

Journal 2025



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Journal 2025

Familial Dysautonomia Foundation
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Dear FD Families, Friends and Supporters—

Thank you for participating in the 2025 FD Journal. Your contributions support the many essential programs and services funded by the Familial Dysautonomia Foundation including top-notch medical care at the Dysautonomia Center at NYU Langone Health, cutting-edge research to identify effective treatments for FD and the many programs and services we offer to enhance quality of life for people living with FD and their loved ones.

The FD Journal is a window into our community. Glancing through the pages, one can witness special milestones and accomplishments—births, graduations, weddings and anniversaries—commemorated; family relationships—parents & children, grandparents & grandchildren; siblings, cousins and more—honored; and special friendships celebrated. Poignantly, we also see many loved ones remembered. These pages tell the story of a community that is stronger together.

Though our small-but-mighty community certainly faces more than our fair share of challenges, we also feel fortunate that many brilliant and hard-working individuals have dedicated so much of their professional lives to making the world better for people living with familial dysautonomia. Looking back over the years, there have been physicians, scientists, nurse practitioners, social workers and more—our very own FD “brain trust”, so to speak—whose work has been nothing less than transformational.

In this edition of the FD Journal, we shine a spotlight on Dr. Horacio Kaufmann, who joined the Dysautonomia Center in 2007, to work alongside Dr. Felicia Axelrod. Building on Dr. Axelrod's legendary commitment to patient care, since becoming Director of the Center in 2015, Dr. Kaufman has led the Center to even greater heights. Under Dr. Kaufmann's direction, we have seen tremendous advances in FD care, treatment and clinical research, resulting in even longer and better-quality lives for people living with FD. Just in 2024, Dr. Kaufmann and his team launched two clinical trials at the Dysautonomia Center, with each showing encouraging results in the very early stages.

Strongly committed to preparing the next generation of neurologists, Dr. Kaufmann not only stewards a robust neurology fellowship program at the Center, but perhaps even more importantly he has recruited the highly compassionate and extremely talented physician Dr. Alejandra Gonzalez-Duarte to join him as Co-Director of the Dysautonomia Center.

We are proud to dedicate the 2025 FD Journal to Dr. Horacio Kaufmann and thank him for 18 “chai” years of extraordinary service to our community.

With heartfelt appreciation for your continued support,

Faye Ginsburg
President

Lanie Etkind
Executive Director



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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 ELP1 gene to their unborn child. The misread DNA “blueprint” profoundly disrupts the normal development of the sensory and autonomic nervous systems. Infants are born unable to sense information coming from inside their own bodies.

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

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

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

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

Features of FD include:

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



OUR MISSION & HISTORY

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

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

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

The Familial Dysautonomia Foundation is proud to have funded the research that led to the 2001 discovery of the gene that causes FD. This breakthrough enabled scientists 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 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 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. In 2024, the Foundation established Tikun Therapeutics, a wholly owned subsidiary public benefit corp. whose sole aim is to accelerate drug development for FD. Among rare disease groups, ours is an amazing success story, but our mission will not be fulfilled until we achieve an effective treatment for this highly debilitating disorder.



Dear Familial Dysautonomia Community,

As we step into 2025, we are filled with excitement and optimism. This past year has been one of remarkable progress, and we are eager to build on these advancements.

In 2024, genetic therapy for FD became a reality. We launched a groundbreaking clinical trial using an antisense oligonucleotide (ASO)—a disease-modifying approach that holds great promise for changing the course of FD. This marks a pivotal step in our ongoing efforts to find a cure.

Another major milestone is the ongoing Igalmi trial, which offers new strategies for managing autonomic crises at home. We continue to enroll patients in this FDA-sponsored clinical trial and recently secured an important expansion: patients as young as 11 years old are now eligible to participate. This expansion increases access to therapies that may ease the burden of FD.

We warmly welcome the two newly diagnosed FD patients who have joined our community. Receiving an FD diagnosis can be overwhelming, but you are not alone. The FD community is strong and supportive, and the Dysautonomia Foundation is committed to ensuring that every individual has access to the best possible care and resources.

We enter 2025 with renewed determination and an unwavering commitment to our mission: improving the lives of individuals with FD through cutting-edge research, innovative treatments, and comprehensive clinical care. None of this would be possible without the support of the FD community, and we are deeply grateful for your continued trust and partnership.

As we forge ahead, we remain hopeful that each discovery brings us closer to a future where FD is more manageable—and, ultimately, people can enjoy life to the fullest.

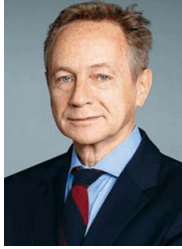
With warmest regards,

Horacio Kaufmann, MD
Director, NYU Dysautonomia Center

Alejandra Gonzalez-Duarte, MD
Co-Director, NYU Dysautonomia Center



THE TEAM AT NYU'S DYSAUTONOMIA CENTER



Horacio Kaufmann, MD



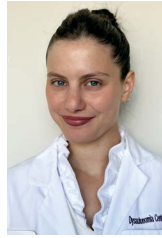
Maria Alejandra Gonzalez-Duarte
Briseno, MD



Andreana Barnett,
FNP-BC



Kaia Dalamo,
DNP, FNP-BC



Margarita Grobocopatel
Marra, MD



Juan Carlos
Lopez, MD



Patricio Millar, MD



Daniel Rebolledo
Garcia, MD



Jesus Romero-
Mera, MD



Mecky Kuijpers



Grace Nkrumah



Britney Paredes
Lopez

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



Lee-Ann Lugg



GENETIC RESEARCH

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

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. In 2001, after a decade of searching, researchers discovered the FD gene as a splicing mutation in the ELP1 gene on chromosome 9q. This finding not only sparked a flurry of interest into how the gene functions, but also allowed general population carrier testing.

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

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

Today, the FD community of researchers are pursuing several promising treatments including small molecules, anti-sense oligonucleotides and gene therapy. We are deeply encouraged by the interest of the n-Lox Foundation, which enabled us to launch a clinical trial for the ASO in one patient during 2024. This would not have been possible without the advocacy of Dr. Adrian Krainer of Cold Spring Harbor Laboratories and Dr. Horacio Kaufmann and his clinical team at NYU Langone.

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



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THE FD FOUNDATION THANKS

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and
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Barbra Waldfogel
Karen Wexler

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



**WE ARE GRATEFUL FOR
THE LONGSTANDING AND
LOYAL SUPPORT OF**

OUR CHAPTERS

CHICAGO

ISRAEL

MONTREAL

SOUTH FLORIDA

UNITED KINGDOM



To our hero,
Michael



We all adore you and are so proud of how you push yourself every day to be happy and laugh and joke around despite your challenges.

