To all who contributed to the 2022 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.
Dear Families, Friends and Allies -

I am hoping that this letter finds you and yours thriving despite the many challenges that we all have faced over the last 12 months. Living with FD has prepared many of us for dealing with unexpected difficulties, but we are ready to put this behind us!

This year’s Journal is a wonderful and moving chronicle of tributes, support, beautiful words, charming photos, joy, and memories, shaped by the experience of a second year of surviving the pandemic. As always, I am so moved by the generosity of your support not just for the Journal, but especially for our loved ones with FD who stay positive in the face of so many challenges. The pages in this year’s Journal are both a sign of your support for our community, and an important contribution to the ongoing work we do to help those with FD live their best lives possible through expert medical care, social and mental health support, and exciting new research that we expect to launch in 2022. Additionally, we are excited that we have welcomed Dr. Alejandra Gonzale-Duarte to our expert medical team at NYU, a physician and researcher who brings her longstanding knowledge of FD to both the bedside and to research.

The 2022 Journal is testimony to the astonishing commitment of so many people who keep the FD community moving forward, even when times are tough. Along with our dedicated Foundation staff and Board, I want to thank every one of you for generously supporting our efforts, and wish you the best for the year ahead.

With gratitude,

Faye Ginsburg
President, Dysautonomia Foundation
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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 six 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. 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 & scientists; and providing FD patients with oxygen concentrators for air travel.

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.
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
Dear FD community,

Looking back, 2021 was a transition year. The worst of the pandemic is now over, and we can see a light at the end of the tunnel. There is reason to celebrate. The FD community needs to continue being cautious, but strict isolation is over. It is still winter, but we can imagine spring.

The NYU Dysautonomia Center was a high-energy hub of clinical and research activity during 2021. That has not changed. Working together, the Center’s clinical team covered the medical needs of FD patients around the world, every day, 24 hours a day, seven days a week. Not a simple task, but one we love and take pride in. The exciting news was the arrival of Dr. Alejandra Gonzalez Duarte, a well-known investigator in neurological disorders with vast experience in managing complex clinical cases. She trained at the NYU Dysautonomia Center 12 years ago and now returns as Associate Professor of Neurology and Associate Director of the Center. We are delighted to have her back, caring for FD patients. Dr. Gonzalez Duarte joined Dr. Patricio Millar, a brilliant neurologist and recent graduate of our Fellowship program, and two excellent nurse practitioners, Zenith Kahn and Kaia Dalamo. Kaia has a doctorate in nursing science, and Zenith is doing her doctorate in nursing at NYU. Both are outstanding in their care and dedication.

Delivering this comprehensive, knowledge-based patient care is demanding and only possible thanks to the generous donors that support the Dysautonomia Foundation, to whom we are deeply grateful. A special thanks to the Montreal FD Chapter for their support of the mental health and psychotherapy program.

Bringing science to the clinic is a long and complex process. Fortunately, thanks to the work of Sue Slaugenhaupt, Frances Lefcort, and Adrian Krainer, three extraordinary scientists and their teams of collaborators, several potential options to fix the gene defect in patients with FD are possible. The development and authorization process has been longer than expected, and none of the treatments are ready yet for a clinical trial. We hope this will change soon.

New research collaborations began during the pandemic. One includes the genetic and cellular problems that patients with FD share with those with Hirschsprung disease, with Sumantra Chatterjee, Ph.D. at the NYU Center for Human Genetics and Genomics. Another is the development of FD-induced pluripotent stem cells (iPSCs), to assess responses to treatments with Nadja Zeltner, Ph.D. at the University of Georgia, GA. Clinical treatments to prevent organ damage are ongoing, and hopefully, we will soon have more options for treating autonomic crises.

Life with FD remains challenging, but brighter days are on the horizon. As always, the team at the NYU Dysautonomia Center is here for you and your family.

We wish you the best for 2022.

