The Dysautonomia Foundation is a 501 (c)(3) non-profit public charity supporting medical treatment, research, public education and social services on behalf of people afflicted with familial dysautonomia (FD), a hereditary neurological disease.
FD Fact Sheet

Name of disease: familial dysautonomia (FD), also known as Riley-Day Syndrome
Carrier frequency in Ashkenazi Jews: 1 in 27
Carrier frequency in the general population: unknown
Age of onset: birth

Symptoms: FD causes dysfunction of the autonomic and sensory nervous systems. It is a progressive disease. Symptoms and severity vary in each patient. Symptoms include:

- Absence of overflow tears / corneal drying
- Poor suck at birth
- Drooling
- Swallowing and feeding problems
- Hypotonia / poor muscle tone
- Short stature
- Delayed developmental milestones: motor, language, social
- Inappropriate temperature controls
- Wide swings in blood pressure
- Gastro-esophageal reflux
- Frequent lung infections / pneumonias
- Decreased or no reaction to pain and temperature
- Episodic vomiting
- Excessive sweating
- Biotchy reddening of skin with excitement and/or feeding
- Smooth tongue / lack of taste buds
- Spinal curvature
- Poor weight gain and growth
- Impaired renal function
- Osteoporosis and osteopenia
- Fainting and cardiac arrhythmias
- Sleep apnea
- Restrictive lung disease

What is the basis of disease: Inefficient gene splicing results in decreased production of a vital protein called IKAP. This protein is an essential component of a complex that aids in expression of multiple other target genes that are critical for growth and development of the sensory and autonomic nervous systems as well as their function.

Treatment or management: At present, only supportive treatments are available. Supportive therapies include topical lubrication of the eyes and medications to maintain and regulate cardiovascular, respiratory, and gastrointestinal function. Surgical interventions include fundoplication, gastrostomy, spinal fusion, and tear duct cautery. Various therapies are used to promote strength and speech development.

Carrier testing: Carrier testing is available for the two most common mutations. All patients have one or two copies of a single splicing mutation; over 99% of cases of FD in the Ashkenazi Jewish (AJ) population have two copies of this splicing mutation. A second mutation paired with the AJ splicing mutation accounts for all other cases in the AJ population. A third mutation from a non-Jewish parent, again paired with the AJ splicing mutation, is responsible for a single case of FD.

Other testing information: Carrier screening is based on DNA analysis. Screening is 99% accurate for the AJ population.

Current research: Basic scientific research focuses on understanding the splicing defect and the role of IKAP in order to develop improved therapies. Researchers are constructing mouse models to further this aim. Clinical investigations include assessment of disease progression, assessment of cardiovascular, renal, ophthalmologic and respiratory complications and clinical trials of new medications and additional supportive therapies.
The Dysautonomia Foundation 63 years of care, treatment, research and advocacy for the FD population

The Dysautonomia Foundation, Inc., founded in 1951, is a registered 501(c)(3) nonprofit charitable organization. Our mission includes supporting medical care, scientific research and public awareness for the benefit of people afflicted with, and at risk for, familial dysautonomia (FD).

Major Accomplishments
- Established the world’s only treatment centers dedicated exclusively to FD
- Established the world’s only clinical research laboratory focused on FD
- Endowed the world’s only two professorships that focus on FD research and treatment
- Largest source of funding for FD research (more than government, private industry, or nonprofit organization)
- Funded treatment that has increased life expectancy, dramatically reduced morbidity and improved quality of life for FD patients.
- Funded research that led to the understanding of the disease as a neurological condition.
- Funded research that led to discovery of the FD gene.
- Funded research that led to general population carrier screening, resulting in a significant reduction in the birthrate of new FD cases.
- Advocated for government recognition of FD as a developmental disability.
- Advocated for ACOG to require doctors to inform patients of the risk of FD and need for genetic testing.
- Advocated for NIH to provide greater focus and funding for FD research.