LOVE, Mom, Dad and the rest of the gang ❤️

Many thanks to the FD staff
for their constant support!





**IN HONOR OF
OUR THREE BEAUTIFUL GIRLS**

PERRY

SYDNEY

CODY

**LOVE,
MOM and DAD**



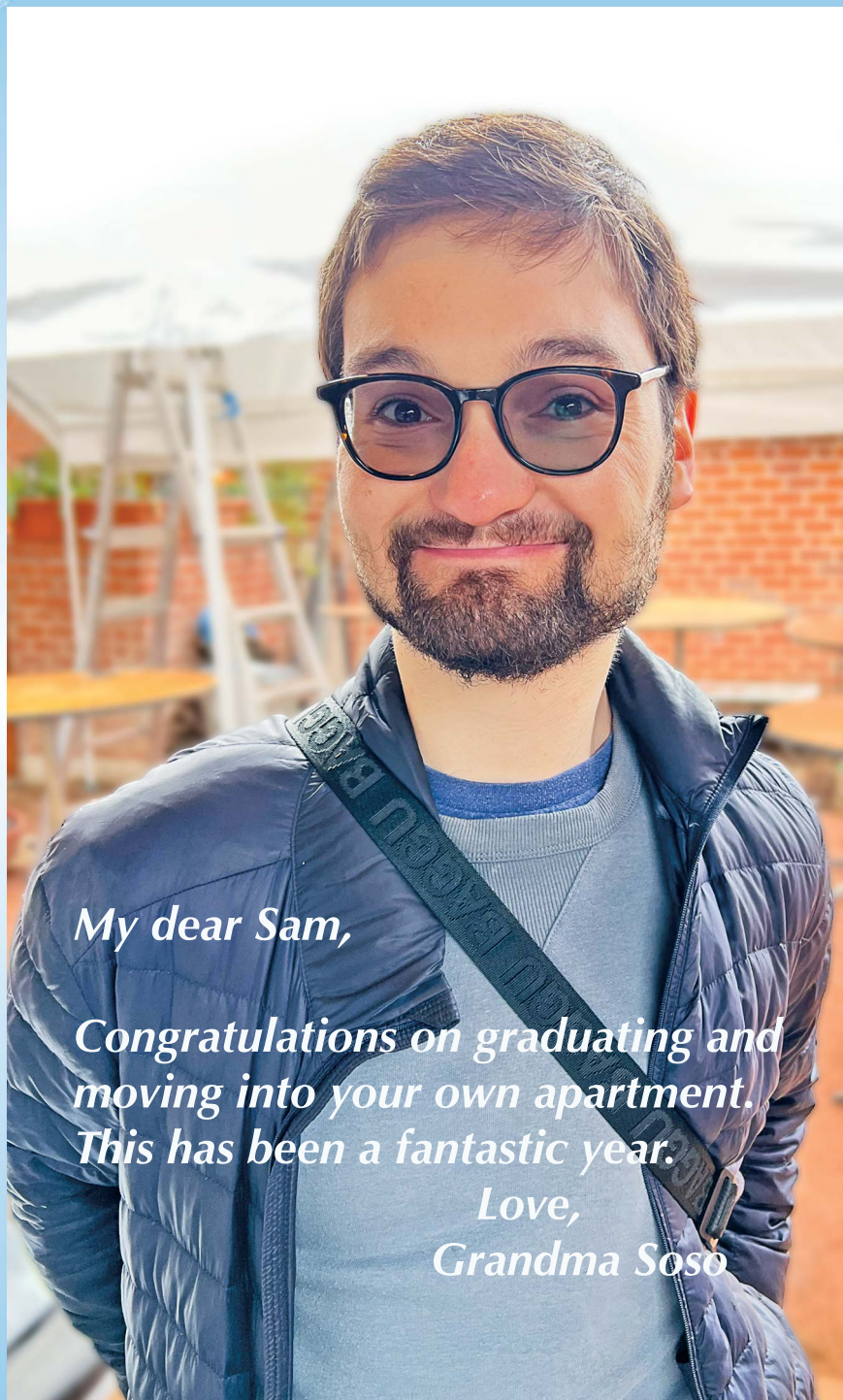
In Honor of
Dr. Kaufmann



Thank you for all you do. We really appreciate all of your hard work and dedication for the past 18 years and for helping improve the wellbeing of the FD population!

Freddi and Eddie Baranoff and family





My dear Sam,

*Congratulations on graduating and
moving into your own apartment.
This has been a fantastic year.*

*Love,
Grandma Soso*





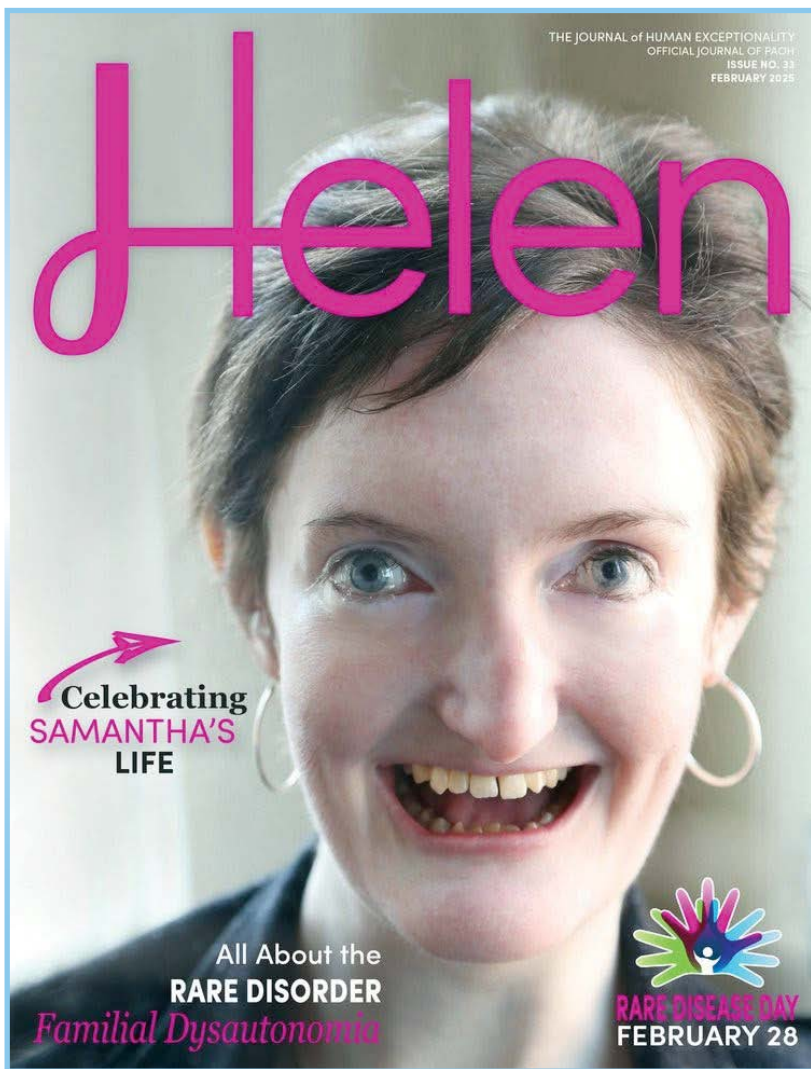
In Loving Memory of

Balfura Lemer

and

Merle Byrne





Still teaching people about FD in 2025

Our beloved Samantha Myers, z"l

1989-2022



Steven,

You know that we have always considered you our
SUPERMAN.

