is a non-profit organization that was founded in 1951 by parents of children with FD who had nowhere else to turn for help and support. More than seven decades later it has grown to include chapters throughout the USA, Israel, and Canada. The Foundation is the leading source of funding for FD treatment and research and maintains the world's only FD treatment centers in NY and Israel. The Foundation raises funds and operates programs to pursue the best possible medical treatment, scientific research, public education, and social services for the benefit of those afflicted with, or at risk for familial dysautonomia.

We have established the world's only clinical research lab for the investigation of new FD therapies. Through expert medical care, patients who once had a 50% chance of reaching age 5, now have a 75% chance of living to 40 years old and beyond. While improvements in treatment and research have increased life expectancy for patients, FD remains a life threatening and heartbreaking disease with no cure.

The Foundation has funded scientific and medical research around the world. Through drug trials, animal models, and studies on blood pressure, gait, eyesight and the underlying genetics of FD, our researchers aim to eliminate the daily struggles faced by people with the disease. Additionally, one of the goals of the Foundation is to provide a continual flow of information to FD families and offer a variety of programs that include: an annual symposium for FD families; medical conferences for doctors and scientists; oxygen concentrators for air travel; and community building programs including virtual hang-out groups.

The Familial Dysautonomia Foundation is proud to have funded the research that led to the 2001 discovery of the gene that causes FD. This breakthrough enabled scientist to provide prenatal and carrier screening for FD for the first time. As a result, general population screening has become available to Jewish couples, and countless healthy babies have been born to FD affected families. In addition, we have successfully petitioned the American College of Obstetrics and Gynecologists (ACOG) to recommend genetic screening for FD, so that, as with Tay-Sachs, physicians have an obligation to offer carrier screening to at-risk patients.

Discovery of the FD gene has also opened the door to a better understanding of FD and to the development of genetic therapies that will hopefully alleviate the symptoms, slow the progression of the disease, and provide a better quality of life for those affected. It is only through the support of our generous donors that we have been able to accomplish so much. Among rare disease groups, ours is an amazing success story, but our mission will not be fulfilled until we achieve out ultimate goal: a cure for FD.

Dear FD Community,

2023 is the post-pandemic Year One. The strict isolation is over. At the FD Center we have re-started face-to-face medical visits but continue to offer telemedicine.

COVID had a profound effect on the community. It increased isolation and the need for mental health programs and psychotherapy. For that, we started a support group for FD families and caregivers coordinated by Matthew Hertzberg at the FD Center. Matthew complements the work of Lily Armstrong who provides psychotherapy via telemedicine for FD patients. Together they help with the challenges and difficulties of living with FD.

Those who contacted the Center in recent months likely encountered Mike Yates, who joined our Center with a background in behavioral sciences. Since his first day, Mike has shown communication skills and the temperance needed to tackle the multiple tasks and emergencies coming from the Center's Front Desk.

By now, you have all met Dr. Alejandra Gonzalez Duarte, our new co-director. She has the medical knowledge, the warmth and dedication necessary for the role. Together with Dr. Patricio Millar and our nurse practitioners Zenith Khan and Kaia Dalamo they provide the best medical care to our patients.

The Center provides the link to connect experienced FD specialists with treating physicians in the US and abroad. Not only do we communicate frequently with local physicians, but we also have a monthly conference gathering physicians and caregivers from different countries with different specialties treating FD patients. This close communication and shared expertise allowed patients to successfully undergo procedures in their own environment. This past year we opened our doors at the FD Center at NYU to doctors from Mexico, Spain, and Italy. They spent 3 to 6 months at the Center learning about the medical care of people with FD. These physicians will help diagnose and treat FD in their home countries.

Our goal is to provide the best medical care and find a cure. There are roadblocks to implement a safe treatment that corrects the genetic defect in FD. We are confident that we will get eventually there with the extraordinary scientific work of our long-established research collaborators Sue Slaugenhaupt, Frances Lefcort, Adrian Krainer and Nadja Zeltner.

All this would not be possible without the extraordinary support of the FD Foundation, the Foundation's Scientific Advisory Board, and your participation. As always, the Center is here for you and your family.

Wishing you all the very best for 2023!

Horacio Kaufmann, MD and Alejandra Gonzalez Duarte, MD

x

The Team at NYU's Dysautonomia Center

Horacio Kaufmann, MD

Maria Alejandra Gonzalez-Duarte Briseno, MD

Kaia Dalamo, DNP, FNP-BC

Zenith Khan, FNP-BC, MSN, RN

Jose Martinez, MS

Patricio Millar, MD

Matthew Hertzberg

Mecky Kuijpers

Lee-Ann Lugg

Mike Yates

Exceptional personnel dedicated to the well-being of the FD community

GENETIC RESEARCH

The Familial Dysautonomia Foundation has always supported biomedical research including the quest to find the FD gene mutation, believing from the outset this would reduce the number of FD births, help us better understand the disease and open the door to possible gene therapy.

Our first breakthrough came in the 1990's, when researchers identified a DNA marker that enabled prenatal testing for families that already had a child with FD. This allowed these at-risk families to have healthy babies. In 2001, after a decade of searching, the FD gene mutation was finally discovered within chromosome 9Q. This finding not only sparked a flurry of interest into how the gene functions, but also allowed general population carrier testing.

In 2004, the American College of Obstetricians and Gynecologists formally recommended that FD testing be offered to at-risk families. As a result of this push, the birth rate of FD newborns plummeted worldwide. This was the starting line in our race to end FD; but we did not stop there.

After more than 15 years of continued efforts in the laboratory and in the clinic, 2020 marked a turning point for FD research. Under the new leadership of Dr. Frances Lefcort and Dr. Adrian Gilbert, the Scientific Advisory Board (SAB) added outstanding talent from the scientific, pharmaceutical and medical fields from the US, Israel and worldwide. The re-energized SAB is now taking a more active role in stewarding the progress of prospective FD therapies through the development pipeline.

Today, members of the SAB are pursuing a number of promising treatments including small molecules, anti-sense oligonucleotides and gene therapy, and they are optimistic that one or more may soon be ready for testing in the clinic. We are especially encouraged that several niche organizations have shown interest in supporting our efforts to take some of these initiatives to the next level.

We are grateful for the time, talent and dedication of our SAB. With the ongoing support of our community, together we will continue to prevent, treat and hopefully one day cure FD.

SCIENTIFIC ADVISORY BOARD

Co-Chairs

Board

WE ARE GRATEFUL FOR THE LONGSTANDING AND LOYAL SUPPORT OF

OUR CHAPTERS

Chicago

Israel

Montreal

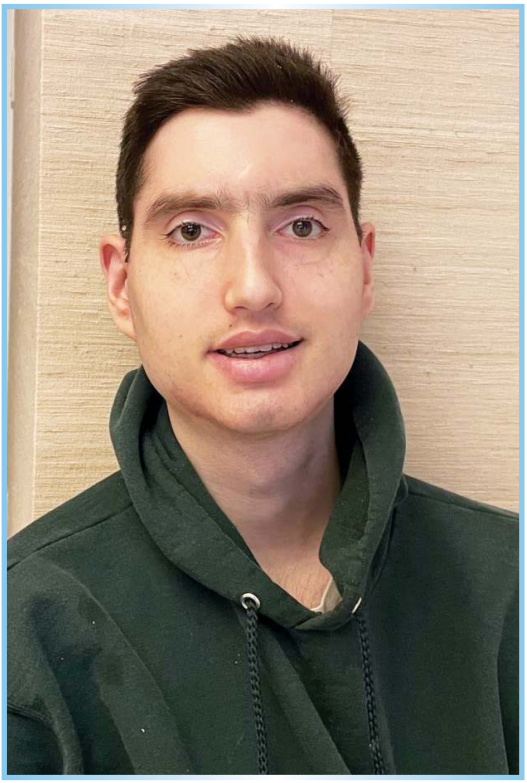
South Florida

United Kingdom


Rare Disease Day
POWER RANGERS
PARTY
EAT SLEEP
FD Community observes Rare Disease Day 2023

Michael,

We know so many days are hard;
we pray for a cure.
You are the kindest,
funniest, bravest !!!