Horacio Kaufmann, MD
The Team at NYU’s Dysautonomia Center

Horacio Kaufmann, MD  Maria Alejandra Gonzalez-Duarte Briseno, MD

Patricio Millar, MD  Kaia Dalamo, DNP, FNP-BC  Zenith Khan, FNP-BC, MSN, RN

Jose Martinez, MS  Mecky Kuijpers  Lee-Ann Lugg

Exceptional personnel dedicated to the well-being of the FD community
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.
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WE ARE GRATEFUL FOR THE LONGSTANDING AND LOYAL SUPPORT OF OUR CHAPTERS

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The FD Foundation Thanks

Its Wonderful Staff

ALBULENA PRELVUKAJ

and

ERIN DUMMY

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ROBIN LANDAU

Intern

EMILY SILVESTRI

Your Efforts Make All
Our Good Work Possible.
Thank You!
To our shining star,

Michael

You are amazing!!!

We love you SOOOO MUCH! 💖💖

Love, Mom, Dad and the gang

MANY MANY THANKS TO THE ENTIRE FD TEAM WHO CONSTANTLY STRIVE TO HELP MAKE OUR LIVES BETTER !!!!
IN HONOR OF

OUR THREE BEAUTIFUL GIRLS

PERRY

SYDNEY

CODY

LOVE,
MOM and DAD
Sammy,

You are always number one in my eyes!

All my love,

Grandma Soso
In Honor of

Balfura Lemer

A one-of-a-kind person
who is loved by all
Kudos to Samantha Myers for keeping our spirits flying during the pandemic.

Lots of love,
Faye and Fred
CHRISTOPHER REEVE (SUPERMAN) SAID:

“A HERO IS AN ORDINARY INDIVIDUAL WHO FINDS THE STRENGTH TO PRESERVE AND ENDURE IN SPITE OF OVERWHELMING OBSTACLES”

STEVEN- YOU ARE OUR HERO
YOU ARE OUR SUPERMAN

LOVE MOM AND DAD
In honor of the 70th anniversary of the FD Foundation and in honor of our two creative, independent daughters, Julia and Becca. We love both of you so much!

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
Wishing

Steven Wexler

a happy
and healthy
2022.

Love,

Mark and Melissa
Halperin
The Board of Directors of the
FD Foundation
Congratulates

Dr. Howard B. Ginsburg

On his retirement as Director of
NYU Langone’s Division of Pediatric Surgery

On behalf of FD Families,
We recognize Dr. Ginsberg for many years of
Compassionate, innovative and personalized care
For our loved ones
YOU MADE IT TO COMIC CON THIS YEAR IN SPITE OF EVERYTHING, AND YOU REMAIN OUR ULTIMATE SUPERHERO!

WE LOVE YOU, MOM AND SARAH
SUNRISE: A new day to cherish
A recent painting by

ALEXIA DE GUNZBURG
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
IN LOVING MEMORY
of
MY PARENTS
JULIAN and PHYLLIS LINKER
and
MY BROTHER
STEPHEN LINKER

YOUR STRENGTH, HUMOR AND LOVE
CONTINUES TO GUIDE ME

~FOREVER IN MY HEART
SUSAN LINKER
Stevie,

From the moment you were born you brought so much light, joy and happiness into our lives. You attracted people like a magnet with your beautiful smile and upbeat personality. The way you lived your life has inspired us to be better people, more genuine, selfless and loving. Stevie, your passing has left a hole in our lives and hearts that can only be filled with the wonderful memories of the beautiful person you were. We miss you every minute of every day.

Love,
Dad, Mom and Daryl
IN HONOR
OF
BRIAN SOLOMONS
AND HIS FAMILY

BEST WISHES FOR HEALTH
AND
HAPPINESS.

Love,
Jill, Sandy, Johnny and Brittany
Sirulnick
In Loving Memory of our
Lauren Jamie

Whose love and laughter we miss always
But keep in our hearts eternally

&

In Honor of
And with tremendous love and pride for
Our children
Joseph and Eliana

And our amazing granddaughter
Perry

Vivian and Gerry Adler
The King of Diamonds emerges from his escape hatch and sees all through the looking glass where his disguises are kept. He commands the dragon and keeps the talisman hanging to guard the wardrobe from opening and further skewing the Calendar that attempts to control both action and time. The white door makes you larger and the time capture makes you smaller but you control time by making it speak to you at your will. Time may wait for no man but it obeys the King of Diamonds.

