

JOURNAL 2020

65th Anniversary Sapphire Edition

FAMILIAL DYSAUTONOMIA FOUNDATION, INC

The First ANNUAL JOURNAL

of the

DYSAUTONOMIA ASSOCIATION, INC.

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JOURNAL 2020

Celebrating 65 Years

65th Anniversary Blue Sapphire Edition

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

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Dear Friends, Families and Allies -

One of the most heartening jobs I have as President of the Familial Dysautonomia Foundation is the wonderful opportunity to read the many heartfelt entries that our extended family makes to our annual journal, a wonderful book of congratulations, memories, possibilities, and images bound together by affection and commitment. Every page is a reminder of the remarkable achievements of those who live rich lives, despite the many challenges FD brings on a daily basis. Of course, the journey of so many members of our community into adulthood is a huge accomplishment, achieved with your support, and the outstanding work of our medical team at the Dysautonomia Treatment Center at NYU Langone Medical Center. Our family just celebrated our daughter Samantha's 31st birthday; every year is testimony to the dedication of families, friends and our doctors, nurses, research scientists, and more.

On behalf of the Foundation staff and our tireless board members, I want to thank every one of you who has taken the time to generously contribute to supporting clinical care and groundbreaking scientific research, as well as bringing recognition and joy to those living with Familial Dysautonomia. This year's journal offers a wonderful glimpse into the many lives woven together by FD, and the extraordinary devotion and love that keeps all of us moving forward.

With Gratitude,

Lay Cemery

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 50% chance of becoming 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 funds 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.



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



Dear Friends.

As Director of the Dysautonomia Center it has always been a great privilege to partner with the Familial Dysautonomia Foundation in our mission to take care of families with familial dysautonomia (FD). Over the last decade, we have changed the way we think about and treat FD. We have come closer to understanding the neurological underpinnings of the disease and brought several new therapies to the clinic. This has come through a meticulous approach to clinical research and working with a talented group of scientists inside and outside the Center.

Our work is far from done. Right now, more than ever, it is critically important for us to come together and push harder to translate ideas into new treatments that not only prolong survival but also improve symptoms so that patients can live better today.

Thanks to the unwavering support of the Foundation, we have hired two extraordinary nurse practitioners, who are there to answer your calls, come rain or shine. We were fortunate to be able to bring to the Dysautonomia Center Zenith Kahn and Kaia Dalamo, who place their hearts and minds into helping families face the challenges of FD on a daily basis.

Without a doubt, the progress that we have made in FD has come from our incredible research team that have dedicated their time to understanding and thinking about FD from its molecular basis to its clinical symptoms. I am thrilled Dr. Frances Lefcort and Dr. Adrian Gilbert now head the Foundation's Scientific Advisory Board. Their combined expertise in basic science and drug development gives us the best chance of translating treatments from the bench to the bedside. As the science of treating rare inherited diseases like FD moves forward, we are expanding our expertise to include members of the scientific community that have been at the forefront of some of the biggest breakthroughs in gene technology in the last 5-years. These are exciting times, filled with promising therapies, and a dedicated team of clinical scientists that are ready to cure FD.

Now more than ever we are relying on the patient community to come together and face these challenges with us. Without patients and families behind us, new therapies will not make it into the clinic. There are several ways in which you can help us make progress. The patient voice is one of the most impactful tools we have when it comes to FD. Together with the Foundation we are planning to go to the Food and Drug Administration to tell them why we need new therapies for FD today. We need you to participate in research. With our robust clinical development plan we know what we need to do and how rigorously we must test new potential treatments for FD patients. We are aware of the time and effort that goes in to participating in research, but there has never been a more critical time for us to come together, join our efforts, and do what we must do to find safe and effective treatments.

I do believe that the future for FD patients and their families is bright. I know that the community we have created will get behind our efforts. The path to bringing new therapies to the clinic is not always easy, but we can never give up and we must try. It's been an enormous pleasure to Direct the Dysautonomia Center for the past 11-years. I look forward to the day I can announce we have cured FD.

Sincerely.

Horacio Kaufmann, MD Director, Dysautonomia Center



The Team at NYU's Dysautonomia Center



Horacio Kaufmann, MD



Lucy Norcliffe-Kaufmann, PhD



Alberto Palma, MD, PhD



Jose Martinez, MS



Bhumika Balgobin, MD



Maria Cotrina Vidal, PhD



Zenith Khan, FNP-BC, MSN, RN



Kaia Dalamo, DNP, FNP-BC





Lee-Ann Lugg



Miguel Perez



Barr Morgenstein



Siobhan Bhirangi



Schneider

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



GENETIC RESEARCH

To discover the underlying cause...

The Familial Dysautonomia Foundation has always supported genetic research and 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
- 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: a single base-pair change within an enormous chain of DNA. This small, but catastrophic error, tightly wound up into the double helix, affects the entire development of the nervous system. A finding that not only sparked a flurry of interest into how the gene functions, but also allowed general population carrier testing.

In the summer of 2004, the American College of Obstetricians and Gynecologists formally recommended that FD testing be offered to at-risk families. This push made FD testing an essential part of family planning, much like testing for Tay-Sachs. As a result, the birth rate of FD newborns has plummeted worldwide.