All our love,
Mom, Dad, Rob and Rikki, Nate,
Prissy and Ricky, El, Em, and Ruby 🐾

*Special thanks to the doctors, nurses,
and staff who help us daily ❤

IN HONOR OF

OUR THREE BEAUTIFUL GIRLS

PERRY

SYDNEY

CODY

LOVE,
MOM and DAD

Dear Sam,

You are always ready for adventure. I'm so proud of you and love you very much.

Grandma Soso

In memory of our beloved daughter
Samantha Ginsburg Myers (z"l),
February 8, 1989 - September 25, 2022/Elul 29,
the last day of 5782.

She lived a vibrant and remarkable 33 years, advocating for those with FD, and always bringing joy to those around her, despite the challenges she faced. We miss her every day.

STEVEN WEXLER

Steven,

President John F. Kennedy won the Pulitzer Prize when he wrote
"Profiles in Courage"

Had he Known you,
The first chapter would have been about you!

You inspire everyone you meet with your upbeat inquiring personality.

We are so proud of you and love you very much,

Mom and Dad

Wishing

Steven Wexler

a happy
and healthy
2023.

Love,

Mark and Melissa
Halperin

In honor of our

Faye Ginsburg

for her tremendous dedication and commitment to the Dysautonomia Foundation!

We are all so lucky to have you as our leader!

With much love and gratitude,

The Goldbergers
Laurie, Jeffrey,
Perry, Sydney & Cody

We dedicate this year's ad to our two beloved daughters, Julia and Rebecca, and to Faye Ginsburg, for her decade of leadership as President of the FD Foundation.

Lisa and Jeff Newman

In honor of

Brian Solomons

We salute the outstanding research being funded by the Familial Dysautonomia Foundation.

Jeffrey and Andrea Lomasky

MICHAEL BRENNER

YOU CONTINUE TO AMAZE US!
YOUR SMILE LIGHTS UP OUR
WORLD.

WE LOVE YOU,
MOM AND SARAH

In loving memory of

David Brenner

May his memory be a blessing

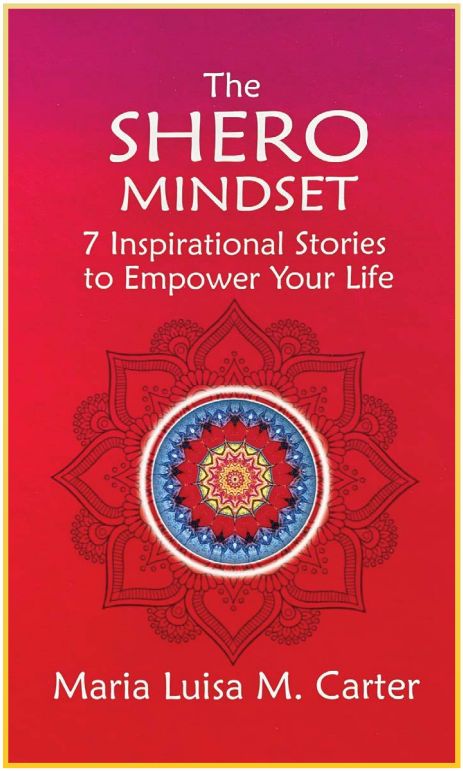
The Steiner Family

The author of this recently published book asked

Alexia de Gunzburg

to write one of the 7 chapters:

"Creativity: Alexia's Story - The Can-Do Attitude"



"Alexia inspires me every day to be a better person, and to be as grateful for my life as she is for hers. During the past 10 years, I have seen her: thrive through her art; publish a book; become a speaker; and travel the world…. Alexia is courageous, generous, and kind…. I am so incredibly proud of her achievements."

—Maria Luisa M. Carter

To Mitchell Joseph

Love from your family and friends in

Dallas, New York, and Portland

In Honor of

our children

Joshua

Adam + Liz

We love you so much

Mom and Dad

Steven Schwartzberg

Stevie,

We will remember your beautiful smile,
loving heart and joyous spirit always.

Love, Dad, Mom & Daryl

Our gratitude to Faye Ginsburg to her
years of dedication to the FD Community.

IN HONOR

OF

BRIAN SOLOMONS

AND HIS FAMILY

BEST WISHES FOR HEALTH

AND

HAPPINESS.

Love,

Jill, Sandy, Johnny and Brittany Sirulnick

PETE SONENSHEIN

Pete with Rogers Stevens,
founder of the band BLIND MELON.
Sharing a Halloween birthday, and then
singing and playing music for the crowd.

Best Wishes to

Steven Wexler

For a Good Year

And All My Best to

Karen and Paul

Phyllis Rosen

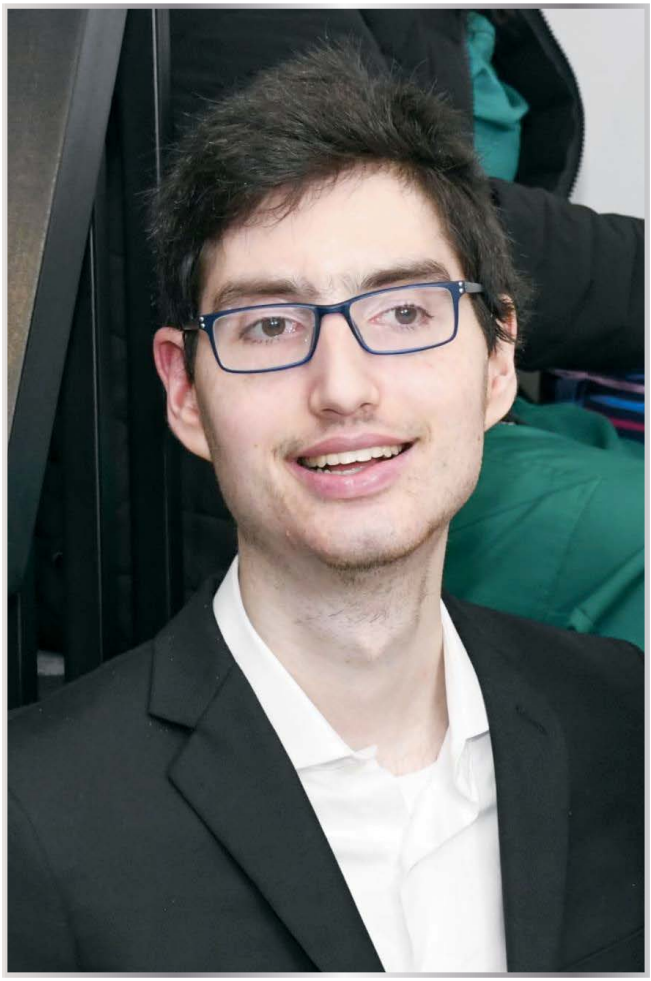
In Loving Memory of our Lauren Jamie Adler
We will never stop missing her!
&
In Honor of our awesome children
Joseph and Eliana Adler
&
Our beautiful and amazing grandchildren
Perry and Sammy Adler
We Love you all so much!!
&

In honor of Faye Ginsburg
and everything she has done for
the Foundation!

Vivian & Gerry Adler

In Honor of

Michael Baranoff



The Ades Family
Alan, Carla, Renna, Louis & Nancy

In honor of

Michael Brenner

our amazing
nephew and cousin.

May all good things
come your way in 2023!

With Love,

Aunt Robin, Uncle Brian,
Cousins Alex and Maddie.

MICHAEL BRENNER

WE LOVE YOU!
YOU SMILE BRIGHTER THAN ANYONE!

AUNT ADELE & UNCLE PAUL
COUSINS DANIELLE, ETHAN, HENRY & REISS
COUSINS ALYSON, CRAIG, ERIC & ABIGAIL

Scott

Even though it has been five years,
there isn't a day that goes by
in which we don't think about
you and feel your presence.

You are always in our hearts
and words cannot express
how much we miss you.