We the few, we the humble, believe that Morgan is faith, love, and, on a good day, He is Rock & Roll.

*Queen Carole, Bernie from da Block, Lauren of Aragon, Alex of the Saints, Francis of the Si-Si, James, a kindred King, and of course Cousin Sydnee of the Big Apple.*
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 2022!

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
The Clawson Family is forever grateful to Dr. Horacio Kaufmann & the Dysautonomia Center team

XO
Mara, Michelle, & Lance
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
Scott Fass

“I miss you like crazy, I miss you like crazy
Ever since you went away, every hour of every day
I miss you like crazy, I miss you like crazy
No matter what I say or do, there’s just no getting over you”

Natalie Cole

The void we feel every day is only exceeded by the
positive impact you continue to make on our lives.

You are in our every thought!

We love and miss you!

Aunt Harriette, Uncle Neal
Stacey, Gary, Marnie, Jeff
Ally, Casey, Dani and Sam
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
PTC Therapeutics Congratulates the Familial Dysautonomia Foundation on their 70th Anniversary!
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
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
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


WE MISS YOU!
LOVE FOREVER

TO OUR CHILDREN, GRANDCHILDREN AND GREAT GRANDCHILDREN

Amy & Michael
Barbara & Steve
Ronni & Philip

Alex & Zach
Rebecca & Jacob
Liz & Adam
Emily & Will
Josh, Brian
& Jacob

Avery
Ruthie
Nate
Sam

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
My dear Sam,

You are certainly one of the greats! Keep up the good work. We are all very proud of you.

Love,
Aunt Ruthie
In Memory of

Elaine Jamie Lipson

and

Arthur Lipson

Always in our hearts

The Lipson Family
Our Amazing Son & Grandson

In Memory of Adam

In Honor of Jack

Forever Loved

Gail & Stan Posnack
In Loving Memory of

The Rosenthal Men

Richard David
Evan Robert
Seth Andrew

Always in my Heart

Loren
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

Sheryl and Scott Haberman
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
LET THE GOOD TIMES ROLL!
Peter Sonenshein

To the Van Gogh in the family.

Love,
The Konrads
& Houghtons
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

—

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In Honor of

STEVEN WEXLER

“The strongest people are not those who show strength in front of the world but those who fight and win battles others do not know anything about”

-Johnathan Harnisch

You display extraordinary courage and strength in the daily battles you continue to fight and win.

You are an inspiration to us all!

We love you,

The McAuliffe Family
I am happy to be part of the progress.

With Love,
Andy
In Honor of

Steven Wexler

and the Wexler Family

Leslie and Michael Rosenberg
In Honor of

Steven Wexler

And all his family and friends who fight this disease.

We all look forward to the day that there will be a cure!

With love,

The Zack Family
Lauren Jamie Adler

Dearest Lauren,

A hug and a kiss and a smile. All we have are the memories of years gone by that fill our hearts. Yesterday, today and tomorrow, forever we will think of you and forever we will miss you.

Love,

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

Mikey

You are an amazing, brave, and very accomplished young man. (And a great Rummikub player as well!)

Will love you always,

Grandma Prissy
Michael Baranoff

We love you!!

Amy, Scott, Mia, Rachel and Jacob Gottesfeld
You continue to amaze us! Your smile lights up our world.

We love you, Mom and Sarah

Michael Brenner
We are so proud of the beautiful young woman you have become and all of your accomplishments along the way!!

Love you so
Mommy & Daddy
We are so proud of the young woman you have become and all of your accomplishments along the way!

Love you so
Mommy & Daddy
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 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 our precious

Jonathan Michael Gordon


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

You are in our hearts forever!

Love,
Debbie, Daniel,
Benjamin and Shayla Gordon
and Edna Sydney
Gabi Jassie

May 2022 bring you great success in your new endeavors. So pleased that you are using your time to pursue your education! So proud of you!