Major Initiatives

Funding Clinical Care  
The Dysautonomia Foundation supports clinical medical care for people with FD by:
- Maintaining the Dysautonomia Treatment & Evaluation Center and the Dysautonomia Clinical Research Lab at New York University Langone Medical Center;
- Maintaining the Israeli FD Center;
- Sponsoring public awareness and social services projects.

Funding Scientific Research  
The Dysautonomia Foundation supports research studies into FD and the FD gene. Basic scientific research and clinical medical research regarding FD is supported at a number of prestigious hospitals and universities.

Supplying Informative Material  
The Dysautonomia Foundation provides a continual flow of information to families, the medical community and other lay and professional persons who request medical, educational or promotional material concerning FD.

Advocating for the FD Population  
The Dysautonomia Foundation works with the medical community, national organizations and government entities for the benefit of people with FD.

FD Treatment

UNIQUE CENTERS OF EXCELLENCE
OFFER TREATMENT FOR FAMILIAL DYSAUTONOMIA

New York University Langone Medical Center, New York  
Felicia B. Axelrod, MD • Horacio Kaufmann, MD  
Lucy Norcliffe-Kaufmann, PhD

Sheba Medical Center, Tel Hashomer, Tel Aviv, Israel  
Dr. Ori Efrati

Familial Dysautonomia is an Ashkenazi Jewish genetic disease present at birth that causes dysfunction of the autonomic and sensory nervous systems. One in 27 individuals of Ashkenazi Jewish decent is a carrier of FD. In 2001, carrier and prenatal testing became available, helping to reduce the number of children born with FD. Yet new cases of FD are identified every year, and all people afflicted with FD require extensive medical treatment.

One of the most important accomplishments of the Dysautonomia Foundation is the establishment of dedicated treatment facilities in the U.S. and Israel. These facilities serve as centers of excellence for medical care and research specifically for the benefit of FD patients. The Dysautonomia Center, located at the NYU Medical Center in New York City, and the Israeli FD Center, at Tel Hashomer / Sheba Hospital in Tel Aviv, are both funded by the Dysautonomia Foundation.

The NYU Dysautonomia Center is the only such facility for FD in the United States. It is co-directed by Dr. Felicia Axelrod and Dr. Horacio Kaufmann. Dr. Axelrod, the world’s foremost authority on FD, is a professor of Dysautonomia Treatment and Research in the departments of Pediatrics and Neurology at NYU School of Medicine. Dr. Kaufmann, one of the world’s foremost authorities on all forms of dysautonomia, leads the Center’s clinical research program and has appointments in the departments of Neurology, Medicine and Pediatrics. The staff at the Center provides comprehensive treatment services through acute care, periodic evaluations and personalized treatment plans.

The NYU Center works closely with the Israeli FD Center directed by Dr. Ori Efrati. Both FD Centers conduct clinical research, provide ongoing treatment, and consult with physicians treating FD patients all over the world. Current projects at the Centers include research into the underlying mechanisms of FD and investigation of new drugs which could alter the genetic error that causes FD or alleviate some of the life-threatening symptoms.

Because of the incredible dedication and expertise of the doctors working at the NYU and Israeli centers, and due to the over sixty years of support from the Dysautonomia Foundation, FD individuals, who once only had a 50 percent chance of reaching age five, now have dramatically improved quality of life and significantly increased life expectancy. In fact, children recently born with FD are projected to have a 50 percent chance of reaching age forty. The Dysautonomia Foundation is proud of the accomplishments of the Dysautonomia Center, and of the FD patients whose improved quality of life has enabled many of them to pursue careers, live independently, and even marry and have children. However, there is still much work to be done to ensure that all children with FD achieve adulthood and that all adults with FD achieve an improved quality of life. Additional research is necessary for the development of definitive treatments. This is why continued support of the Dysautonomia Foundation is crucial. For more information about FD, please contact the Dysautonomia Foundation at 212-279-1066 or info@famdys.org.
Pursuing our Goals

Enhanced care and new therapies for FD

The enduring goals of the Dysautonomia Foundation are to provide the highest level of medical treatment, research, social services and education for the benefit of people with familial dysautonomia (FD).