Love,
Mom and Dad

Scott,
You have the soul of an angel, a heart of gold and a spirit that will forever remain with those who love you. You exemplify grace, courage, compassion, sweetness, love and everything that is good. Your quiet wisdom, your capacity to love and your bravery is something we will always admire and strive for. You led your life with dignity and you truly enjoyed life to the fullest. We will miss that sweet smile, but will carry it with us, always and forever. We love you with all of our heart.

Love,
Rachel and Mark

REMEMBERING

SCOTT FASS

From Pepperoni to Piledrivers,
and everything in between,
We miss laughing, playing,
and learning with you.
Your impact on us is forever.
WE LOVE YOU

Aunt Harriette and Uncle Neal
Stacey and Gary
Marnie and Jeff
Ally, Casey, Dani and Sam

In loving memory of

Scott Fass

You will continue to inspire us.
You were the strongest person
who defied all the odds and will
always be remembered.

Love,

Brooke, Jeremy
Luke & Ben

In Honor of all the
fabulous FD patients and
their incredible families.

You have enriched my life
immeasurably and will
forever be in my heart.

Dr. Felicia Axelrod

In Honor of

All Those Who Work So Hard

In the Fight Against FD

Howard and Tova Weiser

In Memory of

Adam Scott Gerson

—

Susan and Jim
Michelle - Alexis
Shari and Mike

The Clawson Family is forever grateful
to Faye Ginsburg for her leadership
and to the entire Dysautonomia Center Team!

❤️ Lance, Michelle, & Mara Clawson ❤️

IN MEMORY

ANDREA LYNNE HAUBEN

FEBRUARY 2, 1984 – MARCH 21, 2009

FOREVER IN OUR HEARTS

The Hauben Family

In Memory Of

Jeffrey A. Horowitz

10/12/1963 — 8/6/1997

and

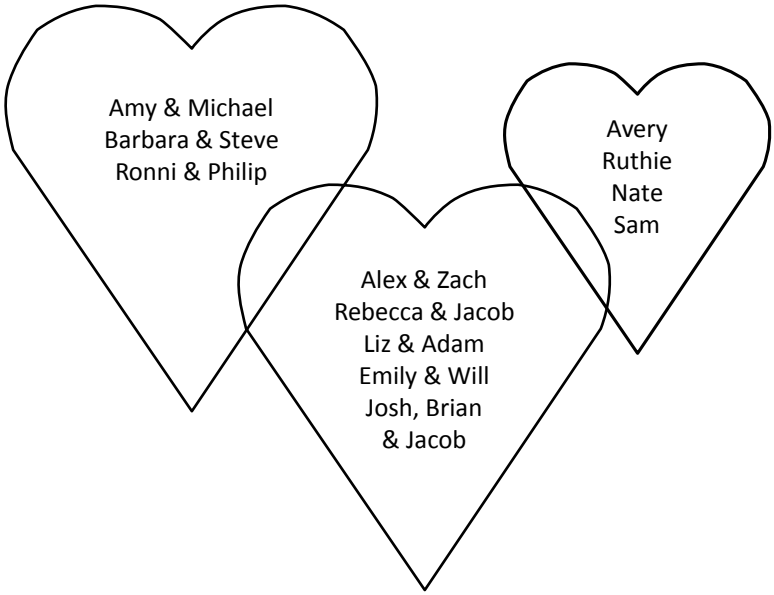
Carla A. Horowitz

6/29/1942 — 3/29/2020

WE
MISS
YOU!

LOVE FOREVER

TO OUR CHILDREN, GRANDCHILDREN
AND GREAT GRANDCHILDREN



Grandma & Grandpa
Anita & Stan

Josh Kietz

We constantly learn from you what the really important things are:

Love, kindness, caring, family.

You are truly special.

Your accomplishments inspire all of us.

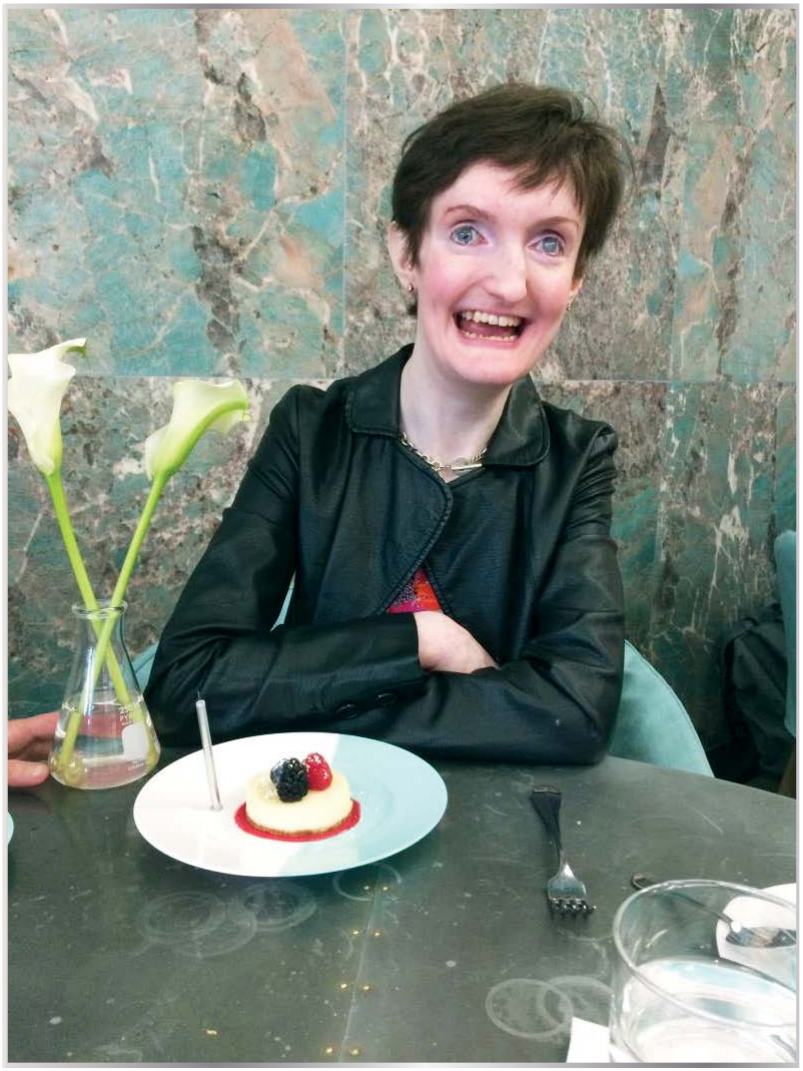
We Love you !!!!

Aunt Judi, Uncle Lenny, Shara, David, Kim, Jake

Dear Sam,
World traveler! Just like your aunt!!
I hope you have many more adventures.

All my love,
Aunt Ruth

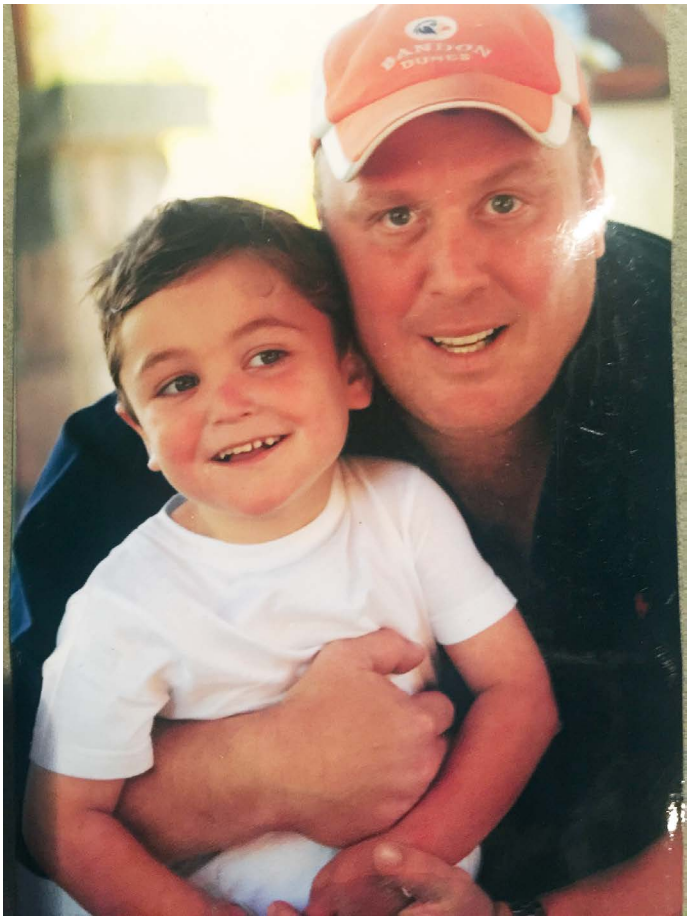
Scotland Highlands



In memory of my beloved niece, Sam, who brought joy and delight to all who knew her. With love forever in my heart,