Much Love,

Gma, Aunt Roni, Cousin Alexa, Gibs & Milo
Evan,

Take pride in how far you’ve come, have faith in how far you’ll go!

All our love,
Mom, Dad, Max & Rachel
(& Oliver too!)
Heartfelt loving wishes to

Evan Kaplan

for all the finest blessings in life, as you recently celebrated your 25th birthday...

Grandpa Bobby & Grandma Nancy
In loving memory of

Katherine Merle Irlen
1964 – 2006

Harvey and Barbara Irlen
Kevin and Anita Irlen
Steve and Jennifer Irlen
In Honor of

Josh Kietz

With Love,

Brian and Robin Potash
All together in 2021!
All together in 2022!

We love you to the moon and back, Josh!

XOXO Aunt Amy, Uncle Mike, cousins Alex, Zach, Avery, Nate, Sammy, Becca, Jake, Ruthie, Emily & Will (also Kayla, Desmond, Marge, Lola, Nala & Chops)!
Hollie Krain

Another year has flown away. Our memories of your smile, laugh, courage and strength stay firm. You accomplished so much in your short time with us. We will love you forever. Hug mommy close and strong for her sister.

Love always

Jerry, Dale, Barry, Lauren, John, Mia-Hope, Nicole, Kasie, Peyton, Mindy, Manolo, Daniel, Amy, Richie, Sarabeth, Jesse & Jacob
In Honor of Our Dear Grandson

EZRA KRESS

Happy 24th birthday to the best grandson ever. Have a great year and stay well.

We love you very much,

Grandma & Grandpa
With love to our grandson, Ezra Kress

We celebrate your 24th birthday
Inspired by you every day.

Saba and Savta, Bill & Beverly Lebeau
IN LOVING MEMORY
OF
PHYLLIS,
STEPHEN,
AND
JERRY
LINKER

JEAN AND STEVE ANREDER
In Loving Memory of **Evan Rosenthal**

We remember your heart

We remember your smile and laughter

We remember your enthusiasm

We remember your sweetness and compassion

We remember you

We miss you so much

You are always in our hearts

With love,

![Heart](heart.png)

Debbie and Stephanie and Susan and Joan
and our families
In Memory of

Randi Salen

Linda & Robert Horowitz
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

The Haberman and Wexler Families

For their dedicated & tireless commitment to the FD Foundation

Susan & Bruce Cohen
In Honor Of

STEVEN WEXLER
"A Real Life Superhero"

Best wishes for a happy and healthy year.

THE ESTEROW FAMILY
Lots of love to our FD hero,

Steven Wexler

Wishing you and the Wexler family a 2022 filled with health and happiness.

Amy, Michael, Ethan and Samanatha
In Honor of

Steven Wexler

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

With love for 2022 and beyond

Carol Weissman
Richard Kopelman
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
Always Our Teacher

Sandy and Sandy Goodman
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
In loving Memory of
Our Precious Daughter,
Sister and Aunt

Lori Ann Fishel
1965-2013

Mom and Dad
Brad and Lori
Scott, Max, Jordan
To honor the memory of Benson and Pearl Ginsburg:

Truly a couple for the ages

Mark and Susan Hamilton
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
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IN LOVING MEMORY

OF

PAUL NORMAN GOULD

HE LIVES IN OUR HEARTS FOREVER

STEVEN GOULD and FAMILY

MARSHALL GOULD and FAMILY
Remembering

Lisa & Bob Gross

With Lots of Love

Bobbi, Jason & Kevin
In Honor of

Jason and Kevin Gross

and

In Memory of

their Fabulous Sister, Lisa

Bonnie and Bob
In Loving Memory Of Our Son and Brother

David Halle

After 61 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
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
We’re the lucky ones. Mitchell picked us. He’s forever in our hearts.

With Love,
Lisa, Mark, Alyssa, Jason and Janice
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
In Honor of

Ezra Kress

Our favorite teacher

You’ve taught us how to appreciate the small things life has to offer and to put things into perspective.

We love spending time together and learning about Facebook and iPhones.

We love you for you.