Our two endowed FD professorships are primary examples of the realization of these goals. The endowed Felicia B. Axelrod Professorship in Familial Dysautonomia Research, held by Horacio Kaufmann, MD since 2007, along with the endowed professorship held by Felicia B. Axelrod since 1990, insure that there will always be at least two professors at the NYU School of Medicine who devote their work to FD treatment and research. Both Dr. Axelrod and Dr. Kaufmann devote their full time and attention to dysautonomia treatment and clinical research in an effort to provide the highest level of medical care to people with FD.

In 2007, the Dysautonomia Center was completely remodeled and expanded. The Center, located at NYU Langone Medical Center, is the focal point of academic activity, treatment and research. Since then, our team of doctors and research scientists has begun several initiatives focused on improving the lives of people with FD. Patient exams have been enhanced with more sophisticated and thorough testing, yielding vital information that helps shape each patient’s individual treatment plan. All data obtained in the exams, treatments and clinical investigations are used to create individualized treatment plans and are compiled and analyzed to identify long-term trends and unravel the mysteries that surround the underlying mechanisms and progression of FD.

The Center also has a rotating Dysautonomia Fellow in the Department of Neurology which is filled annually by a medical doctor and researcher who learns the intricacies of FD under the guidance of Drs. Axelrod and Kaufmann. Upon completion of the fellowship, the doctor returns to the wider medical community with an advanced understanding of FD, thus spreading FD awareness and expertise far beyond the walls of the treatment center.

In 2013, we continued to distribute $1 million in funding for scientific research projects, that was committed in 2012 to be dispersed over two years. These projects, taking place across the United States, Europe and Israel, focus on better understanding of the FD gene, development of genetic therapies, the creation of an improved animal model of FD, and methods for identifying drugs and compounds that may be useful in treating FD. Research into the optic nerve, gait, respiration and blood pressure problems in FD offer great hope for better therapies and, in turn, better lives for people with FD. Progress has been encouraging.

Since 2010, a number of clinical trials have been conducted with drugs and compounds never before used for the treatment of FD. In this time, Foundation-funded advances in FD clinical research have been published in over 29 papers in prestigious journals such as Neurology and Brain, and our understanding of the mechanisms underlying FD has progressed substantially.

All of these accomplishments were made possible by the strong and generous support of the FD community. Your contributions make these and other important projects possible, and your support provides hope for all FD families.

The pages of this Journal highlight the names of some of the families, donors and people with FD who have inspired us in 2013. The Dysautonomia Foundation extends its sincere gratitude and congratulations to everyone who has been involved with our cause. With your help, we will continue to make progress toward our most important goals: improving the lives of people with FD and, ultimately, finding a cure.

FD Events - Year in Review

This year, the Foundation collaborated with a local, Brooklyn-based artist to create No Tears: Life with FD, a comic strip that communicates the trials and tribulations of having a chronic illness like FD. We hope we have made you laugh and nod in agreement with the weekly series posted on our website, Facebook page and Twitter feed. For the full collection, visit us at famdys.org/comic or follow us on Facebook at facebook.com/famdys.

Originally scheduled for November, then postponed due to complications surrounding Hurricane Sandy, the Third Annual Walk for FD took place on a sunny and unseasonably warm Sunday, March 10th. More than 150 people walked the seven mile circuit from Manhattan’s Greenwich Village up the Hudson River Parkway. Spirits were high and more than $30,000 was raised. Our thanks go to Sarah Strongin, Shira Falk, Jessica Raab and Tova Cohen for once again organizing this wonderful event and gaining the support of the NYU student population.
The 28th Annual **FD Day** Conference included featured speakers pictured above left to right: Dr. Horacio Kaufmann, Lucy Norcliffe-Kaufmann, Faye Ginsburg, Adrian Krainer, Susan Slaughenhaupt, Dr. Felicia B. Axelrod and David Brenner. Our esteemed guests presented updates on their work on FD research and treatment. The presentations were followed by an inspiring panel of FD adults discussing their achievements and challenges in college. Alexia de Gunzburg, Lindsay Ross, Nathaniel Sharir and Zoe Schvan provided poignant and humorous accounts of FD life after high school.