Christopher Reeve said it best:

*“A hero is an ordinary individual who finds the
strength to persevere and endure in spite of
overwhelming obstacles.”*



He must have known you!

You are our HERO as you inspire everyone you
meet with your upbeat inquiring personality.

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

Mom and Dad





Wishing
Steven Wexler

a happy
and healthy
2025.

Love,
Mark and Melissa
Halperin



In honor of our beautiful daughters,
Julia and Rebecca,
and to the entire FD Center for their
devotion and commitment to
the FD community.

Lisa and Jeff Newman

In Loving Memory of
our

Lauren Jamie Adler

'Who would you be?
What would you look like
Not a day goes by
That we don't think of you
We are always asking why
this crazy world had to lose
Such a ray of light
Gone too soon'

and

In honor of our awesome
children and grandchildren

Joseph, Eliana, Perry & Sammy Adler

We love you so much!!

Vivian and Gerry Adler

IN LOVING MEMORY OF

DAVID BRENNER

MAY HIS MEMORY BE A BLESSING

THE STEINER FAMILY

IN MEMORY



ANDREA LYNNE HAUBEN

FEBRUARY 2, 1984 – MARCH 21, 2009

FOREVER IN OUR HEARTS

The Hauben Family

**The Board of Directors
of the
Familial Dysautonomia
Foundation**

Honors and Thanks

HORACIO KAUFMANN, MD



For 18 “chai” years at the
NYU Dysautonomia Center
where he has made
extraordinary strides
improving and extending
the lives of
children and adults
living with FD.

IN HONOR OF
OUR CHILDREN
AND GRANDCHILDREN

JOSHUA

ADAM + LIZ

* * * * *

MADELEINE ELLE
JORDAN ISAAC

WE LOVE YOU SO MUCH
MOM AND DAD

In Honor Of

Josh Kietz

*Amy & Joseph
Perella*

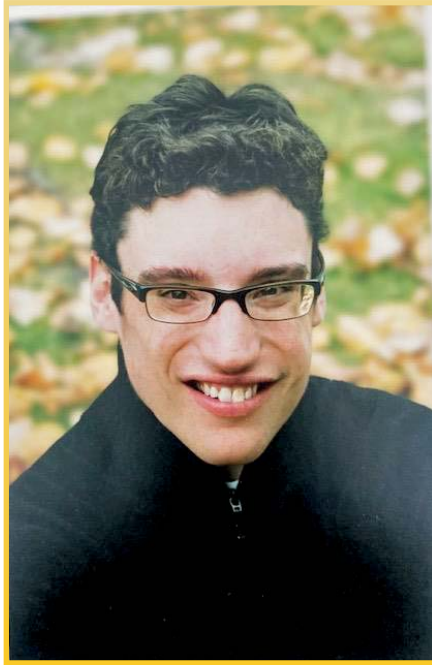


IN LOVING MEMORY
of
MY PARENTS
JULIAN and PHYLLIS LINKER
and
MY BROTHER
STEPHEN LINKER

YOUR STRENGTH, HUMOR AND LOVE
CONTINUES TO GUIDE ME

~FOREVER IN MY HEART
SUSAN LINKER

Steven Schwartzberg



Stevie,

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

Love,
Jack, Rowena and Daryl

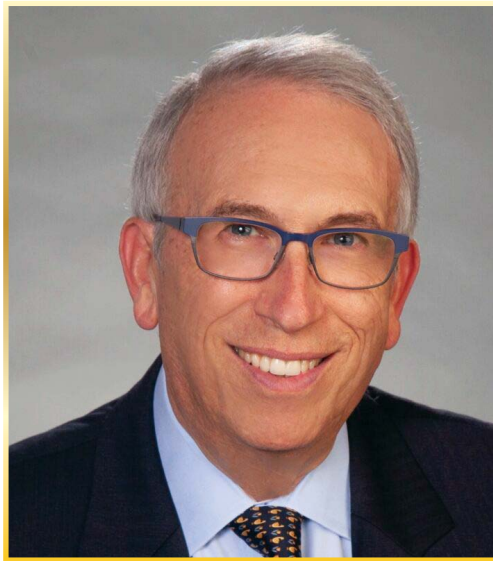
IN HONOR OF
BRIAN SOLOMONS

AND IN MEMORY OF
MARK HABERMAN

WE SUPPORT THE EFFORTS ON
BEHALF OF FD TO FIND A CURE.

JILL AND SANDY
SIRULNICK AND FAMILY

In Memory of HOWARD WEISER



Howard served on the Foundation board for an unprecedented 50 years, including a term as president.

A generous donor, leader, mentor and advisor, Howard will be missed by all.

Morgan Asinowski



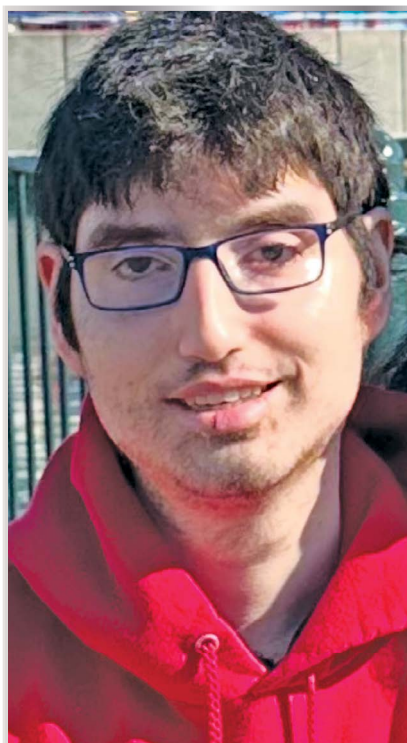
Ya got your own Pad! It's your own place, your apartment, your digs, your sanctuary, your man cave, your peds a terre, your quarters, your shelter from the storm, your place of residence, your box within a box, your kindly hovel, your accommodation, and most importantly your home away from home. It is almost as if everywhere you go ends up being where you are.