Love,

Aunt Sherry & Uncle Ira
Sam and Bebe,

This was a great year to escape to Ramatuelle. Let’s all stay healthy and happy. You both continuously exceed our expectations and are growing into amazing people.

Love
Mom and Dad
For Sam Landau

WE LOVE YOU!

Aunt Susan and Uncle Butch
In everlasting Memory
of our beloved daughter
Amy Jill Lehrer

and her beloved father &
my dearest husband

Donald Lehrer
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

In memory of mom, grandma, bubby, Florrie. You're in our hearts.
You Are With Us Always
Mom, Pop, & Samara
Zak Rosen
In Loving Memory of Evan Rosenthal

“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
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

and

Steven Wexler

Your courage and strength are an inspiration

Lynda and Hal Katz
In Honor of Peter L. Sonenshein

Aunt Gail, Uncle Linc and Cousin Dina were thrilled to be able to visit Peter in November 2021 (shortly after his 37th birthday) in the home of his parents Jennifer and David in Bala Cynwyd, PA. The pandemic had prevented us from being able to visit with the family for more than two years. We were amazed at how well Peter was doing and his many wonderful paintings, one of which is now proudly displayed in our front hall. In a sense, this is not surprising since Peter won a prize for his artwork in a recent FD competition.

Peter has clearly recovered from the difficult problems that had him hospitalized earlier in 2021. We were extremely happy to be with him and his family (Jennifer and David, sister Emily and her husband Judah and their two boys Sam and Ari).

Much love and a boatload of virtual hugs,
Aunt Gail and Uncle Linc Sonenshein (Brookline, MA)
Cousin Dina Sonenshein (Somerville, MA)
Cousins Adam and Jenna Sonenshein and their children Samantha and Jack (Culver City, CA)
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
In Honor of

Steven Wexler

With Much Love,

Jay and Claire,
David and Allison,
Emma and Ted
Sending good wishes to

Steven Wexler

and the whole Wexler 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
To our wonderful daughter and sister

SARAH ZUCKER

We’re so proud of the successful young woman you’ve become!

Love, Mom, Dad, Josh & Lido
It’s hard to put into words how much we love her and how she continues to amaze us. She recently completed her certification as a medical assistant, which she added to her previous awards of an Associate degree and a Bachelor’s degree. Since the last FD journal, she has continued what we thought was temporary employment, but now is a permanent position as an assistant in a veterinary office. Sarah has just started volunteering at a local Audubon nature center. She managed to weather the loss of her two older dogs and is pouring her love for animals into the “baby” (Lido) who reciprocates with intensity. No matter the challenge, she overcomes.

We are so glad that we moved near to her and her family so we can share in her enjoyment of life up close. Sarah, we love you!!
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 memory of
Zoe’s and Sydney’s brother

ZACHARY

With love,
Steven, Naomi and Sam
In Honor of

Michael Brenner

Nicky, Priscilla and Harold
IN HONOR OF
FRANNNIE 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
In loving memory of our wonderful cousin
Scott Fass.
We miss him very much.

Cousins Sue Lipkowitz, Marcel Lipkowitz and Robert Fass

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
Our generous supporters
The devoted NYU Treatment Center Staff
Our brilliant Scientific Advisory Board
I am inspired by all of you
And I’m proud to be part of the FD community

Lanie Etkind
Executive Director

In Memory of

Sy Feit

Sandy Z”L
AND
Larry Greebel
IN LOVING MEMORY
OF MY NIECE

JAMIE GOLDBLAT

GAIL GOLDBLAT

Wishing
Josh Kietz
& the FD Community
A New Year full of Hope, Health, Happiness & Hugs

With Love,
Aunt Pam, Uncle Jordan
& Cousin Lauren
Wishing
Josh Kietz
and his family
all the best in 2022!!

With much love,
The Settle family

JOSH
KIETZ
ROCKS!!