We can't stop there. This was only the starting line in our race to cure FD. Our efforts are focused on bringing genetic therapies to those living with FD and we must do it including projects with stem cells and animal models. We've identified compounds that fix the genetic problem and restore the faulty protein IKAP. We are funding clinical trials to see if gene therapy can delay the downhill spiral of movement problems, blindness and organ damage. The potential benefits make this exciting and crucially important for our affected children. With your ongoing support, we hope one day to prevent, treat and ultimately 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

NATASHA WEINSTEIN

and

AARON BREEN

Volunteers

PERRY GOLDBERGER
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RACHAEL EISENSON
SAM LANDAU
ROBIN LANDAU

Intern

XUAN ZHANG

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

























(FD)

IN HONOR OF OUR THREE BEAUTIFUL GIRLS

PERRY

SYDNEY

CODY

LOVE, MOM and DAD







Thank you, Samantha Myers, for an amazing three decades of joy and possibility!! Love, Faye and Fred





Steven Wexler



Chris Burke said "It's not our disabilities, it's our abilities that count."

This is how you live your life. We are so grateful for your strength and character. You continue to make us better people everyday.

> We love you, Mom and Dad



FD

Wishing

Steven Wexler

a happy and healthy 2020.

Love,

Mark and Melissa Halperin





In honor of our daughters, Julia and Becca. We are so proud of you both!

LISA AND JEFF NEWMAN



Michael Baranoff,

You continue to make us so proud.

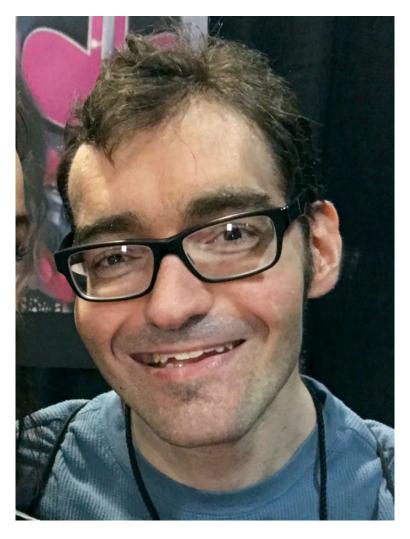


We love you beyond words !!!

Xo Mom, Dad, Rob, Joe, Nate, Prissy, Elly and Emmy ♥



Michael Brenner



You continue to amaze us!
Your smile lights up our world.
We love you,
Mom and Sarah

IN LOVING MEMORY OF

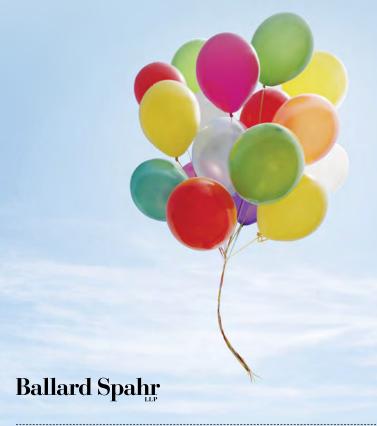
DAVID BRENNER

MAY HIS MEMORY BE A BLESSING

THE STEINER FAMILY

Ballard Spahr is proud to support the Familial Dysautonomia Foundation

Together, we can work toward a better and brighter tomorrow.



www.ballardspahr.com



Congratulations to

Alexia de Gunzburg

who has just been named a Leader in the Capernaum Club, an organization in Naples, Florida that focuses on teens and young adults of all abilities with special needs.



Alexia with other Capernaum Leaders and Co-Heads

As Alexia puts it, "To be a Leader gives me more responsibility. I get to be more outgoing and build confidence and willpower within myself. I call members outside of meetings to develop closer relationships, and let people know they can rely on me if they have issues or need advice. I want to teach them that God created them for a purpose and that they are valued and loved."



To Mitchell Joseph

Love from your family and friends in Dallas, New York, and Portland





We are proud to support the Dysautonomia Foundation and join the FD community in honoring Dr. Horacio Kaufmann.



Committed to helping advance therapies for familial dysautonomia.

IN HONOR

OF

BRIAN SOLOMONS AND HIS FAMILY

BEST WISHES FOR HEALTH

AND

HAPPINESS.

Love,

Jill, Sandy, Johnny and Brittany Sirulnick





Love and admiration to Pete from your whole family



IN MEMORY OF

LAUREN JAMIE ADLER

'Until the rainbow burns out the stars in the sky Until the ocean covers every mountain high Until the dolphin flies and the parrots live at sea Until the day is night and night becomes the day Until the trees and seas jump up and fly away Until the day the earth starts turning right to left'

We'll be loving you ALWAYS

Her mom and dad

Joseph & Eliana

HE LOVED LIFE, HIS FAMILY, HIS PEOPLE, HIS SYNAGOGUE

DAVID "DOVIE" BORENSTEIN שמעון מרדכי דוד

ב"רישראל גדלי' הלוי ו'מריס May 20, 1954 – March 17, 1990

Miriam and Irving Borenstein Hindy and Michael, Sharon and Avi Assaf and Tova, Amy, Alec and Lea & Family Amanda and Yonaton & Family



To my darling grandson

Michael Brenner

I love you, and I'm always thinking of you!

Grammy

In honor of

Michael Brenner

our amazing nephew and cousin.

May all good things come your way in 2020!

With Love,

Aunt Robin, Uncle Brian, Cousins Alex and Maddie.



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



Also many thanks to
the Dysautonomia Foundation
Lanie Etkind
curator Kristina Hagman
Alexia, Rachael, Peter, Mara, Keshi
& the Allouche Gallery

TEARLESS

AN EXHIBITION
FEATURING ARTISTS WITH
FAMILIAL DYSAUTONOMIA

FD

In Honor of the 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

Scott



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 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 MEMORY



ANDREA LYNNE HAUBEN

FEBRUARY 2, 1984 - MARCH 21, 2009

FOREVER IN OUR HEARTS

The Hauben Family

FD

In honor of my Gabi.