Aunt Deb

Our Amazing Son & Grandson



In Memory of Adam

In Honor of Jack

Forever Loved

Gail & Stan Posnack

I would like to thank the Foundation for creating hangouts, movie nights and FD day virtually. It's been very helpful and comforting to keep in touch with the community. I like to chat with my friends especially because I live far in South America.

Veronica Segal

FOR A SPECIAL UNCLE,

BROTHER AND FRIEND

BRIAN JAY SOLOMONS

WE LOVE YOU SO VERY MUCH!

WE RESPECT AND ADMIRE YOUR

COURAGE, STRENGTH AND CHARACTER.

Love,

Scott, Sheryl, Alex, Rachel, Josh & Ali Haberman

In Honor of

BRIAN SOLOMONS

Amy and Cliff Goldman
and Family

We are honored to support

Brian Solomons

and the

Familial Dysautonomia Foundation

Sheryl & Scott Haberman,
we are proud of all the work you do!

Bonnie & Jason Spodek

In honor of those who fight this disease

and the people who support them…

May there one day be a cure!

The Ginsberg Family

Stephanie, Ian, Alec, Wendy & Reed

IN HONOR OF

BRIAN SOLOMONS

STEVEN WEXLER

and

IN MEMORY OF

SCOTT FASS

Your courage and strength inspire us.
May a cure be found soon!

Adela and Mitchell Kahn

In Honor of

Steven Wexler

The most courageous
and kind person
we ever met.
He is truly a hero!

With love for 2023 and beyond

Carol Weissman
Richard Kopelman

In Honor of

STEVEN WEXLER

"Strength does not come from winning. Your struggles develop your strengths. When you go through hardship and decide not to surrender, that is strength."

Arnold Schwarzenegger

Steven,

Though the hardships you have faced have certainly made you impressively strong, the positive attitude with which you approach the hardships is even more impressive.

We Love You,

The McAuliffe Family

In Honor of

Paul and Karen Wexler

For the boundless love and support you have given to your amazing son Steven

–

Continue this important work

–

Deby & Steve Cohen

Lauren Jaime Adler

Your beautiful smile
Your never-ending love
Brought so much joy to the world.

You touched our lives
In so many ways
It had to last for eternity.

The pain is deep
But so is our love for you
Forever and ever.

Love,

Uncle Simon & Aunt Robin
Bracha & Oded, Chanoch & Ester,
Yoel & Tali, Daniel & Yael
Cherut, Elkana, Bat Shachar, Eitan,
Hodaya, Ayala, Yosef, Sinai, Achinoam,
Shai, Lavi and Harel

Mr. Awesome,

We all agree to the pedigree of the shirt and the man that wears it. Sometimes when we dream, we enhance who we are and we dance to the colors of that person we placed on the pedestal. Also true, when we dream of others in need of change, but that change is rarely physical, that change is to have greater care, empathy, dedication, sweetness, and the calm of being the best of what you can be. In other words, all of us who need to change, need to change to be more like you. If that was not clear before, then after 3 years of hiding from the pandemic, the world should know this as a truth. We should all be more like you.

We love you Morgan but don't think we don't see your tipple of choice behind you,

James & Francis, cousins Alexandra, Sydnee, and Lauren, Uncle Bernie, and Auntie Carole

To my amazing grandson,

MICHAEL BARANOFF

You always surprise me with your talents and constant efforts. I'm so proud of you!

How blessed am I to have you in my life!

Love you forever,

Grandma Prissy

In honor of our beautiful daughters

Frances Emily
Natalie Rose

We are so proud of both of our daughters!!
You continue to awe us with your
determination, drive and tremendous
joy you bring to us each and every day!!

We love both of you so with all of our hearts!!

Mommy & Daddy

In honor of my two beautiful nieces and cousins

Frannie & Natalie

I'm so incredibly proud of both of you and
your Extrordinary accomplishments!
Love you both!!

Uncle Ellis and Tessa

IN HONOR OF

FAYE GINSBURG

With sincere appreciation for her 10 years of service to the Dysautonomia Foundation

Love,

The Brenner Family

For our fabulous **PRESIDENT**
who has kept our Foundation alive with her sound ideas, her strength and her humor!

We thank you **Faye** for your continuing years of selfless service to our "small but mighty" (your phrase) organization.

Congratulations on this 10 year milestone!

With appreciation from

The Sonenshein Family

Our dear Jamie,

Your life was a blessing,
Your memory a treasure.
You are loved beyond words
And missed beyond measure.

All our love … always,

Mommy & Daddy
Jessica, Matt, Leah & Emma

In loving memory of our precious

Jonathan Michael Gordon

March 11, 1990 – October 3, 2008

Always smiling, feeling great
and never complaining
no matter what the situation was!

You are in our hearts forever!

Love,
Debbie, Daniel,
Benjamin, Shayla, and Mila Gordon
and Edna Sydney

In Honor of

Sheryl and Scott Haberman

Randy & Jay Raubvogel

In support of our friends,

The Habermans

and

The Wexlers

it is our great pleasure to
contribute to the amazing work
and the dedicated people of the
Dysautonomia Foundation.

Karen and Steven Hess

In loving memory of

Katherine Merle Irlen

1964 – 2006

Harvey and Barbara Irlen
Kevin and Anita Irlen
Steve and Jennifer Irlen

In honor of our beautiful Gabi,

We're so proud of your accomplishments! A Life Coach! How exciting!

You are always studying to improve yourself and helping others. Assisting people to identify goals and develop the plans to reach these goals! We're just so proud!

Our love ❤

GMA, Aunt Roni, Cousin Alexa,
Gibbs, Milo and Thor

Evan Kaplan

To a courageous young man,

We are so proud of you.
You have displayed remarkable perseverance through a year with many obstacles.

We love you,

Mom, Dad, Max, Rachel
& Oliver

JOSH KIETZ

Ready to party again in 2023.
We love you to Waxhaw and back!

XOXO ❤ from North Carolina!!

Aunt Amy, Uncle Mikey, Cousins Alex, Zach, Avery, Nate, Sam, Becca, Jake, Ruthie (and Benny), Emily, Will, and all the puppers, Kayla, Desmond, Marge, Lola, Nala, and Chops!!!

In Honor of Our Dear

EZRA KRESS

Congratulations on turning 25.
May you celebrate many more
quarter centuries.

You are a wonderful person
and we love you very much.