In the afternoon, a panel of FD experts met with FD families in small groups to answer questions and give more detailed accounts of their work. Additionally, the 5th Annual FD Photo Competition, the entertainment of illusionist Elliot Zimet, the exotic animal show and an appearance by “No Tears: Life with FD” comic artist, Mindy indy, all combined to make FD Day a truly special event.

The **8th Annual FD Bowlathon** on Sunday, April 14th at Woodmere Bowling Lanes on Long Island, New York was a resounding success. The event, co-chaired by Ally Kaplan, Lexi Sirota and Sydney Sirota, cousins of Scott Fass, drew great support from the community and raised more than $25,000.

The annual **golf outings** in Long Island and Chicago on May 13 and July 29 were both wonderful successes thanks to the hard work of organizers Paul Wexler, Steve Fass, Adam Posnack and Paul Sunderland, for Long Island, which marked its 17th year, and Gregg and Laura Meyers, for Chicago, which marked its 10th year. Combined, 300 golfers turned out to play the courses and show their support for our cause. In addition to golf, the Chicago outing had a “Ladies Lunch and Play” mah-jongg and card tournament that attracted over 200 participants. Together, the events raised over $300,000.

The **10th Annual Tour de Foliage, FD Cycle Tour** on Sunday, September 22, 2013 was an exciting day for everyone who participated both at the event and virtually from afar. Riders and sponsors raised $200,000 for treatment and research, amounting to three quarters of a million dollars over the course of the cycle tour’s history. Our gratitude goes to the tireless organizers, Jeff and Lisa Newman, Lisa Rudley and Melissa Slive. Their ambition in starting this event 10 years ago and dedication throughout the years has brought us to this milestone and we aim to reach even more.

*For more information on these events visit [www.famdys.org](http://www.famdys.org)*
Dysautonomia Foundation’s

2014 Events

- FD Research Conference
- Walk For FD - NYC
- FD Day
- Long Island Golf Outing
- Chicago Golf Outing
- Tour de Foliage - FD Cycle Tour

For details on these events and news about the Foundation and the FD community, check our web site, join our Facebook Page, follow us on Twitter, and see our videos on YouTube!

www.famdys.org
facebook.com/famdys
twitter.com/famdys
youtube.com/famdys

FD Treatment Manual

The most recent edition of the FD Manual of Comprehensive Care, published by the Dysautonomia Foundation, has been available since 2009. While this reference is not intended to be a substitute for advice from a qualified medical professional, it does provide a wide range of extremely useful information about all aspects of caring for a person with FD. Prepared by our medical and research staff at the NYU Dysautonomia Center, it is the only resource of its kind.

The manual deals with all aspects of day-to-day life for people with FD. It can be used as a guide for understanding the many challenges presented by FD, and can be extremely useful when shared with therapists, nurses and doctors who may not be familiar with all aspects of FD.

All FD families registered with the Dysautonomia Foundation should have already received a copy. If you have not received your copy, or if you need additional copies, please contact the Dysautonomia Foundation to make arrangements.

For more information on how to obtain a manual, email us at info@famdys.org
Handbook on FD and Jewish Law

Dr. Channa Maayan and the Israeli FD Treatment Center, along with a group of Rabbis from Israel, recognized the need for a book about how Halacha (Jewish law) applies to people with FD. This comprehensive handbook covers a wide range of topics, and applies to FD and other serious illnesses. The Foundation has copies available in both Hebrew and English.

For more information on how to obtain a copy, email us at info@famdys.org
Honoring the NYU Dysautonomia Center

Felicia B. Axelrod, MD
Horacio Kaufmann, MD
Lucy Norcliffe-Kaufmann, PhD
Carlos Mendoza, MD
Alberto Palma, MD, PhD

A unique facility with exceptional personnel dedicated to the well-being of the FD community
With Gratitude to the
Miriam Brucker Legacy Fund
For their Generosity and Support
In honor of

Mitchell

and the
Joseph Family
In memory of our beloved father and grandfather

Sidney J. Lemer

Richard, Marty, Margot and Liza Byrne
HAPPY 25TH BIRTHDAY SAMANTHA MYERS!

