The
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of the
DYSAUTONOMIA
ASSOCIATION, INC.

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June, 1955
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,

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.
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

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Kaia Dalamo, DNP, FNP-BC
Patricio Millar, MD

Lee-Ann Lugg
Miguel Perez
Barr Morgenstein
Siobhan Bhirangi
Isabella Schneider

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

VII
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

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and

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Your Efforts Make All Our Good Work Possible. Thank You!
Thank you for all the great leaps and bounds made by the Familial Dysautonomia Foundation! I am happy to support your efforts.

Solange
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
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
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 💖
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](image)

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
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

DAVID “DOVIE” BORENSTEIN

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

 rideψ"ם רבדה זמ"א — ז"א ו"א

ר"א לракти ל"א — ל"א ו"א ו"א

22
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
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
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
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
Hope - Love - but most of all gratitude. For our children, grandchildren and great grandchildren.

Bubbe & Zaidie
Anita & Stan
In Honor of
our Friend

Joshua Kietz

Julie Eckert
and the
IPC Family
Sam and Bebe
It’s a thrill to watch both of you grow into responsible, involved young adults. We can’t wait to see what the future brings.

Love,
Mom & Dad
Sam,
Your accomplishments and perseverance are an inspiration. Keep it up!

Love,
Aunt Ruthie
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
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
“So little from so few can do so much for so many... It only takes 1%”

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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
Morgan,

We never figured you for a gym rat, and yet, there you are on life’s treadmill showing it who is the Boss. Then there was the pic of you lifting weights over your head like you were Hercules. Or the one of you on the rowing machine: The Titanic could have used your muscle. Something tells me you would have reached LDC and saved him (even though there was room on the door.) We also like the one of you on the cycle…put on a backwards cap and a yellow jersey and the Tour de France would be yours for the taking. Unfortunately, your uncle spends too little time in a gym and is envious.

We all love you and wish you another great year of discovering new adventures and passions. Love from all of us,

Carole and Bernie, Lauren, Sydnee, Alexandra and Francis
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 BARANOIFF

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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and its mission to help families worldwide

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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


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
Thank you for all of the joy you bring us!
We are so proud of both of you!
Love,
Mom and Dad
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

With Lots of Love

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, Mia-Hope, Nicole,  
Kasie, Peyton, Mindy, Manolo,  
Daniel, Amy, Richie, 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  

“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
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
Jennifer Taylor Bell

A little tribute small and tender
Just to say we still remember.

Sadly missed
Lovingly remembered
The Fina Family

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
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 Ž’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 + Nick
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
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
In support of
Steven Wexler
and his fight against
Familial Dysautonomia

On behalf of
EYEKING
and the Goldman family

To Steven Wexler and Family,

Wishing you health and happiness
today and always!!!

With Love,

The Lisann and Silver Families
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
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

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 Lieberman
Dr. Shiloh Leiberman

Aaron Menzel
Maija & Barry Nobel

Samuel Sernovitz
Lee & 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
Boosters In Honor Of

*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

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 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

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

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In memory of our beloved father and grandfather

Sidney J. Lemer

Richard, Marty, Margot and Liza Byrne
IN HONOR OF
STEVEN WEXLER

ALL OUR LOVE,

Rena, Josh,
Elana & Jacob
Kopelman