JANET AND NICK
TORTORELLA
In Honor of
Josh Kietz

Law Offices of
Harry Weinberg, PLLC

One Penn Plaza
Suite 2110
New York, NY
10119

(212) 889-4100

Labor and Employment Law

In Honor of my grandson

Mitchell Kofsky

and in recognition of

The Dysautonomia Foundation

Sandra Kofsky
In Loving Memory
of My Sister

Carly Allison Posner
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 and Devorah

Thank you to
Unsung Heroes

Kaia Dalamo and Zenith Khan, NPs

For your Outstanding Support
And for Always Taking that Extra Step to Help

Love,
Debbie Schoenholz
Brian,

Your wonderful attitude all these years has warmed our hearts.

Joan and Mark Haberman

In Honor of

Brian Solomons

Perry and Penny Berger
In honor of

Brian Solomons and family

with best wishes for a happy
and healthy new year.

Love,
The Siskind Family

---

In Honor of

Brian Solomons

and

Steven Wexler

May 2022 bring you a year filled with
health and happiness.

Sheree and Jeffrey Markowitz and Family
In honor and in celebration of our great friend

**Peter Sonenshein**

With love from the Hoxter-Levine family

Debi and Ron
Andrew and Heather
Deanie, Gary and Sylvie

---

**IN HONOR OF**
**A WONDERFUL FRIEND AND TALENTED ARTIST**

**PETER SONENSCHEIN**

**WISHING YOU THE BEST ALWAYS...**

**FERN AND STEVE ROTFELD**
In honor of our granddaughter

Simi Steiner

who fills our lives with music and love.

“If music be the food of love, play on.”

Shakespeare, Twelfth Night

In Honor of

Paul and Karen Wexler
In Honor of
Steven Wexler
and the
Wexler Family

In HONOR of
STEVEN WEXLER

SOMBODY whose STRENGTH, KINDNESS and HUMOR,

makes SOMEONE a MUCH BETTER person….G.W.
In Honor of
Steven Wexler

To Wish all
a happy and healthy
holiday and New Year!

God Bless!

Angela Gustavson

WISHING
THE WEXLER FAMILY
ALL THE BEST.
GOD BLESS YOU!

THE MCGRAIL FAMILY
In Honor of

Steven Wexler

From

The McGuffog Family

In Loving Memory of

Lauren Adler

Laura and Eric Green

In Loving Memory of

Lauren Adler

Karyl and Asher Miller
In Memory of
Gregory Asher Brandt
1991-2021
You will always be our Hero! Not a day goes by when we don't think of you! You are so missed and forever in our hearts!
We love you,
Mom, Jason and Ben

In Honor of

Michael Brenner
Cousins Linda & Bob

In loving memory of
Scott Fass
Elaine & Brian Rappaport

SCS Agency
Insurance

Peter Luftig
Vice President

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pluftig@scsai.com

1981 Marcus Avenue
Suite 125
Lake Success, NY 11042
Judy Fettman Dreyfus
1970 - 2020
We miss her terribly.
Love,
Mom & Dad

HILLCREST JEWISH CENTER
In Honor of
Robert and Florence Gropper
In Memory of
Leo and Gladys Gropper
Jeanne Carol Gropper and Alan Gropper

We love you and are very proud of you Gabi!!!
Love,
Suzie, Hope & Aaron

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!)

---

FOR JOSH KIETZ
WE LOVE YOU!
SENDING BIG HUGS FROM YOUR MASSACHUSETTS COUSINS
XOXO
THE MAIMANS & THE WANZERS

---

Love you Josh!

Hal and Carole Fass

---

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

Barbara & Steve Kietz

–Rob & Alyssa Kuppersmith

The Myer Family
remembers with love

Natalie Myer 1958-1963
Scott Myer 1963-1978

In honor of my amazing and inspirational cousin Rebecca Newman and her entire family.

With love,
Wendy Leibowitz
Dear Rebecca,
We are so proud of you.
You have grown into a lovely woman!

We love you!!
Carol and Bill Meyers

In Memory of

Ellen Sue Nuger
1952-1957

The Nuger & Weinroth Families

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
In Honor of
Brian Solomons
Richard Allerton

THE BOCHNER FAMILY
OF EAST HILLS CLEANERS
PROUDLY SUPPORTS
THE DYSAUTONOMIA FOUNDATION!