Grandma & Grandpa

With love to our grandson, Ezra Kress

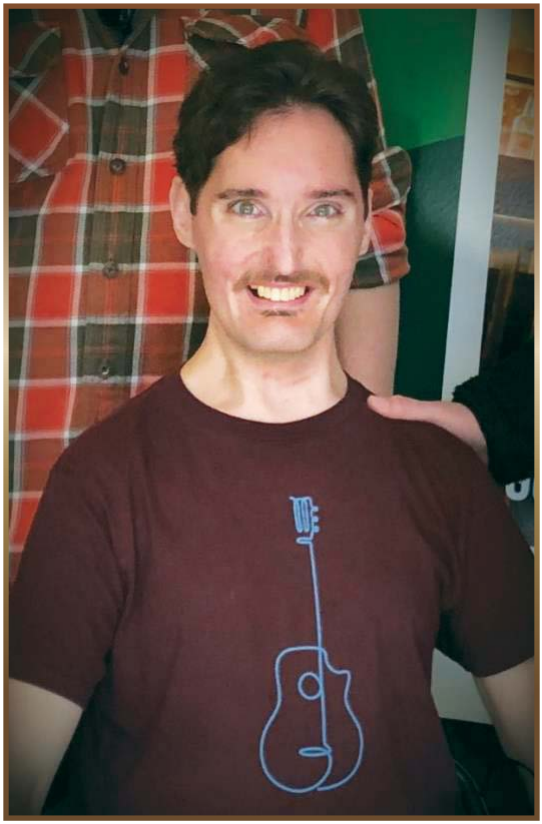
We celebrate your 25th birthday with joy, inspired by your spirit, love, and courage.

Saba and Savta, Bill & Beverly Lebeau

In Honor of

Matthew Kutner

on his **25th** Birthday



Matthew, you are a wonderful human
who continues to inspire us & bring
much joy & pride to your family.
May 25 be an awesome year for you!
Much love, *Mom & Dad*

TO **SAM LANDAU**

WE LOVE YOU

SUSAN AND ARNOLD
SCHARF

In everlasting Memory
of our beloved daughter

Amy Jill Lehrer

and her beloved father &
my dearest husband

Donald Lehrer

IN LOVING MEMORY
OF

PHYLLIS,
STEPHEN,
AND
JERRY
LINKER

JEAN AND STEVE ANREDER

In Loving Memory of

Evan Rosenthal

We cherish our sweet and special memories
of you and your beautiful smile.
You are always in our hearts.

With love,

Susan and Debbie and Joan and Stephanie
and our families

In Honor of

Brian Solomons

and

Steven Wexler

Wishing you the best of health and happiness always!!!

Joanie & Don Fisher

In honor of

Brian Solomons

and

Steven Wexler

Your courage and strength
are an inspiration

Lynda and Hal Katz

In Honor of Peter L. Sonenshein

We love to be with Pete whenever we can and to see his wonderful paintings, such as the one above. We are honored to have many of his paintings in our homes and to see his collection when we visit. As everyone knows, the Familial Dysautonomia Foundation has recently made some of his paintings available to those who would like to donate to FD.

With much love to Pete and his parents, sister, brother-in-law and nephews,

Aunt Gail and Uncle Linc, and cousins Dina, Adam and Jenna, Samantha and Jack Sonenshein

Sonenshein Family

We love you.

Leslie, Noel
Warren,
Bruce

In Honor of

Steven Wexler

In Honor of

Steven Wexler

and the Wexler Family

Leslie and Michael Rosenberg

Steven~

We are so proud of you!

You are such an awesome person!

Love you~

The Segal Family

In honor of the Adler Family

WE ARE PROUD

TO SUPPORT

THE FOUNDATION'S WORK

REYNA and PIERRE GENTIN

In Honor of
Our Good Friends

Vivian & Gerry Adler

In recognition of all the work
they do for the Foundation.

Bonnie and Russ Mannis
Caron and Steve Gelles

Jennifer Taylor Bell

Time Goes on but Memories Live Forever
Always in our Hearts

In Loving Memory of

Scott Fass

Caring • Selfless • Smiling • Adorable
Thoughtful • Brave Warrior
Superhero • Angel

You are missed every day

Aunts Adele Fass
and Barbara (Fass) Young

In Loving Memory of
our wonderful cousin

Scott Fass

We miss you very much.

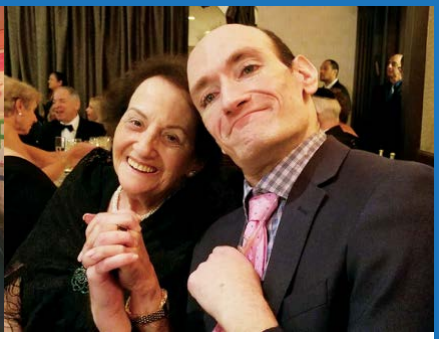
Cousins Sue Lipkowitz,
Marcel Lipkowitz
and Robert Fass

In Loving Memory of

Scott Fass,

a very special young man,
who brought joy into the
lives of all who knew him.

Sue and John Korn



In Loving Memory

Of

Maryon Weill

&

Scott Fass

Your courage and dignity in the face of adversity

is an inspiration to all of us.

Forever you will remain in our hearts.

We miss you both.

Elena, Barry, Andrea, Steve

Matt, Kelly, Joey, Marissa,

Andy, Jon, and Charlotte

Joseph P. Navarra, R.Ph., FACA
Owner
joseph.navarra@towntotalcompound.com

Town Total Compounding Center
415 Crossways Park Drive, Suite B
Woodbury, NY 11797
t. 516.249.7436 x122/ f. 516.249.7437
www.towntotalcompound.com

To honor the memory of

Benson and Pearl Ginsburg:

Truly a couple for the ages

Mark and Susan Hamilton

In Memory of our
son & brother

Elliot Louis Goldberg

June 1973 - July 2020

Always in our hearts,
forever an inspiration,
he turned struggles
into strength.

With Love,

The Goldberg Family

In loving memory of

Barbara A. Gould

Miriam K. Gould

Richard H. Gould

And with eternal gratitude

For all you were

Judith E. Gould

THE PAUL NORMAN GOULD
MEMORIAL FUND

IN LOVING MEMORY

OF

SANA GOULD

and

DAVID GOULD

LOVING PARENTS, GRANDPARENTS and

GREAT GRANDPARENTS

STEVEN GOULD and FAMILY

MARSHALL GOULD and FAMILY

THE PAUL NORMAN GOULD
MEMORIAL FUND

IN LOVING MEMORY

OF

CAROL SUE GOULD

WE LOVE YOU AND MISS YOU

STEVEN GOULD and FAMILY

MARSHALL GOULD and FAMILY

THE PAUL NORMAN GOULD
MEMORIAL FUND

IN LOVING MEMORY

OF

PAUL NORMAN GOULD

HE LIVES IN OUR HEARTS FOREVER

STEVEN GOULD and FAMILY

MARSHALL GOULD and FAMILY

So happy to have this opportunity to honor Faye and remember Samantha ...

When we think of kindness and caring, we think of Faye.
Thank you for ALL you do!

When we think of special people and incredible FD advocates, we think of Faye and Sam.
You both put FD on people's radar screen ... so appreciated!

*****

Remembering

Lisa & Bob Gross

With Lots of Love 💛

We miss you . . .