She believed she could and she did it! After years of hard work, Gabi graduated from Hunter College in May of 2019. I am just so proud of you! I also kvell for my other granddaughter Alexa, who similarly graduated in May 2019 from TCNJ. I am just so proud of you too! Plus thank you Roni for baking delicious cakes for FD and the people at Jamaica hospital for buying the cake. I love you all!

-GMA

IN HONOR OF

OUR CHILDREN

ADAM & JOSHUA KIETZ & NOW LIZZY!

WE LOVE YOU SO MUCH

MOM and DAD



Honoring Josh Kietz supporters

1992-



THANK YOU!

Barbara and Steve Kietz

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





IN HONOR OF OUR FRIEND

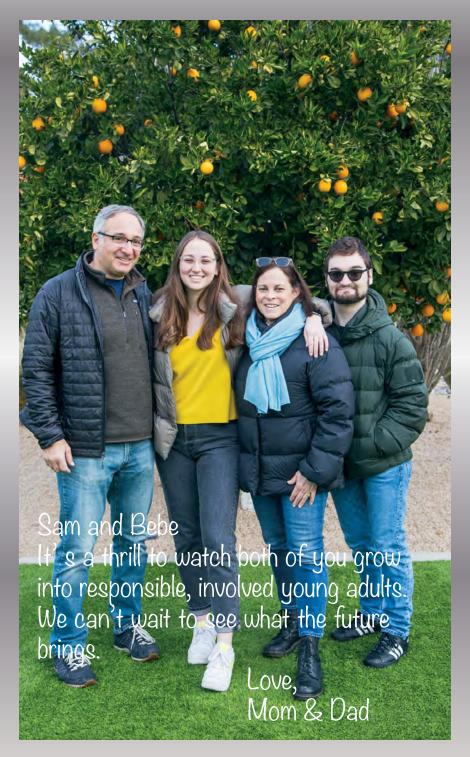
JOSHUA KIETZ

JULIE ECKERT

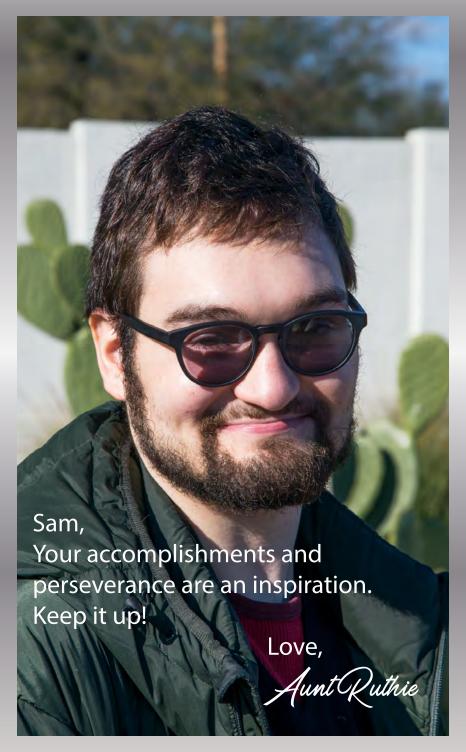
AND THE

IPC FAMILY









In Memory of

Elaine Jamie Lipson and Arthur Lipson

Always in our hearts
The Lipson Family

In memory of our precious DONNA LYNN MICHAELSON



Always loved Never forgotten In our hearts forever

Mom
Howard and Sheila
Chase and Spencer
and
All who knew and loved her





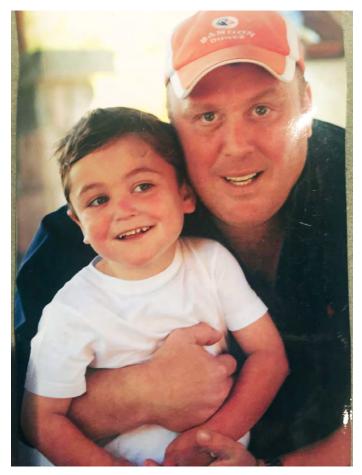
Samantha Myers

Always my inspiration!

Love, Aunt Deb



Our Amazing Son & Grandson



In Memory of Adam
In Honor of Jack

Forever Loved

Gail & Stan Posnack

(F)

In Honor of

Jack Posnack



In Memory of

Adam Posnack

Brill and Jason Garrett





STEVEN MATHEW SCHWARTZBERG

OCTOBER 29, 1982 - DECEMBER 26, 2017

WE WILL REMEMBER YOUR BEAUTIFUL SMILE,
LOVING HEART AND JOYOUS SPIRIT.
ALWAYS

LOVE, DAD, MOM & DARYL

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 Haberman



In honor of those who fight this disease and the people who support them...

May there one day be a cure!

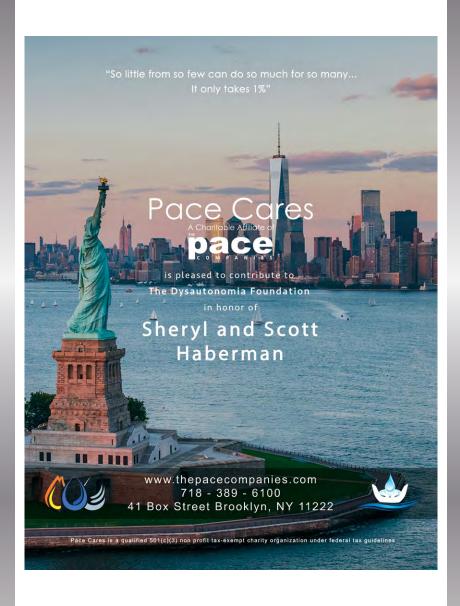
The Ginsberg Family
Stephanie, Ian, Alec, Wendy & Reed



In Honor of

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

In Honor Of Steven Wexler

Dear Steven,

You have brought us joy beyond anything we could have imagined. We are proud not only of your accomplishments but of your compassion, love of life and optimism that endears you to all who meet you. We love you so very much.