We are all so proud of you. You continue to grow and you continue to do new things and be in new places and when you meet new people, they grow to love you almost immediately. This new dependent independence can be a wonderful thing as long as you remain independently dependent on those that remain dependent on you for your smiles and your can-do attitude.

We love you and we depend on you,

Cousins Lauren, Alex, Francis, James, Lily, Sydnee, and of course Auntie Carole and Knuckles McFried

In Honor of
Michael Baranoff



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

Michael Brenner



Your smile lights up our world!
We love you,
Mom and Sarah

IN HONOR OF
MICHAEL BRENNER

IN LOVING MEMORY OF
HIS GRANDPARENTS

**ERV AND DEBORAH
BRENNER**

In honor of
Michael Brenner

our amazing
nephew and cousin.

May all good things
come your way in 2025!

With Love,

Aunt Robin, Uncle Brian,
Cousins Alex and Maddie



We were so blessed to have you as our son. You touched the lives of everyone who knew you with your warmth and kindness. Your charm and persistence made it impossible for anyone to say no when it came to raising money for FD.

We love you and miss you with all of our heart.

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

Our Scott

*They say time heals all wounds.
This one is the exception.*

*Memories of our special times together
are all we have now.*

We love and miss you beyond words.

*Harriette, Neal, Stacey, Gary,
Marnie, Jeff, Ally, Casey.*

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

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

Dr. Felicia Axelrod

In Honor of
All Those Who Work So Hard
In the Fight Against FD

Howard and Tova Weiser



*The Brenner Family thanks
The Dysautonomia Center
for their dedication and hard work!*



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

Veronica Segal

IN MEMORY OF

ADAM SCOTT GERSON

—

SUSAN AND JIM
MICHELLE - ALEXIS
SHARI AND MIKE

IN LOVING MEMORY OF

KATHERINE MERLE IRLLEN

1964 – 2006

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

For Gabi

What more can your Gma say about you.

- 1 - Beautiful
- 2 - Smart as can be
- 3 - Great ambition
- 4 - Work ethics - Supreme
- 5 - Goals - Very close to fruition
- 6 - Next step - Credentials (Wellness Coach)
- 7 - Loved by all - Especially me

Love
Gma Lois

Dear Josh,
We love you three!

Love,
Grandma & Grandpa
Anita & Stan

Josh Kietz

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

Love, kindness, caring, family.

You are truly special.

Your accomplishments inspire all of us.

We Love you !!!!

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

IN HONOR OF
THE KIETZ FAMILY

ARTHUR & MEME
PEPONIS

Friends of
Josh Kietz

IN HONOR OF
STEVE KIETZ

MEIR ROTH



***Congratulations Sam on another
incredible year.***

***All my love,
Aunt Ruth***

Our Amazing Son & Grandson



In Memory of Adam

In Honor of Jack

Forever Loved

Gail & Stan Posnack

***FOR A SPECIAL UNCLE,
BROTHER AND FRIEND***

BRIAN JAY SOLOMONS

***WE LOVE YOU SO VERY MUCH!
WE RESPECT AND ADMIRE YOUR
COURAGE, STRENGTH AND CHARACTER.***

Love,

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

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

May there one day be a cure!

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

IN HONOR OF
BRIAN SOLOMONS

AMY AND CLIFF GOLDMAN
AND FAMILY

IN HONOR OF
BRIAN SOLOMONS

WE SALUTE THE OUTSTANDING
RESEARCH BEING FUNDED BY
THE FAMILIAL DYSAUTONOMIA
FOUNDATION.

JEFFREY AND ANDREA
LOMASKY

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



Peter and his teacher Mike, recalling old times at The School In Rose Valley, Pete's elementary school where her began his love of art -- just keeping in touch after all those years!

In Honor of

Steven Wexler

Brothers are the people that teach us about life.
They teach us what it means to be kind and
care, to be fair, and know we will not always be
right. They teach us about teamwork, conflict
resolution, and most importantly they teach us
what it is to love and to be loved.

Steve,

You are our SUPERHERO!

LOVE

Stef, Jay, Ella, LJ and Ari
Bryan, Nicole and Eli

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

Wishing
Steven Wexler
a great 2025

With Love and Admiration

All of the Greenlands

In Honor of
Steven Wexler

*“a hero is an ordinary individual who finds
strength to persevere and endure in spite of
overwhelming obstacles.”*

-Christopher Reeve

Your courage, strength and perseverance
make you a hero to us!

We love you,
The McAuliffe Family

IN HONOR OF
STEVEN WEXLER

**AND THE WEXLER
FAMILY**

**LESLIE AND MICHAEL
ROSENBERG**

Lauren Adler

Dear Lauren,

The hole in our hearts grows deeper with every passing year. Yet the memories remain to remind us of your endless love, contagious smile, and the wonderful times we had together. The tears may have stopped, but we miss you more and more. Life is just not the same without you.

With all our love,

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

To my amazing Grandson,

Michael Baranoff

I'm so proud of you and all your accomplishments. You're such a delight to be with. I feel so lucky to have a Grandson as special, bright, and handsome as you are.

All my love always,

Grandma Prissy

Michael Baranoff,

we love you!

**Amy, Scott, Mia,
Rachel and Jacob**



In honor of our two beautiful daughters!

**Frances Emily
Natalie Rose**

We are so proud and love both of you so much

XOXO

Mommy & Daddy



In honor of my lovely niece,
Frannie Cohen!
You bring so much love and laughter to our family!

Love,
Your Uncle Ellis

Thanks to all at the
Dysautonomia Clinic
for your expertise and
guidance over the years.

Thanks to you, Aaron has,
and continues to, overcome
so many challenges!