Bobbi, Jason & Kevin

In Honor or our
Two Fantastic Nephews

Jason Gross
and
Kevin Gross

and

In Memory of
Their equally
Awesome sister

Lisa Gross

Aunt Bonnie
and
Uncle Bob

In Loving Memory of Our Son and Brother

David Halle

After 62 years, we remember and miss you,

Ruth Halle, Esther Marcovici, and Linda Halle

And the rest of the family who wishes they knew you,

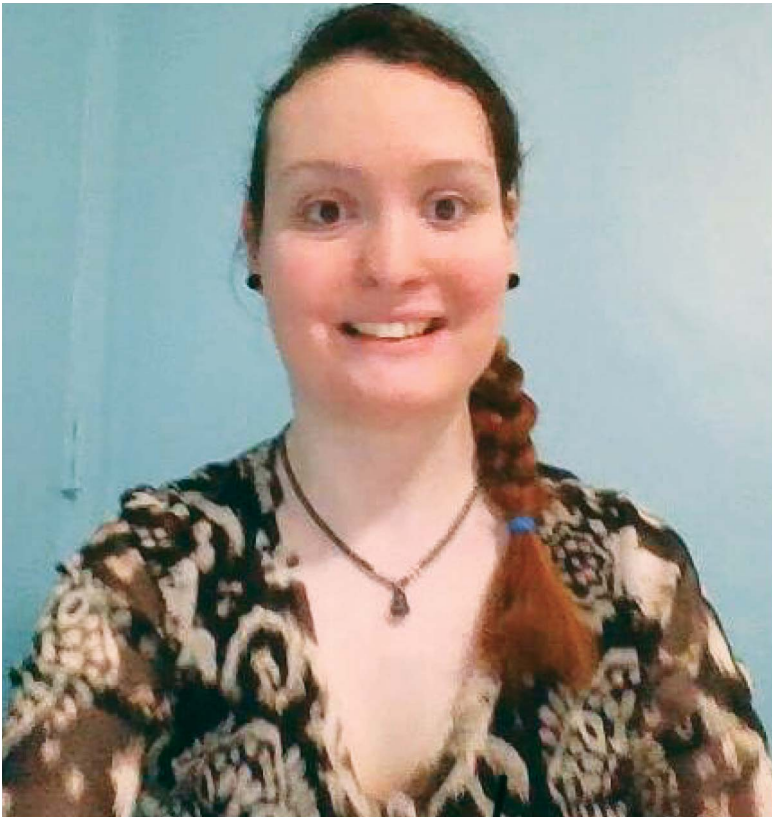
Richard, Rachel, Zach, Ben & Annie

Gabriel, Devin, Michael & Jack

GABI

We are just so proud of the woman you have become; so proud of all you have achieved and what you will achieve. Your integrity, thoughtfulness and kindness shine through all challenges that you encounter. It's an honor to be your parents.

Mom & Dad



Love to all of those who support us as we continue to hold Mitchell close to our hearts.

Always our SUPERHERO.... ❤

Lisa, Mark, Alyssa, & Jason

In Honor of
my Grandson

EVAN KAPLAN

Love,
Grandma Nancy
(and in memory of
Grandpa Bobby)

FOR MY GRANDSON,

JOSH KIETZ

TO THOSE WHO

WORK SO HARD

TO HELP US

DREAM THE POSSIBLE

DREAM...

FOR MY GRANDSON, JOSH

AND ALL THE FD KIDS...

THANK YOU SO VERY MUCH.

WITH LOVE AND HOPE,

GRANDPA AL AND GLORIA

Dear Ezra,

We are so proud of the amazing, sweet, kind and epic young man you've become.

We love you!

Aunt Sherry and
Uncle Ira

Dear Sam and Bebe,

We're so proud of both of you.

Love,

Mom and Dad

IN MEMORY OF AUNT BESS

WE WILL ALWAYS LOVE YOU

MARC, BRETT, AND BROOKE

WE ARE SAD THAT WE NEVER HAD
THE OPPORTUNITY TO KNOW YOU.

LOVE YOUR GRAND NEPHEWS AND NIECE

ALEX, CARLY, JACKSON, AND RYDER

Rebecca,

We are so proud of all your accomplishments.
You are an amazing young woman and
we love you very much.

Sue and Rich, Eric and Julie, Josh,
Lisa and Tony, Jeremy and Aliza

Zak Rosen

Forever in our hearts
Love, Mom, Pop, & Samara

In memory of:

The Rosenthal Men

Richard Davis Rosenthal

Evan Robert Rosenthal

Seth Andrew Rosenthal

Always in my heart,

Loren Rosenthal

In Loving Memory of Evan Rosenthal
January 27, 1983 – July 17, 2007

"There are stars up above
So far away we only see their light
Long, long after the star itself is gone.
And so it is, with people that we love,
Their memories keep shining, ever brightly
Though their time with us is done.
But the stars that light up the darkest night,
These are the lights that guide us…
As we live our days, these are the ways we remember ~
We remember."

Memories of our Evan shine brightly every day,
and we pause to remember our wonderful friend and courageous young man!

You are Forever in Our Hearts

Ronnie and Bob Powers
Lauren, Daniel, Fiona, and Aidan Powers
Julie, Josh, Abigail, and Adam Lurie

THANK YOU, RENI
FOR BEING YOU.
MORE THAN ONE LIFE
HAS BREATHED EASIER
BECAUSE YOU HAVE LIVED.
WE TALK ABOUT YOU
REGULARLY AND YOU WILL
ALWAYS REMAIN A PART
OF OUR FAMILY.

RENETTE MÉROSE SHAFIQ-BERGER

October 8, 1952 October 28, 1984

We are thankful for all the loving things Reni has given us, the memoires of innocence, sweetness and strength; her thoughtful ways, her gentleness, her caring and giving nature.

Reni was deeply devoted to those she loved.
She added to the world these precious qualities –
and they will be missed.

TAMAR JACOBS
ADDY AND AURIANNE

In honor of
Brian Solomons,
an inspiration to us all.

Love, Mom

In loving memory of
David Solomons

The Solomons
and Haberman
Families

In Honor of

Brian Solomons

Sheryl and Scott Haberman

We honor and support
Your hard work, devotion
And dedication to the
FD Foundation.

With Love,

Deborah & Joel Brooks
Sharon & Michael Tyner

In honor of
all the FD patients
and their loving families

Sheree & Jeffrey
Markowitz

Bette & Jeffrey
Rubin

In honor of
Steven Wexler
and
Brian Solomons

Your courage and strength
are an inspiration.

Alyssa and Steven Ackerman

"SOMETIMES BEING A BROTHER IS EVEN BETTER THAN BEING A SUPERHERO." ~

MARC BROWN

STEVE,
YOU'RE OUR
SUPERHERO.

LOVE,

STEF, JAY, ELLA, & LJ
BRYAN & NICOLE

We love you, Steven.

You make us proud every day.

Love,

The Diton Family and

The Wealth Alliance

THE WEALTH ALLIANCE

Eric Diton, CIMA®
President/Managing Director
105 Broadhollow Road
Melville, New York 11747
(631) 670-0702

Florida Office:
6501 Congress Ave. Suite 100
Boca Raton, FL 33487
(561) 910-8626

Experience the Future Today

Good wishes

to

Steven Wexler

and

family

From the Greenlands

Dear Steven:

We truly admire your courage and perseverance. May this year bring only good things… health, happiness and a bright smile each and every day!

Love,
Mark and Rachel

In Honor of

The Wexler Family

In Honor of

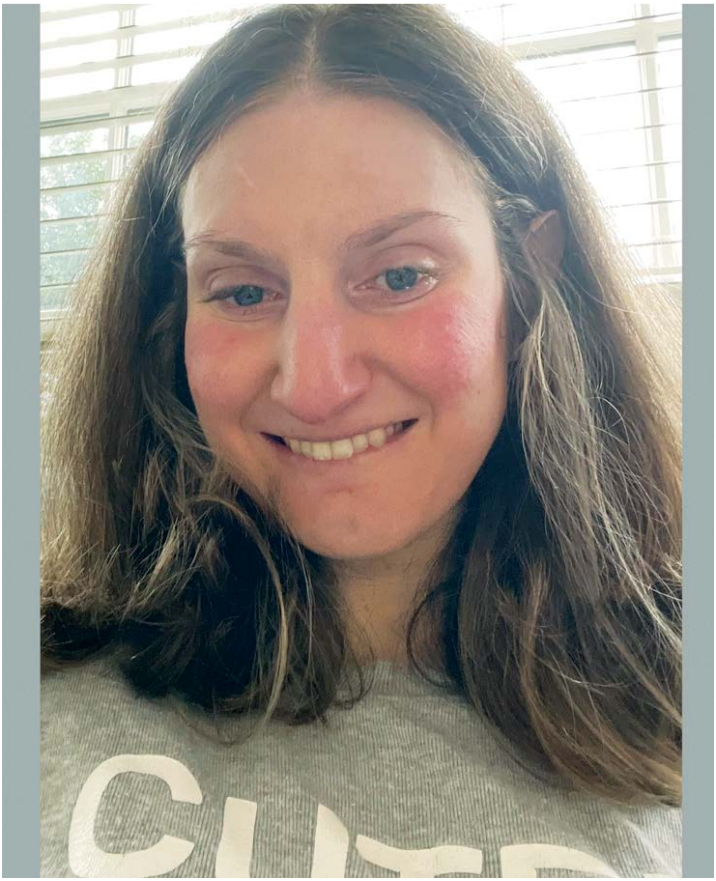
Sarah Zucker

OUR GRANDDAUGHTER

SARAH ZUCKER

There aren't enough adjectives to describe what a ***wonderful*** woman she is and how much we ***love*** her. (insert as many synonyms as you can come up with- they're all appropriate.)