Grandma Yvette & Grandpa Harvey

Jeannie ~

There are no words that can properly express our gratitude for all that you did to help Steven get through 24 days in the hospital and his subsequent recovery.

Please know that we will be forever grateful to have you in our lives.

Love,

Karen and Paul

Charlie and Joy. Joy and Charlie.

Steven is an amazing man. You have as much to do with that as do we.

You are family and we are forever grateful to have you in our lives.

Love, Karen and Paul

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



I am happy to be part of the progress.

With Love, Andy



In Honor of

Steven Wexler

You continue to inspire us with your daily display of courage, strength and positivity while facing such adversity.

Love,

The McAuliffe Family



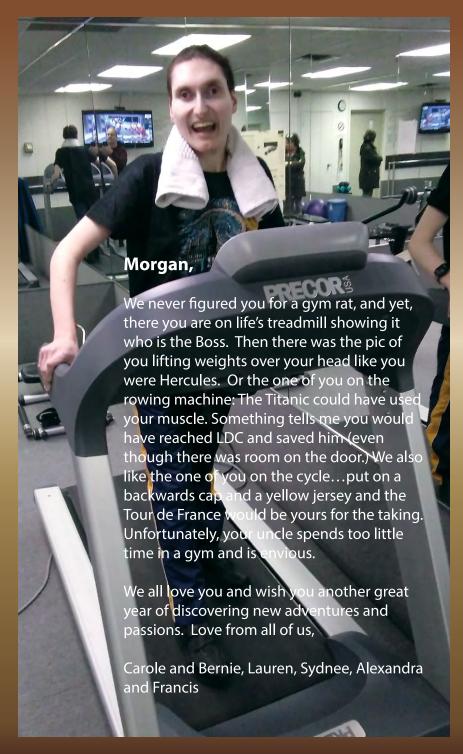
Dearest Lauren,

Thirty-six years ago you first brought sunshine into this world and filled our hearts with an overabundance of love and joy. "Absence makes the heart grow fonder." Today, all these years later we love you even more and miss your endearing smile and golden heart.

With much love,

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







To Our Mikey Baranoff,

M multitalented

I intelligent

C charming & caring

H happy

A attractive

E enthusiastic

L loving

These are just a few adjectives to describe our amazing Grandson.

We love you so much. You're so special!

Grandma Prissy & Grandpa Mike



WE LOVE YOU MICHAEL BARANOFF



Love, The Frank Girls



We love you!

Michael Baranoff

Mia, Rachel, Jacob, Amy, and Scott Gottesfeld



MICHAEL BRENNER

WE LOVE YOU! YOU SMILE BRIGHTER THAN ANYONE!

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

In Memory Of

DAVID BRENNER

For His

Brilliance, Humanity, Passion, and Dedication to his Family and Work

Love.

His Sister and Brother-in-law Nieces and their Husbands Great Nieces and Great Nephews



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Life ends ... love never does.

We love and miss you, Jamie, our amazing daughter, sister, sister-in-law, aunt, and cat mommy.

You will be in our hearts ... always.

Mommy & Daddy Jessica, Matt, Leah & Emma & Chloe Cat





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 and Shayla Gordon and Edna Sydney



LARRY GORDON

JUNE 4, 1956 — OCTOBER 22, 1960

LOVING SON OF ENID WEINBERG

BELOVED GRANDSON OF JULIA AND NAT HOFF

A LIFE TOO SWEET AND TOO SHORT

FOREVER REMEMBERED



CONGRATULATIONS TO

HORACIO KAUFMANN

ON BEING SELECTED FOR THE AAN'S IRWIN SCHATZ AWARD FOR AUTONOMIC NEUROLOGY.

WE ARE FOREVER GRATEFUL

FOR ALL THAT YOU AND

THE DYSAUTONOMIA CENTER

DO FOR THE FD COMMUNITY.

THE WEXLER FAMILY



With love to our grandson, Ezra Kress



Your smile and your spirit bring us such great joy as we celebrate your 22nd birthday.

Saba and Savta, Bill & Beverly Lebeau



Sam Landau

All the best wishes.

We love you.

Arnold and Susan Scharf

In everlasting memory of our beloved daughter

Amy Jill Lehrer

and her beloved father & my dearest husband

Donald Lehrer



IN LOVING MEMORY OF

STEPHEN AND JERRY LINKER

JEAN AND STEVE ANREDER



In Loving Memory of The Rosenthal Men

Richard David

Evan Robert

Seth Andrew

Always in my Heart Loren



IN LOVING MEMORY OF OUR BELOVED

LUCIEN SEGAL

1946 - 2018

MAY HIS MEMORY BE A BLESSING

ILANA, VERONICA, HENRIQUE, KELLY & IAN SEGAL



IN HONOR OF

BRIAN SOLOMONS

AND

SHERYL AND SCOTT HABERMAN

AND FAMILY

PAM AND DAVE WAILL



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



To Peter Sonenshein

With love and admiration

Leslie and Warren

Noel and Bruce



In Honor of **Steven Wexler**

Dear Steven,

You have the most amazing smile that spreads warmth and inspiration to all who know you.