Diane & Ron
Menzel

IN MEMORY OF OUR
SON & BROTHER

ELLIOT LOUIS GOLDBERG

JUNE 1973 - JULY 2020

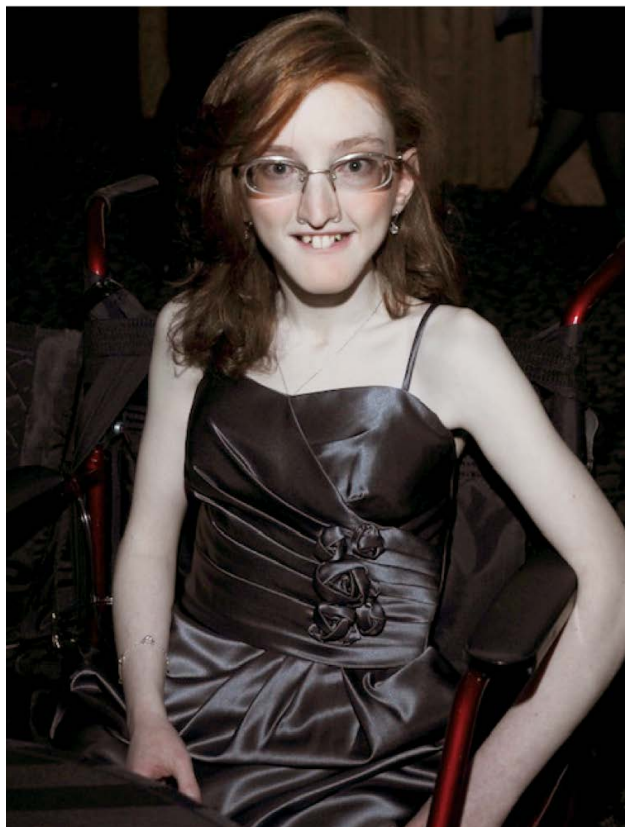
ALWAYS IN OUR HEARTS,
FOREVER AN INSPIRATION,
HE TURNED STRUGGLES
INTO STRENGTH.

WITH LOVE,

THE GOLDBERG FAMILY

Our dear Jamie,

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



All our love ... always,

*Mommy & Daddy
Jessica, Matt, Leah & Emma*

In loving memory of our precious

Jonathan Michael Gordon

March 11, 1990 – October 3, 2008

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

You are in our hearts forever!

Love,
Debbie, Daniel,
Benjamin, Shayla,
Mila, and Mason Gordon

In Honor of Horacio Kaufmann

Your dedicated ability to
Combine medical care and research
Has benefitted our FD community enormously.
With my great appreciation,

Felicia Axelrod



In Honor of
Uncle Josh



Lots to look forward to in 2025! A wedding, a month in North Carolina and who knows what else is in store! We love you so much, Josh! And we are beyond proud of you! Keep those FaceTime check-ins coming!

Lots of XOXO,
Aunt Amy & Uncle Mike
and your whole NC family!

Jordan & Leslie
Mayer

Honoring

Joshua Kietz

To Our Dear Grandson

EZRA KRESS

We know that 2024 was a difficult year for you but you have come out on top of it all. We hope 2025 will be a better year for you and your family.

We love you and are
very proud of you,

Grandma & Grandpa

In honor of
Epic Ezra Kress

We love you even if we're
terrible at your quizzes!

Love,

Lisa, Brian,
Shayna and Ari

IN LOVING MEMORY
OF

PHYLLIS,
JERRY,
AND
STEPHEN
LINKER

JEAN AND STEVE ANREDER

Song of Innocence

F.D.

Having F.D. has given me
An outlook on the world
Given me humility and a noble look
Through heaven I look with happiness

Always looking on the bright side
Never giving up the glorious hope
Praying, wishing for a cure
Never losing faith never giving up fighting

Fighting between me and my disease
Seeking wonderful victory over my troubles
Finding ways to overcome my problems
Searching in the wilderness of my mind

To find solutions to my disease
Receiving help when I need it most
Laying down when having excruciating headaches
Watching television calming my blood pressure

Forgetting my troubles, forgetting my worries
Hoping with every step I take
Moving on forward day by day
Each day with a new beginning

by Zak Rosen 2009

In Memory of Zak Rosen (1992-2010)

In Loving Memory of
Evan Rosenthal



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

With love,



Susan and Debbie and Joan and Stephanie
and our families

IN MEMORY OF:

THE ROSENTHAL MEN

RICHARD DAVIS ROSENTHAL

EVAN ROBERT ROSENTHAL

SETH ANDREW ROSENTHAL

ALWAYS IN MY HEART,

LOREN ROSENTHAL

IN HONOR OF

BRIAN SOLOMONS

YOUR COURAGE AND STRENGTH
ARE AN INSPIRATION

LYNDA AND HAL KATZ

To Sheryl & Scott
Haberman

In Honor of All That You Do

Randy & Jay Raubvogel

In support of our friends,

The Habermans

and

The Wexlers

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

Karen and Steven Hess

BRIAN SOLOMONS
&
STEVEN WEXLER

WITH FRIENDS
SURROUNDING YOU,
THERE IS ALWAYS HOPE!

ELLEN & BRUCE BELSKY

IN HONOR OF
BRIAN SOLOMONS
AND
STEVEN WEXLER

**WISHING YOU THE BEST OF HEALTH
AND HAPPINESS ALWAYS!!!**

JOANIE & DON FISHER

IN HONOR OF PETER SONENSHEIN



In the photo, Pete is with his nephews Sam and Ari and they are surrounded by just a few of Peter's wonderful paintings. As his uncle, aunt and cousins, we love to be with Pete in person and are delighted to have some of his fantastic artwork at our home. We are grateful to the Dysautonomia Center at NYU Langone for helping him to survive despite his disease and we hope to be with him for decades.

Much love to Pete, his parents (Jennifer and David), his sister Emily and her husband Judah and their boys Sam and Ari, and a big thank you to the FD Foundation.

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

Sending love to all
the Sonensheins

The Houghtons
and Konrads

In memory of our
giant among men,

Howard Weiser

He will be sorely missed.

The Sonenshein Family

In Honor of

The Wexler Family

Julia & Charles
Badlato

In Honor Of

STEVEN WEXLER

“A Real Life Superhero”

Best wishes for a happy
and healthy year.

THE ESTEROW FAMILY

IN HONOR OF

THE WEXLER FAMILY

THE PETERS FAMILY

IN HONOR OF
STEVEN WEXLER

FROM
MICHAEL & AMY
KOPELMAN

Steven~

We are so proud of you!

You are such an awesome person!