Grandma Dorothy and Grandpa Joel



IN MEMORY OF **LAUREN ADLER**
AND
IN HONOR OF ALL THOSE WHO
HAVE MADE THINGS HAPPEN.
MAY THE RESEARCH CONTINUE
AND BE SUCCESSFUL.

Nina & Brian Hirshman
and Family

In Honor of

Michael Brenner

Nicky, Priscilla and Harold

IN HONOR OF

FRANNIE COHEN

OUR INSPIRATION

THE RAFFLER FAMILY

In Memory of

JILL COPLIN

Beloved Daughter and Sister
1966-1977
&

DIANE COPLIN LIPSITZ

Beloved Wife, Daughter, Sister and Aunt
1968-2010

The Coplin Family

In loving memory of

Jill Anne Coplin

and

Dede Coplin Lipsitz

The Homer Family

In Loving Memory of

Maximiliano and Lionel Donzis

Graciela, Carlos, Sebastian,
Tracie, Sienna, Greyson,
Ashton, Hernan, Melissa,
Samuel & Reid Donzis

Forever Remembered,
Forever Missed

Scott Fass

Geri, Harold, Jared,
Mariel, Blake, Cori,
Alex, Lexi & Bernie

In tribute to:

All those with FD and their loving families
Our dedicated board, staff and volunteers
The devoted NYU Treatment Center team
Our brilliant Scientific Advisory Board

And with special recognition to:

Faye Ginsburg
For a decade of service as Foundation President

I am inspired by all of you and
I'm proud to be part of the FD community

Lanie Etkind, Executive Director

"If the only prayer you ever say in your entire life is thank you,
(Kaia Dalamo and Zenith Khan, NPs)
it will be enough."

-Meister Eckhert

With love and appreciation,

Debbie Schoenholz

In Memory Of

Mavis & Al Feinberg

"Nana" & "Papa" to Matthew Kutner

In Recognition of their years of work supporting FD research through active fundraising

In Memory of

Sy Feit

Sandy Z"L
and
Larry Greebel

IN LOVING MEMORY
OF MY NIECE

JAMIE GOLDBLAT

GAIL GOLDBLAT

JOSH KIETZ IS:

WE LOVE YOU!
Aunt Pam, Uncle Jordan
& Cousin Lauren

In Honor of

Josh Kietz

With Love,

Brian and Robin
Potash

In honor of
our dear friend

Josh Kietz

The Tortorellas

In Honor of my grandson

Mitchell Kofsky

and in recognition of

The Dysautonomia Foundation

Sandra Kofsky

In memory of
our beloved
goddaughter,

Samantha Myers,

who brightened
our lives with her
luminous spirit.

Barbara and Max
Gimblett

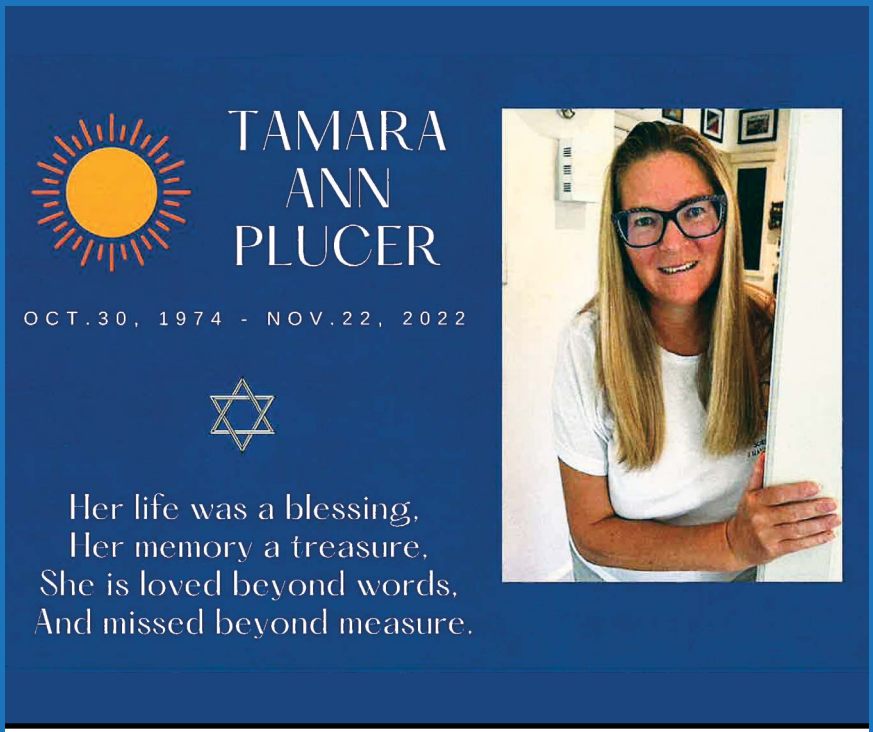
With lots of love and praise to Samantha Ginsburg Myers (1989-2022), a member of Fearless Theater Co. for 23+ years. She played every role from the heart. And to her mom, Dr. Faye Ginsburg, dedicated to the mission of making change happen.

Go to www.HopeScenarios.com and enter promo code "FD2023" to watch Sam's season of *The Hope Scenarios* - free for FD Journal readers during March and April.

In Honor of the One and Only
Rebecca Newman!!

A Star to All Who Know Her

Love,
Terry and Barry Zingman



In Loving Memory
of My Sister

Carly Allison Posner

Sam Sernovitz

We are so proud of how much you've grown and how you've approached the opportunities and challenges that come during the teenage years. We can't wait to see what is in store for you in the year to come and are grateful for your continued good health and the blessings that you bring to us and everyone who knows you.

Love,
Mom, Dad, Daniella, Eden and Peaches

Since I moved to Florida, I made a great group of friends. Love our peeps parties, game nights, dinner with friends and many great conversations.

Andrew Sigman

In Honor of

Brian Solomons

Mark and Joan Haberman

In Honor of

Brian Solomons

Perry and Penny Berger
and Family

In honor of
Brian Solomons and family

with best wishes for a happy
and healthy new year.

Love,
The Siskind Family

In honor and celebration of our incredible friend

PETER SONENSHEIN

With love from

The Hoxter-Levine Family

Debi and Ron

Andrew and Heather

Deanie, Gary, Sylvie and Teddy

IN HONOR OF
A WONDERFUL FRIEND AND
TALENTED ARTIST

PETER SONENSHEIN

WISHING YOU THE BEST
ALWAYS…

FERN AND STEVE ROTFELD

In Loving Memory of

Lauren Adler

Karyl and Asher Miller

In Honor of

Michael Brenner

Cousins Linda & Bob

In Loving Memory

To our most beautiful wonderful girl
Falon Bromberg

From
Mom, Dad & Philip

In loving memory of
Scott Fass

Elaine & Brian Rappaport

In Memory of
Chany Perelstein, Samantha Myers & Falon Bromberg
with love & gratitude for your being such sweet friends,
especially to our **Jamie**.

In Honor of the
Dysautonomia Foundation & its ten-year President,
Faye Ginsburg, with love & gratitude for your tireless efforts
to better the lives of those with FD.

Elise & Robert Goldblat

SCS AGENCY INSURANCE

Peter Luftig
Vice President

D: (516) 726-2635
C: (516) 476-7840
F: (516) 829-5857
pluftig@scsai.com

1981 Marcus Avenue
Suite 125
Lake Success, NY 11042

Thank you to the
staff of the FD Center
for your care and support.

Louis Kaley
Roslyn Kaley
Stefanie Kaley Linakis
Alisa Robin Kaley

Judy Fettman Dreyfus

1970 - 2020

We miss her terribly.