The love from your parents and sister Stefani and brother Bryan surrounds you wherever you are.

We wish Godspeed to the devoted FD researchers and pray that they are able to find a cure real soon.

We love you a whole bunch.

Grandpa Phil and Betty



In honor of Steven Wexler and Brian Solomons

Your courage and strength are an inspiration.

Alyssa and Steven Ackerman



Lots of love to our FD hero,

Steven Wexler

Wishing you and the Wexler family a 2020 filled with health and happiness.

Amy, Michael, Ethan and Samanatha



Steven-

We are so proud of you!

You are such an awesome person!

Love you-

The Segal Family



With great appreciation to Lanie Etkind and the entire staff of the FD Foundation for all that they do in helping us accomplish our goals

THE WEXLER 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



In Honor of Michael Baranoff



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







In Loving Memory of

Maximiliano and Lionel Donzis

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



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 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



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



Remembering Lisa & Bob Gross



My With Lots of Love My
My

Bobbi, Jason & Kevin





Jason and Kevin Gross

Spending Time with Our Family from across the Country!

We All Wish All the Best for Jason and Kevin

Aunt Bonnie & Uncle Bob



IN HONOR OF

THE HABERMAN AND WEXLER FAMILIES

FOR THEIR DEDICATED &
TIRELESS COMMITMENT TO
THE FD FOUNDATION

SUSAN & BRUCE COHEN



IN LOVING MEMORY OF

KATHERINE MERLE IRLEN

1964 - 2006

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

Gabi Jassie

"Just remember you are BRAVER than you believe, STRONGER than you seem and SMARTER than you think."

Winnie the Pooh got it right.

Gabi, we know you believed you could, so you did! We continue to be in awe of you and your accomplishments. We're so proud of the adult you've become, and not letting FD get in your way.

> We love you so much! Mom and Dad

A special shout-out to all of your FD friends. These friends are an important part of your story.

Also, thank you to the Landau's.











Our Love To A Most Wonderful Young Man:

Evan Reid Kaplan

Congratulations on The Celebration of Your 23rd Birthday!

Grandpa Bobby & Grandma Nancy





Evan,

What a great year you had! You are working so hard and we are very proud of you!

Love, Mom, Dad, Max, Rachel & Oliver



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

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, Mía-Hope, Nícole, Kasíe, Peyton, Míndy, Manolo, Daniel, Amy, Ríchie, Sarabeth, Jesse & Jacob



In Honor Of

Our Wonderful Grandson

EZRA KRESS

You are our rock star! Rock on and have a year of health and fun.

We love you very much,

Grandma and Grandpa

In Honor of

Ezra Kress

You amaze us every day with your "can do" attitude, your smile and your ability to make everyone around you smile.

We love you!

Aunt Sherry and Uncle Ira



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

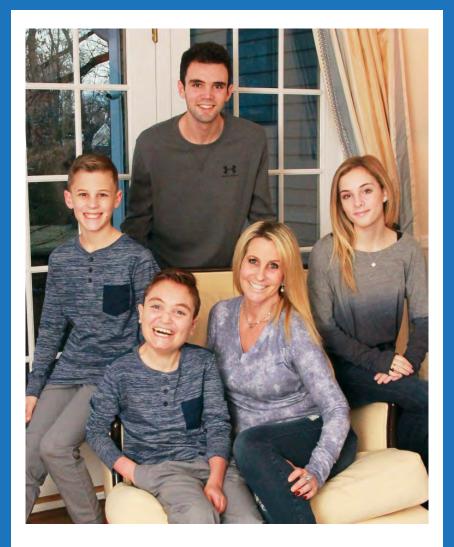


In Honor of

Susan LeVine

With appreciation for your efforts on behalf of the Dysautonomia Foundation





To our loving Jack,

You are the love of our life and the center of our family. Your effervescent laughter and "love of life" shines through us and makes us better!!

Love Mommy, Cody, Hunter and Charlotte

IN MEMORY OF OMA & ZAK



SAMARA ROSEN, URSULA GOLD, ZAK ROSEN



In Loving Memory of Evan Rosenthal

The moments we shared with you, dear Evan, are the moments we keep forever.

You're always in our hearts.

With love,

Debbie Susan Joan Stephanie and our families











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, and Fiona 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

YOU ARE AN INSPIRATION
TO US ALL!!

&

IN LOVING MEMORY OF

DAVID M. SOLOMONS

Mom + Family



In Honor of

Brian Solomons

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

Jeffrey and Andrea Lomansky

IN HONOR OF

THE HABERMAN AND WEXLER FAMILIES

FOR THEIR DEDICATED &
TIRELESS COMMITMENT TO
THE FD FOUNDATION

SUSAN & BRUCE COHEN



IN HONOR OF

BRIAN SOLOMONS AND STEVEN WEXLER

AND IN MEMORY OF

SCOTT FASS

WE PROUDLY SUPPORT THE RESEARCH EFFORTS OF FD

ILENE & PAUL PEARLMAN & FAMILY



In Honor of Peter L. Sonenshein





Pete – we love you and always love being with you! Happy 35th Birthday!

Aunt Gail, Uncle Linc, and Cousins Dina, Jenna, Adam, Samantha and Jack



Steven -

Watching you kick FD's butt every day is amazing to witness. You inspire us daily to be better in every way.