Love you~

The Segal Family

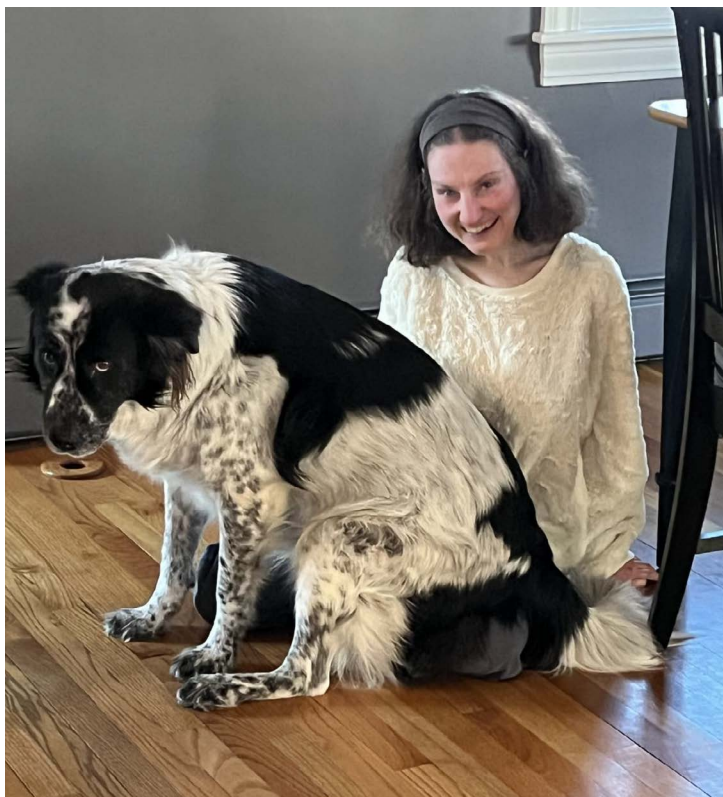
**IN HONOR OF
STEVEN WEXLER
& FAMILY**

STACEY & NEIL STARKMAN
& FAMILY

In honor of our wonderful daughter and sister

SARAH ZUCKER

Love, Mom, Dad, Josh, Kate, & Shelly (she's the furry one)



Many thanks to Dr. Kaufmann for everything he's
done for us and for the FD community!

In honor of the Adler Family

WE ARE PROUD
TO SUPPORT
THE FOUNDATION'S WORK

REYNA and PIERRE GENTIN

In Honor of
Our Good Friends

Vivian & Gerry Adler

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

Bonnie and Russ Mannis
Caron and Steve Gelles



Jennifer Taylor Bell

*Time Goes on but Memories Live Forever
Always in our Hearts*

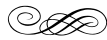
In Loving Memory of

Scott Fass

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

You are missed every day

Aunts Adele Fass
and Barbara (Fass) Young



In Loving Memory of
our wonderful cousin

Scott Fass

We miss you very much.

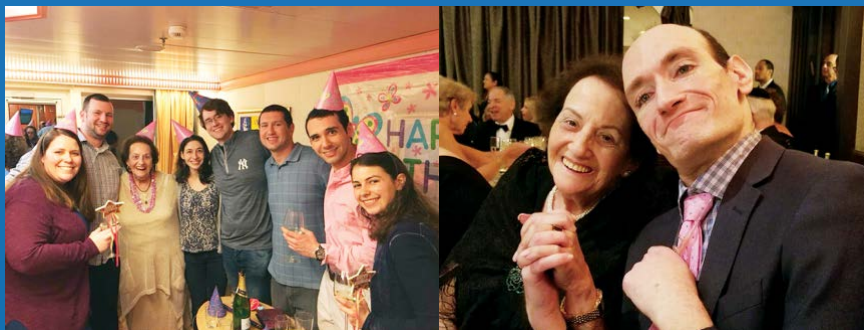
Cousins Sue Lipkowitz,
Marcel Lipkowitz
and Robert Fass

In Loving Memory of

Scott Fass

Always Our Teacher

Sandy and Sandy Goodman



*In Loving Memory
of
Maryon Weill
&
Scott Fass*

Your courage and dignity in the face of adversity
is an inspiration to all of us.

Forever you will remain in our hearts.

We miss you both.

Elena, Barry, Andrea, Steve
Matt, Kelly, Joey, Marissa,
Andy, Jon, and Charlotte



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

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

*To honor the memory of
Benson and Pearl
Ginsburg:
Truly a couple for the ages*



*Mark and Susan
Hamilton*

In 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



mp With Lots of Love mp
mp

Bobbi, Jason & Kevin

In Loving Memory of Our Son and Brother

David Halle



After 64 years, we remember and miss you,

Mom & Esther & Linda

And those who wish they had known you,

Richard, Rachel, Gabriel & Devin, Ben & Annie

Michael & Jack & Sloane

GABI

*If you could only see yourself
as we see you. Your beauty,
your kindness, your empathy
towards others and your sense
of humor just makes us proud.*

We love you!

Mom & Dad





Mitchell
rocks our
world
forever



Wishing everyone a great 2025
Love from the Josephs

FOR MY GRANDSON,

JOSH KIETZ

TO THOSE WHO

WORK SO HARD

TO HELP US

DREAM THE POSSIBLE

DREAM...

FOR MY GRANDSON, JOSH

AND ALL THE FD KIDS...

**THANK YOU
SO VERY MUCH.**

WITH LOVE AND HOPE,

GRANDPA AL AND GLORIA

In Honor of

EZRA KRESS

You are the sweetest and bravest
young man that we know.

Your consideration and sensitivity
toward everyone is so very special.

Your friendliness and smile
make you amazing.

You are truly EPIC!!!

Love,
Aunt Sherry and Uncle Ira

***Congratulations
Matthew Kutner***

On Making It 27 Times Around the Sun!



We Continue to Stand in Awe of You!

Love, Mom & Dad

**And we are so grateful to Dr. Kaufmann
& all the staff at the Dysautonomia Center
for their support and expertise.**



Sam and Bebe,
We are so proud of the adults you have
become. We miss having you home but
love that you are living your lives inde-
pendently!
Sam,
Congratulations on graduating college!

All our love,
Mom and Dad

Rebecca,

We love every minute of our time with you.

Just keep doing what you're doing and

HAVE FUN !!

We are so proud of you and we love you so much.

Sue and Rich and Family





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

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

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

You are Forever in Our Hearts

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

Thank you, Reni, for being you. More than one life has breathed easier because you have lived. We talk about you regularly and you will always remain a part of our family.



RENETTE MÉROSE SHAFIQ-BERGER

October 8, 1952

October 28, 1984

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

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

TAMAR JACOBS
ADDY AND AURIANNE

IN HONOR OF
BRIAN SOLOMONS
AN INSPIRATION TO US ALL



IN LOVING MEMORY OF
DAVID SOLOMONS
AND
MARK HABERMAN

THE SOLOMONS
&
HABERMAN
FAMILIES



IN MEMORIAM

STANLEY STRELISKER

BELOVED HUSBAND, FATHER,
GRANDPA, ZADIE

1929 - 2025

BARBARA, STEVE, ADAM, LIZ,
JOSH, JORDAN AND MADDY

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

Experience the Future Today

In Honor of
Steven Wexler

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

With love for 2025 and beyond

Carol Weissman
Richard Kopelman

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

OUR GRANDAUGHTER

SARAH ZUCKER

We've used all the superlatives in past journals. It's difficult to find additional words (even after consulting a thesaurus) to describe how much we love and admire her for her determination and success.

And for being Sarah!