Love,
Mom & Dad

To Faye -- your love and work are so appreciated.
We think the world of you!

David & Susan Cohen

In honor of

Faye Ginsburg

and her years of dedication to the FD Foundation.
Thank you for all of your efforts to improve
and enhance the lives of those with FD.

With appreciation,
The Lebeau/Kress Family

Thanks to the Foundation and the incredible leadership, and to the FD community for all the support provided to our family. We value the medical and research piece of course, and the social connections with other families that we so desperately need.

With much gratitude,
The Yazer/Kristof Family
Murray, Julie, Alex and especially Mimi.

In Honor of

Gabi Jassie

With Love, Suzie

In Memory of

Sandra Kammerman, MD

Eugene Lind, MD

Dear **Josh**,
You inspire us each and every day.
We love you so much!

Aunt Ronni, Uncle Phil, Jacob, Brian
(and Lucy, too!)

We Love You, Josh!
XOXOXOXOXOXO
Sending Hugs from your loving cousins,
The Wanzers & The Maimans

Dear Josh,
We always love being with you
and seeing your smiling face.

We love you,
Judy & Alan

Josh,
We wish you the best of health and joy in the upcoming year. Keep on rockin'!
The Glaser Family

In honor of
the Kietz Family,
an inspiration to us all.

With love,
Wendy & Jeff Shapiro

Honoring the memory of
Samantha Myers

Barbara and Steve Kietz

In memory of
Samantha Myers
She was a role model and inspiration to all of us.
We are in awe of all that she accomplished in her life.
May her memory be for a blessing.

The Kress/Lebeau Family

In honor of the amazing

Rebecca Newman

and her family.

Cousin Wendy

Best Wishes to

The Newman Family

Phyllis Honig

In honor of Mr. Jack "attack" Posnack

Jack,

You are an inspiration to all that come in contact with you. You make all that know you better humans. Your hard work, never say quit attitude and infectious smile is something I have cherished seeing every day for 17 years.

Love you my Boy!!

Uncle Adam

Chanie, we will always love you - to the moon and back !
You made us laugh, smile, and warmed our hearts with your kindness.
We miss you everyday !

Love,
Mommy, Daddy, Devorah & Gershie

In honor of my awesome nephew

Andrew J. Sigman

He is kind, caring, and loving. Always there to give a helping hand to anyone who many need it. I love you and respect the wonderful man you are.

Love forever,
Aunt Marsha

Benjamin Solomon, you will always be our daily SUNSHINE!!!

Love, Mom and Adam

BRIAN SOLOMONS

WITH FRIENDS SURROUNDING YOU, THERE IS ALWAYS HOPE!

ELLEN & BRUCE BELSKY

IN HONOR AND CELEBRATION OF
PETE SONENSHEIN
AND HIS GREAT FAMILY.

WITH LOVE,
ELLEN AND STEVEN WOLF

With Love and Admiration for
Steven Wexler and **his family**

Jeff and Lori Baker

Wishing you great health
and much love, Steven.

Love,
The Gewirtz Family

LISA AND LON GOLDSTEIN

The McGrail Family

In Honor of
Steven Wexler
and his Family.

Dayle and Carl

Donated with love in honor of

Steven Wexler's

continued good health and happiness!

Always

Sherry and Marty Silver

Best Wishes to
The Wexlers
in 2023.

The Edelmans

In Honor of
Evan White
and
Ezra Kress

David & Betty Roth

Friends in Honor Of

The FD Foundation
Driftwood Day Camp, LLC

Gabi Jassie
Roni and Alexa Schweer

Josh Kietz
Daniel Fram
Julie Erger Miller
Wendy and Shelly Nussbaum

Aaron Menzel
Barry and Maija Nobel

Jack Posnack
Andrew and Jill Feldman

The Haberman Family
Alex Seaman

Justin Sachs
Jeannette and Jerry Olson

Friends in Honor Of

Brian Solomons
The Goldsmith and Bochner Families
Richard and Robin Reubenstone
Jack and Vanita Solomons
Todd Sycoff

Steven Wexler
Kenneth Baer
Miles Braun
Shaina Duecaster and Ben Brown
Karen and Rick Esterow
David and Allison Fialkov
Michael Gorin
Angela Gustavson
Michael and Cecelia Halzel
JoAnn Heinish
Monroe and Florentina Jacobson
Neil Kanner
Leslie Kravetzsky
Sue and Mike Patti
Chris Quinson
Corinne Thompson
Iris and Alex Wagman

Friends in Memory Of

Lauren Adler
Laura and Eric Green

Kathy Ann Fishman
Alvin Fishman

Samantha Ginsburg Myers
David and Susan Cohen

Evan Rosenthal
Lisa Elfenbein

Forever Devoted

Do you have a loved one who is or was affected by familial dysautonomia? Do you wish to ensure the Foundation's mission well into the future? Is philanthropy something you and your family value?

Include the FD Foundation in your estate plan and become an honored member of Forever Devoted.

Contact Lanie Etkind at the Foundation to learn more 212-279-1066; letkind@famdys.org

Boosters In Honor Of

Morgan Asinowski
Florence and Nelson Asinowski
Grandma Goldie Asinowski
Bubby Jenny Fried
Jennie Gindin
Sonia Elisha and Sol Shimshi

Michael Baranoff
Audrey Adjmi

Michael Brenner
Gail and Joshua Wanger

The FD Foundation
Marilyn and Leslie Rice

Faye Ginsburg
Harold and Judith Meyer

Mitchell Joseph
Robert and Catherine Kushner

Josh Kietz
Randy and Amy Levine
Mark and Ilyssa Silver
Gloria Zapin

Ezra Kress
Renee and Hervey Sande

Sam Landau
Betsy Newberry and Ken Friedrich

Rebecca Newman
Lucille Newman and Family
The Reichman Family

Boosters In Honor Of

Lainie Roebuck
Minda and Joel Teicher; Lorinda and Luis DeZayas

Sam Sernovitz
Debra and Arthur Skaroff

Brian Solomons
Fern & Jeff Bernstein
Michelle & Lennert Gruszecki

Peter Sonenshein
Ernest and Jane Dellheim
Laurie and Phil Rubin

Scott Weinstein
Elyssa Springer

Steven Wexler
The Auerbach Family
Mark and Gail Fialkov
Mark & Suzie Harvey
Piper Lutbak
Tobin Family

Boosters In Memory Of

Lauren Adler
Debra and Howard Schub

Scott Fass
Stefi, Craig, Sydney, Shani & Jordan Sirota

Jamie Goldblat
Rich and Karen Heller

Samantha Myers
Harold and Judith Meyer

David Howard Rosenberg
Carla Rosenberg and Jason Rosenberg

The FD Foundation Remembers

Falon Bromberg

12/28/90 – 11/1/22

The FD Foundation Remembers

Samantha Louise Ginsburg Myers

2/8/89 – 9/25/22

The FD Foundation Remembers

Chana Perelstein

11/10/84 – 7/7/22

The FD Foundation Remembers

Tamara Plucer

10/30/74 – 11/22/22

The FD Foundation Remembers

Ben Rainer

4/1/87 – 12/29/22

The FD Foundation Remembers

Family and Friends

Janet Crohn

Mavis Feinberg

Eileen Gold Harris

Nancy Hilty

Dr. Kurt Hirschhorn

Terry Kurtz

Jennifer Posnack de Marchi

Susan Slotnick

Judy Wener

To all who contributed
to the 2023 Journal

THANK YOU!

Through your kindness
and generosity,
the FD Foundation will
continue to provide
vital medical care,
scientific research,
public education,
and social services
for the FD community.

We thank

Faye Ginsburg

for leading the foundation
with an unlimited reservoir of
compassion, caring and expertise.

Your work on behalf of all the families
affected by FD and future generations
is so greatly appreciated.

Anne and Dave Rainer

IN HONOR OF

STEVEN WEXLER

ALL OUR LOVE,

Rena, Josh,
Elana & Jacob
Kopelman