Love,

Bryan, Stef and Jay



We love you, Steven. You make us proud every day.

Love,
The Diton Family and
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

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IN HONOR OF OUR FRIENDS,
FAMILIES, AND THE
MEDICAL FIELD WHO WORK
SO HARD TO CURE FD.

CRISTINA AND DANNY
RACKOW



To our wonderful daughter and sister

SARAH ZUCKER

Congratulations on getting your bachelor's degree from Rhode Island College!

We're very, very proud of you!

"Life's about doing something you love and never giving up."



Love, Mom, Dad, Josh, Larry, Kiva & Ruby





Our congratulations to

Sarah Zucker

for her perseverance and dedication in earning
her Bachelor of Arts in Social Justice
from Rhode Island College.
We are so proud of you.

With Love from Grandma and Grandpa



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

To my Auntie Carole

To the Best and Most Beautiful Aunt!!
I really enjoy our Special Time together
Best wishes as you celebrate a special year.
Happy Birthday
With love from Morgan.





IN MEMORY OF

YAKOV BEGIN

AND

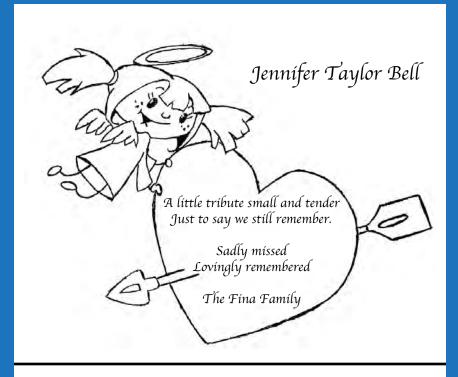
DOV BEGIN

MR. & MRS. BEGIN



Jennifer Taylor Bell Time Goes on but Memories Live Forever Always in our Hearts





In Loving Memory of Zachary Berg

Marcy & Gary Edidin



In memory of Zoe's and Sydney's brother

ZACHARY

With love, Steven, Naomi and Sam

HONORING GREGORY BRANDT



All our Love, Aunt Andrea, Uncle Lloyd Shanna & Noam Alexander & Michelle David & Jessica



We love you Gregory!

Aunt Cynthia, Uncle Jeff, Emily, Melissa, and Julie

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 Honor of our beautiful little angel

> DIANA ESPARZA

With lots of love, Mom and Dad



In Memory of

Scott Fass

We will always remember his smile and his kindness to all.

With love and admiration Elaine & Brian Rappaport

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

Scott Fass

Cousins Sue & Marcel Lipkowitz and Cousin Bobby Fass



Forever Remembered, Forever Missed

Scott Fass

Geri, Harold, Jared, Mariel, Cori & Lexi

In tribute to:

All those with FD and their loving families
Our dedicated board and fabulous volunteers
Our generous supporters
The devoted NYU Treatment Center Staff
And the hard-working FD Foundation Team
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

SEYMOUR FEIT Z'L

MAZEL TOV TO

JUDY and MARC DREYFUSS on their seventh anniversary

WE HONOR

The entire NYU Dysautonomia Treatment and Evaluation Center For their devotion to the care of FD patients

WE HONOR

DR. BERISH RUBIN and DR. SYLVIA ANDERSON

Fordham University Laboratory for Familial Dysautonomia Research For their dedication, successes and for their continuing search for additional nutritional supplements for the FD population

WE HONOR

All other scientists as we eagerly await the results of their research

Beverly and Ted Fettman



IN MEMORY OF

KATHY ANN FISHMAN

DAVID & DEENA FISHMAN ALVIN & CAROL FISHMAN



In loving memory of our forever beloved hero, inspiration, neshume and talented artist. ILAN FRIEDMAN Z'L not a day will ever go by without us thinking of you and of all you taught us and everyone who was lucky to get to know you. We were blessed to share 27 years with the purest and most beautiful soul that touched the earth. We miss you every second.

Mami, Papi and Yael



In Honor of

Jamie Goldblat

With Lots of Love, Aunt Gail



In Memory of Lisa
And to Jason and Kevin—

Wishes for a healthy New Year filled with thousands of special moments and tons of laughter! We love you to the moon and back!

> Love, Aunt Karen, Uncle Dave, Jake, Zac, Drew, David and Emmett





Dearest Josh,
You inspire us all!
With Love,
Aunt Pam, Uncle Jordan
& Cousin Lauren



Josh

You amaze us all! We are blessed to have you in our lives.

Love,

The Feldman Family
The Handy Family
The Levine Family
The Silver Family
The Stern Family
Marcia Levine

We love our dear friend

Josh Kietz

Janet + Níck Tortorella



In Loving Memory of my Children

Karen Kidder and Peter Klier

Karen - from lung cancer in 2010 Peter - from dysautonomia in 1980



In Honor of my grandson

Mitchell Kofsky

and in recognition of

The Dysautonomia Foundation

Sandra Kofsky

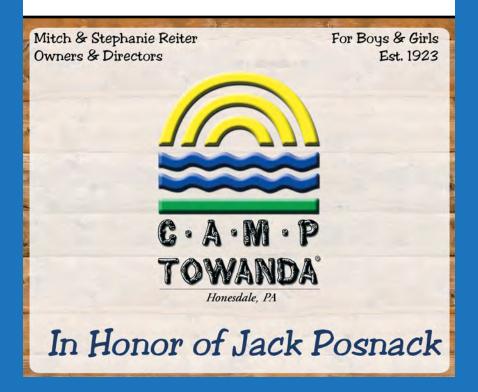


Our Best Wishes to **The Newman Family**

Lisa, Jeff, Julia, and Rebecca

from

Phyllis and Peter Honig





In Loving Memory of My Sister

Carly Allison Posner

IN HONOR OF

BRIAN SOLOMONS

YOUR RESEARCH HAS MADE HIS LIFE POSSIBLE.