Gramma and Gramps

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

*Nina & Brian Hirshman
and Family*

In memory of
Zoe's and Sydney's brother

ZACHARY

With love,
Steven, Naomi and Sam

In Honor of
Michael Brenner

Nicky, Priscilla and Harold

In Loving Memory

*To our most
beautiful
wonderful girl*

**Falon
Bromberg**

*From
Mom, Dad
& Philip*



IN HONOR OF

FRANNIE COHEN

OUR INSPIRATION

THE RAFFLER FAMILY

In Memory of

JILL COPLIN

Beloved Daughter and Sister
1966-1977
&

DIANE COPLIN LIPSITZ

Beloved Wife, Daughter, Sister and Aunt
1968-2010

The Coplin Family

IN LOVING MEMORY OF
JILL ANNE COPLIN
AND
DIANE COPLIN LIPSITZ
THE HOMER FAMILY

In Loving Memory of
Maximiliano and Lionel Donzis

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

***Forever Remembered,
Forever Missed***

Scott Fass

***Geri, Harold, Jared,
Mariel, Blake, Spencer, Cori,
Alex, Payton, Lexi & Bernie***

In tribute to:

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

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

Lanie Etkind, Executive Director

IN MEMORY OF

SY FEIT



SANDY Z" L
AND
LARRY GREEBEL

IN LOVING MEMORY
OF MY NIECE

JAMIE GOLDBLAT

GAIL GOLDBLAT



In honor of Evan Kaplan
Resilient, Courageous, Kind & Compassionate

In Honor of my Grandson

EVAN KAPLAN

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

IN HONOR OF
HORACIO KAUFMANN, MD
FOR HIS EXTRAORDINARY
PATIENT CARE.

STEPHEN AND SHELLY
WINTERS

Josh,
You are the best brother
and uncle in the world!!
We love you!!!

- The Kietzs

JOSH KIETZ IS:



WE LOVE YOU!

Aunt Pam, Uncle Jordan
& Cousin Lauren

Dear Josh...

To the **GREATEST**
Drum Tech in the World!
We love you...

Aunt Ronni and
Uncle Phil

Go Josh!
We are so proud of you

**Dawn, Patrick,
Brendan and Owen**

In Honor of my grandson

Mitchell Kofsky

and in recognition of

The Dysautonomia Foundation

Sandra Kofsky

With tremendous love for our grandson

EZRA KRESS

We celebrate your 27th birthday with joy,
inspired by your spirit, love, and courage.

Saba and Savta, Bill & Beverly Lebeau

In Honor of the
amazing and accomplished

Rebecca Newman

With love and admiration,
Cousin Wendy

In Loving Memory of My Sister

Carly Allison Posner

DEBBIE SCHOENHOLZ

May 29, 1957 - January 24, 2024

The Dysautonomia Foundation
really helped Debbie enjoy life.

Kaia Dalamo NP,
Dr. Gonzalez-Duarte, and Dr.
Millar maintained communication
with the Grandell Nursing Facility
and did their best to help Debbie.

Debbie, you are a true
star who made life as
pleasurable as possible.
We will miss you so much.

God bless you.

The Schoenholz Family



In Honor of

Brian Solomons

and in Loving Memory of

Mark Haberman

*I proudly support the work on behalf
of all those afflicted with FD*

Joan Haberman

IN HONOR OF

BRIAN SOLOMONS

PERRY AND PENNY BERGER
AND FAMILY

IN HONOR OF

BRIAN SOLOMONS

SHERRIE AND MITCH
MAYRSOHN

In honor of
Brian Solomons and family

with best wishes for a happy
and healthy new year.

Love,
The Siskind Family

IN HONOR OF
BRIAN SOLOMONS

IN SUPPORT OF OUR FRIENDS
THE HABERMANS

SHARON AND MICHAEL
TYNER

In Honor of
Brian Solomons
&
Steven Wexler

Sheree & Jeffrey Markowitz
Bette & Jeffrey Rubin

In honor and celebration of
our incredible friend

PETER SONENSHEIN

With love from the
Hoxter-Levine family

Debi and Ron
Andrew and Heather
Deanie, Gary, Sylvie and Teddy

IN HONOR OF
A WONDERFUL FRIEND AND
TALENTED ARTIST

PETER SONENSHEIN

WISHING YOU THE BEST
ALWAYS...

FERN AND STEVE ROTFELD

*In honor of our
granddaughter*

Simi Steiner

*who fills our lives with
music and love.*

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

Shakespeare, Twelfth Night

With admiration and love for

Steven Wexler

and the entire
Wexler Family

Ellen Kessler

In Honor of
Steven Wexler

Best wishes for a
healthy year ahead

Rita & Richard Wein

*In Loving Memory of
Lauren Adler
Karyl and Asher Miller*

*In Loving
Memory of
Florence
Lewis
Baker*



*Barbara
& Peter
Sperber*

IN HONOR OF MICHAEL BRENNER

IN MEMORY OF DAVID BRENNER

COUSINS LINDA & BOB MAZUREK

IN LOVING MEMORY OF
SCOTT FASS

ELAINE & BRIAN RAPPAPORT



*Judy Fettman
Dreyfus*

1970 - 2020

We miss her terribly.

*Love,
Mom & Dad*

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 Honor of

Gabi Jassie

With Love, Suzie

In Memory of
Louis Kaley
Roslyn Kaley
Alisa Robin Kaley

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

Stefanie Kaley Linakis

Horacio Kaufmann: a CHAI Performance Doctor

We would like to give CHAI Regards to Dr. Kaufmann for his CHAI Fidelity work over the the last eighteen years. We hold him in CHAI Esteem and know he is a CHAILY Effective doctor. In conversations with him he comes across as a pretty modest man but it is CHAI Time that he is given CHAI Praise for his CHAI Profile work with his CHAI Maintenance Patients.

Yours CHAILY Appreciatively
Florence, Nelson, and Morgan Asinowski

Dear Tio Josh,

Thank you for the being the best uncle and taking the best care of us! We love playing with you - please keep sharing all of your toys with us!!

Love,

Maddy and Jordan Kietz

For Our Wonderful Cousin
Josh Kietz!

Sending Big Love from Massachusetts!!
The Maimans and The Wanzers

Dear Josh,
Keep on truckin'!
We love you,
Judy & Alan Friedman

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



IN HONOR OF
THE NEWMAN FAMILY

PHYLLIS HONIG

IN MEMORY OF
DR. ROBERT PORGES

EUGENE LIND



*Chanie, we will always love you -
to the moon and back!*

*You made us laugh, smile, and warmed our hearts
with your kindness.*

We miss you every day!

Love,

Mommy, Daddy, Deborah, Gershie & Baby Chanie

Dr. Kaufmann, we are grateful for your
dedication over the past 18 years and are
excited for the future.

The Rappaport Family

Michelle, we are in awe of you. You've come
so far these past few months and we hope
it's just the beginning and that 2025 will be
an amazing year for you.