BRIAN SOLOMONS
IS THE MAN!

In honor of
Brian Solomons
From,
Muriel Goodman

In honor and celebration of
PETE SONENSCHEIN
and his great family.

With love,
Ellen and Steven Wolf
Lisa and Lon Goldstein

In support of
Steven Wexler
and this Foundation

Cindy & Glen Edelman

In Honor of
Steven Wexler

Steven Feldberg

Wishing you great health
and much love, Steven.

Love,
The Gewirtz Family
In Honor of
Steven Wexler
and his Family.

Dayle and Carl

Best Wishes

Rita & Rick Wein
and family

In Honor of
Evan White
and
Ezra Kress

David & Betty Roth
Friends in Honor Of

Kelly Brotman
Susan and Richard Zimmerman

Gabi Jassie
Ephraim and Shirley Garber
Sandra Lichtenstein
Sondra Stoll

Josh Kietz
Jonathan and Randi Altschuler
Julie Eckert and International Plastic Cards, Inc.
Leslie and Ellen Kreisler
Julie Miller
Arthur Peponis
Steve Abrams and Malva Rabinowitz
Jeffrey Shapiro
Alan Spector
Floyd and Barbara Warkol

Aaron Menzel
Maija and Barry Nobel

Rebecca Newman
Laury Hamilton

Brian Solomons
Lorraine Dershowitz
Paulette Kirschenbaum
Eric Rothfeld
Alex Seaman
Bill and Elke Spoor
Friends in Honor Of

Peter Sonenshein
Susan Tachau and Mark Anderson
Michael and Yvonne Libonati

Roxanne Stein
June and Samuel Stein

Steven Wexler
Pamela, Bruce, Zach, and Jake Azus
Michelle Beasley
Pooja Berdia
The Brayson Family
Susan and Michael Goldberg
Joann Heinish
Karen and Steven Hess
Monty and Florentina Jacobson
Ellen J. Kessler
Judy and Fred Komson
Leslie Kravetzsky
Janet and Robert Leeds
Miss Sue's Nursery School
Marvin and Wendy Natiss
Stuart Plotkin
Poseidon Swimming Pool Corp.
Robyn and Marshall Rifkin
Sherry and Martin Silver
Thompson Family
Friends in Memory Of

Philip Bach,
Marilyn Hxel
Marcia Gelles

Lauren Gannet
Arlene and Gary Gannet

Boosters In Honor Of

The FD Foundation
Abrielle Rosenthal

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

Josh Kietz
Amy and Randy Levine
Jim Murphy
Sheldon Nussbaum
Wendy Nussbaum
Mark and Ilyssa Silver
Gloria Zapin

Ezra Kress
Renee and Hervey Sande

Sam Landau
Betsy and Ken Friedrich

Samantha Myers
Harold and Judy Meyer
Boosters In Honor Of

Rebecca Newman
Herb Levitz
Lucille Newman and Family
The Reichman Family
Edith F. Rubin

Lainie Roebuck
Minda and Joel Teicher

Brian Solomons
Richard and Abby Egan
Paula and Harold Freund
Michelle and Lennert Gruszecki
Meryl and Harold Sasnowitz

Peter Sonenshein
Ernest Dellheim

Pyper Stillman
Sharon Polichar

Steven Wexler
Marie-Claire Braun
Miles Braun
The Dolgin Family Foundation
Harvey Fialkov
Mark and Gail Fialkov
Piper Lutbak

Boosters In Memory Of

Jamie Goldblat
Rich and Karen Heller

Howard, Allan, and Owen Riefs
Marty Riefs
The FD Foundation Remembers

Family and Friends

Florrie Lewis Baker
Ben Bishaf
Eddie Franklin
Jeffrey Haber
Jack Held
David Komansky
Howard Kudler
Linda Fiddle Rodgers
Isobel (Sugar) Rosenberg
Jerry Segal
Don Smith
Myra Trinkler
To all who contributed to the 2022 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.
IN HONOR OF
STEVEN WEXLER

ALL OUR LOVE,

Rena, Josh,
Elana & Jacob
Kopelman