MARK AND JOAN HABERMAN



In Honor of

BRIAN SOLOMONS

PERRY AND PENNY BERGER

In Honor of

Brian Solomons,

Sheryl Haberman's Brother



In honor of **Brian Solomons and family**

with best wishes for a happy and healthy new year.

Love, The Siskind Family

In Honor of

Sheryl and Scott

Haberman

and their

dedication

to FD.

June and Michael Cohen

(FI)

To my pal

Pete Sonenshein

Love your artwork.

Hope 2020 is filled with more beautiful and inspiring art.

xxxooo

Beverly B

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



WE ARE HAPPY TO SUPPORT

THE FD FOUNDATION

IN HONOR OF

PETER SONENSHEIN

AND HIS LOVING FAMILY
WITH MUCH LOVE

FERN AND STEVE ROTFELD

We are happy to support this foundation in honor of our friend **Steven Wexler** and wish him a speedy recovery from his recent back surgery.

Love,

Cindy & Glen Edelman & family



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!

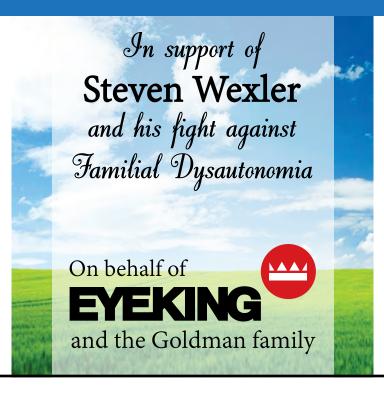
Love, Mark and Rachel

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

God Bless!

Angela Gustavson





To Steven Wexler and Family,

Wishing you health and happiness today and always!!!

With Love,

The Lisann and Silver Families





8 BERRY STREET, BROOKLYN, N.Y. 11249 T. 718-963-3700 F. 718-388-8671

> In Loving Memory of Lauren Adler Karyl and Asher Miller

In Honor of Dr. Axelrod



In Honor of

MICHAEL BRENNER

COUSINS LINDA & BOB

In Memory of
Scott Fass
We miss you and think about you every day.
Forever in our hearts.
Love,
Stefi, Craig, Sydney, Shani, and Jordan

With deep gratitude to

Dr. Horacio Kaufmann, MD
Dr. Jose-Albert Palma, MD, PhD
Zenith Khan, FNP-BC, MSN, RN
Kaia Dalamo, DNP, FNP-BC
and the incredible team at the FD Center
for their dedication beyond the call of duty.

The Profesorske Family

FD Center & Dr. Kaufmann

For your unwavering dedication and compassion to the FD Community.

Love, The Ross Family





Peter Luftig

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

1981 Marcus Avenue Suite 125 Lake Success, NY 11042



To our beloved shining angel

Jay William Fisher

We love you so much. Mitch, Diane, Elliot, Karen and Ryan Fisher

In loving memory of our dear cousin **Felicia Gail Gold**

And with gratitude to the devoted doctors and staff of the Dysautonomia Foundation

Joyce and Bern Saxe

In memory of our beloved nephew
Yuval Henigman
The Klinghoffer Family



IN LOVING MEMORY OF

ALISA ROBIN KALEY LOUIS KALEY ROZ KALEY

STEFANIE, STEPHEN, LAUREN, MATTHEW & SOPHIA

Dear Josh,

May 2020 be filled with only GREAT times! We love you so much.

Aunt Ronni, Uncle Philip Brian and Jacob

Dear Josh,

You amaze and inspire us, each and every day.

We love you!

Judy, Alan, Lauren, and Kimberly.

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





IN LOVING MEMORY OF STEPHEN LINKER AND JULIAN LINKER

PHYLLIS AND SUSAN



To Our Amazing Rebecca,

We love you so much!

Aunt Florrie, Rich and Sue

In Honor of **Rebecca Newman** and her amazing family.

With Love, Wendy

IN MEMORY OF

ELLEN SUE NUGER 1952-1957

THE NUGER FAMILY



With love, and support, and fondness, and never ending friendship, we honor

Jack Posnack

and his wonderful family.

Jack is a true hero in our eyes! May he continue to grow and prosper and be protected by G-D.

Love,

The Weiss Family

IN HONOR OF THE RAINER FAMILY

CAROL BILLOW

IN MEMORY OF

JESSICA FERN SHORE

We support the Slive Family in their efforts to cope with and conquer FD. Sue & Jerry Weinstein



In Honor of **Brian Solomons**

Richard Allerton

In Honor of

Scott and Sheryl Haberman

With Friendship, Lisa & Lon Goldstein

JEFFREY H. MARKOWITZ, D.D.S. TODD H. LERNER, D.D.S., F.A.C.P.

1129 NORTHERN BOULEVARD, SUITE 401 MANHASSET, NEW YORK 11030

> 516-365-3535 Fax: 516-365-3748

In Honor of Maryon Weill devoted supporter and valued friend

Sydelle Mitchell



To Our Nephew Steven Wexler

Your strength inspires us!

Aunt Dayle and Uncle Carl

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

Jeff and Lori Baker

We love you, Steven

Love, Ilene, Michael, & Jordan Gewirtz and Family

Our best wishes to you always, Steven.