Love, Mom, Dad, Jessica, & Aspen



In memory of
Stevie Schwartzberg.
He lit up the world.

Patte and Rabbi Irwin Huberman

SAM SERNOVITZ

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

Love,
Mom, Dad, Daniella, Eden and Peaches

*In honor and in memory of Dear Kyra,
a joy to all those who knew her.*

Cindy and Peter

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

WITH LOVE,
ELLEN AND STEVEN WOLF

IN HONOR OF
THE WEXLER FAMILY
AND THEIR SUPPORT OF
THE FD FOUNDATION

THE EDELMANS

Wishing you great health
and much love, Steven.

Love,
The Gewirtz Family

LISA AND LON GOLDSTEIN

In Honor of
Steven Wexler
and his Family.

Dayle and Carl

IN HONOR OF
EVAN WHITE
AND
EZRA KRESS

DAVID & BETTY ROTH

FRIENDS IN HONOR OF

Haberman & Wexler Families

Jodie & Bruce Cohen

Josh Kietz

Kerri & Anthony Brancato
Brenda Koblick & Jeffrey Hertz
Randi & Harry Weinberg

Sam Landau

Betsy Newberry & Ken Friedrich

Aaron Menzel

Maija & Barry Nobel

Rebecca Newman

Laury Hamilton

Jack Posnack

Jill & Andrew Feldman

Brian Solomons

Dick Allerton & Cathy Stewart
Paulette Kirschenbaum
Pace Cares Corp
Robin & Richard Reubenstone
Eric Rothfeld
Dawn & Alex Seaman

Peter Sonenshein

Mark Anderson & Susan Tachau

FRIENDS IN HONOR OF

Steven Wexler

Pamela & Bruce Azus
Anthony Bartone
Yvette & Richard Chipman
Ellen & Bill Enco
The Dolgin Family
Driftwood Day Camp, LLC
Lisa Enloe & Sandra Tullius
The Friedman Family
Susan & Stu Goldman
Michael Gorin & Nancy D. Lieberman
The Greene Family
Rick Guerra
Angela Gustavson & Family
Jo-Ann Heinisch
Susan & Jonathon Held
Florentina & Monroe Jacobson
Myrna & Morty Kanner
Francis McGrail
Louise & Brian Rind
Sherry & Marty Silver

FRIENDS IN MEMORY OF

Lauren Adler

Laura & Eric Green

Charles Eckstein

Etti Zeldis

Kathy Ann Fishman

Alvin Fishman

Samantha Myers

Judy & Harold Meyer

BOOSTERS IN HONOR OF

Morgan Asinowski

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

FD Center and Foundation

The Kristof-Yazer Family

Horacio Kaufmann

Elise & Robert Goldblat

Josh Kietz

Matthew Bernardini
Amy & Randy Levine
Jim Murphy
Marci & Dan Settle
Lorraine & Alan Spector
Gloria Zapin

Rebecca Newman

Lucille Newman & Family
Reichman Family
Edith Rubin

Brian Solomons

Michelle & Lennert Gruszecki

Peter Sonenshein

Laurie & Phil Rubin

BOOSTERS IN HONOR OF

Steven Wexler

Ellen & Bill Enco

Gail & Mark Fialkov

Carol Gottesman

Susan & Marc Harvey

Stuart Plotkin

BOOSTERS IN MEMORY OF

Lauren Adler

Susan & Bruce Schneider

Debra & Howard Schub

Samantha Myers

Susan & David Cohen

Jamie Goldblat

Karen & Rich Heller

Naomi Walker

Ruth & Ben Walker

The advertisement features a light gray background with a subtle floral pattern of small black flowers and stems. The text is centered and uses a mix of serif and sans-serif fonts. The logo 'Forever DEVOTED' is at the top left, with 'Forever' in a large, elegant script and 'DEVOTED' in a smaller, all-caps serif font. The main text is a paragraph of questions, followed by a call to action, and then contact information at the bottom right.

Forever
DEVOTED

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

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

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



THE FD FOUNDATION REMEMBERS



MICHAEL ERIC FISCHEL

8/12/80 – 2/4/24



THE FD FOUNDATION REMEMBERS

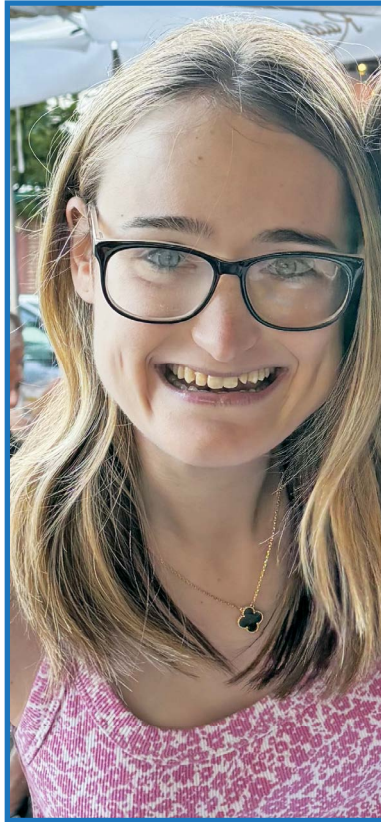


DOVI PORUSH

11/13/97 – 10/12/24



THE FD FOUNDATION REMEMBERS



KYRA BROOKE SLIVE

8/24/00 – 8/4/24



**THE FD FOUNDATION
REMEMBERS**

FAMILY AND FRIENDS



GARY COHEN

DAVID FAINBLATT

ALBERT FINK

SANDRA “SANDIE” JABENIS

ARNOLD SCHARF

LINDA SCHOENHOLZ

STANLEY STRELISKER

ROBERT VEXLER

HOWARD WEISER



**To all who contributed
to the 2025 Journal**

THANK YOU!

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





**FAMILIAL
DYSAUTONOMIA**
FOUNDATION, INC



**FAMILIAL
DYSAUTONOMIA**
FOUNDATION, INC

**MILIAL
SAUTONOMIA**
NDATION, INC



**FAMILIAL
DYSAUTONOMIA**
FOUNDATION, INC



**FAMILIAL
DYSAUTONOMIA**
FOUNDATION, INC



**FAMILIAL
DYSAUTONOMIA**
FOUNDATION, INC

**MILIAL
SAUTONOMIA**
NDATION, INC



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NDATION, INC



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FOUNDATION, INC



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DYSAUTONOMIA**
FOUNDATION, INC

**MILIAL
SAUTONOMIA**
NDATION, INC



**FAMILIAL
DYSAUTONOMIA**
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IN HONOR OF
STEVEN WEXLER

ALL OUR LOVE,

Rena, Josh,
Elana & Jacob
Kopelman