Monty and Florentina Jacobson



In Honor of the Wexler Family Marvin & Wendy Natiss

Best Wishes

Rita & Rick Wein

IN HONOR OF

EVAN WHITE

AND

EZRA KRESS

THANK YOU

To all who contributed to the 2020 FD Journal

Friends

Lauren Adler Chani & Bennett Salamon

> Carrie Baker Beaty Silver

Josh Kietz Aunt Amy & Uncle Mike Cousins Les & Ellen

Rebekah LiebermanDr. Shiloh Leiberman

Aaron Menzel Maija & Barry Nobel

Samuel SernovitzLee & Sharlene Raymond

Brian Solomons
Jason & Jody Schwartz
Alex Seaman

Peter Sonenshein
Lois Frischling
Tachau & Anderson family



Friends

Steven Wexler

Marie & Miles Braun
John Buckley
The Chipman Family
Janet & Robert Leeds
Michael Gorin & Nancy Lieberman
Jeff & Wendy Nackenson
John & Bonnie Salmon
Mark Tobin

Boosters In Honor Of

Morgan Asinowski

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

Michael Brenner

Joshua & Gail Wanger

Familial Dysautonomia Foundation

Eric & Karen Nodiff

Gabi Jassie

Suzie, Hope & Aaron Belzer Ephraim Garber Sondra Stoll

Mitchell Joseph

Mark & Lisa Campbell
Catherine & Robert Kushner

Boosters In Honor Of

Josh Kietz

Jim Murphy The Wanzer Family Gloria Zapin

Ezra Kress

Hervey & Renee Sande

Sam Landau

James Lieber Judy Rothberg

Rebecca Newman

Florence Baker Laury Hamilton Lucille Newman and Family

Jack Posnack

Stephanie Ripps

Lainie Roebuck

Teicher IMO Dr. G. Roebuck

Samuel Sernovitz

Debra & Arthur Skaroff

Brian Solomons

Michelle & Lennert Gruszecki Donna & Dan Levine Richard Reubenstone



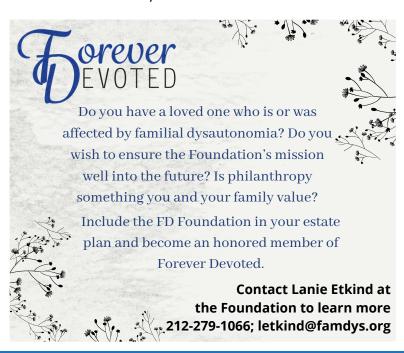
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Peter Sonenshein

Jane & Ernest Dellheim
Spencer Erbe
Yvonne & Michael Libonati
Karal Taylor
Ellen & Steven Wolf
Michael Wolf

Steven Wexler

The Byron Family
Mark & Gail Fialkov
Lisa & Michael Franco
Susan & Michael Goldberg
Carol Gottesman
Jo-Ann Medigovich Heinish
Piper Lutbak
Ryan & Risa Mucatel





Boosters Remembering

Lauren Adler

David & Marla Bart Debra & Howard Schub

David Brenner

Brenda & David Fletcher

Scott Fass

Robert Fass

Jamie Goldblat

Karen & Rich Heller Susan Vercheak & Bennet Zurofsky

Alvin Greenfield

Gloria Greenfield

Stephen Linker

Daniel & Claudette Kornfeld

Owen Riefs

Martin Riefs

Gregory D. Schwartz

Madeleine, Alyson & Amanda Schwartz

Brett L. Zinman

Jodi (Zinman) DeCleene & Family



THE FD FOUNDATION REMEMBERS



JAMIE GOLDBLAT

6/4/90 - 3/27/20



THE FD FOUNDATION REMEMBERS



JESSICA SHORE

1/19/81 - 3/8/19



THE FD FOUNDATION **REMEMBERS**

FAMILY AND FRIENDS



JAIMI ABRAHMS

PAULINE FINE

URSULA GOLD

ALVIN GREENFIELD

BEVERLY GRUBER

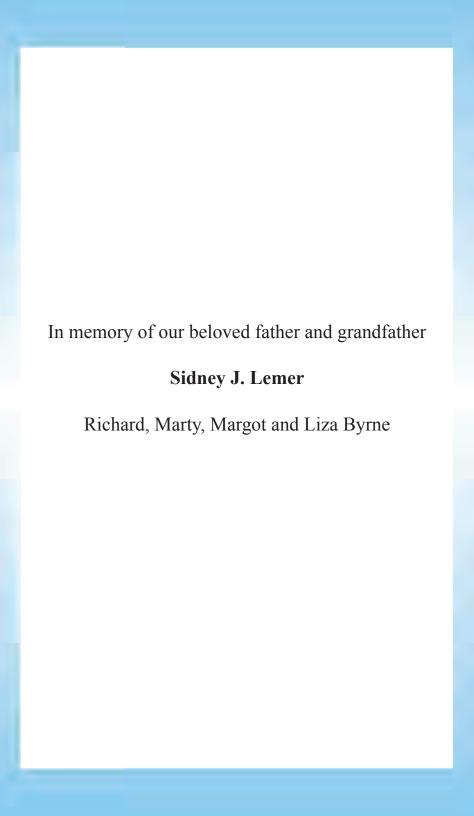
ROZ KALEY

DONALD STILLMAN

HELEN STRAUSS

MEYER "MIKE" SUTTON

WALLACE WERNER 167



IN HONOR OF STEVEN WEXLER

ALL OUR LOVE,

RENA, JOSH, ELANA & JACOB KOPELMAN