You are an inspiring and beautiful young woman!!

Lots of love,
Faye & Fred
Steven Wexler

We often wonder why g-d gave you FD. Although we will never know the answer to that question, we do know that we all have become better people because of you and how you handle the adversities that FD has brought upon you.

Love, Mom and Dad
IN HONOR OF
STEVEN WEXLER

ALL OUR LOVE,
Rena, Josh, Elana & Jacob Kopelman
In honor and recognition of

**Dr. Felicia Axelrod**

for her commitment and dedication to her patients and her immeasurable contributions in finding a cure for dysautonomia.

and

In Loving Memory of

**Dr. Robert Porges**
Michael,
We are so proud of you and all of your accomplishments. Keep it up!

All our love,
Mom, Dad, Rob, Joe, Nate, Prissy, Elly, and Emmy.

~

To Dr. Axelrod, Dr. Kaufmann, and all of the FD Staff, We can’t thank you enough for all you do!

In Memory Of

Zachary Berg
IN HONOR OF
OUR THREE BEAUTIFUL GIRLS
PERRY
SYDNEY
CODY

LOVE,
MOM and DAD

In honor of our daughters,
Julia and Rebecca

2013 has been a wonderful year for our family.
We treasure every moment of joy, laughter and love.

Lisa and Jeff Newman
Dear Michael Baranoff,

We wish you health and happiness always.
May all your dreams come true.

We love you,
Corie, Mark, and all the kids
IN HONOR OF MICHAEL BARANOFF

MANY THANKS TO ALL WHO ARE DEDICATED TO THE FOUNDATION AND THE RESEARCH THAT WILL ONE DAY LEAD TO A CURE

MICHELE AND ED SHOUEL

Michael Brenner

Your smile lights up our lives!

Love,

Mom and Dad
TO OUR SPECIAL PERSON

SCOTT FASS

We constantly are in awe of your ability to win people over.

Every person that we know thinks that you are an exceptional individual,

Caring, loving and perceptive.

I guess that is why we love you so much,

Aunt Harriette and Uncle Neal

Stacey, Gary, Marnie, Jeff

Ally, Casey, Dani and Sam
To Mitchell Joseph

Love from your family and friends in

Dallas, New York, and Portland
In memory of my beautiful and darling daughter

Elaine Jamie Lipson
10/1/63 – 4/7/05

I love you
I miss you
You will be in my heart forever

Mom

In Memory of

Arthur Lipson
In memory of

Harold L. Newman

A founder of the Dysautonomia Foundation

Allen and Neera Lumish

It’s great to see my friends at FD Day every year!

I would like to thank my grandparents, parents, brother, relatives, peers and Foundation’s staff for the support.

All my best wishes!!

Veronica Segal – São Paulo – Brasil
verosegal@yahoo.com
IN HONOR
OF
BRIAN SOLOMONS
AND HIS FAMILY

BEST WISHES FOR HEALTH
AND
HAPPINESS.

Love,

Jill, Sandy and Johnny
Sirulnick

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 & Josh
In Memory of

Allison Tauber

The Teitelbaum Family
IN LOVING MEMORY OF
LAUREN JAMIE ADLER

‘The memories call, like a voice in the ear
And every time I hear it, I see you again
Always out of reach, cause you’re only in my head
I’ve got pictures of you in my in my mind
When I’m dreaming I run, run, run to be with you again
But you’re always out of reach, cause it’s only in my head
The pictures fade, but they won’t let me go’

We never stop loving you or missing you.

Her Mom, Dad and Brother Joseph

In Honor of Steven Wexler

Steven’s courage and strength continue to be an inspiration to us all

Wishing you happiness
The Fialkov Family Foundation
2013
In memory of a very special little girl,
Lauren Jamie,
who is still sorely missed

– Savta Lillian

For all the wonderful children and adults that I have had the privilege to treat

For all their caring and devoted families and friends that I have been fortunate to know

My wish now is that we find together the answers that will give to those who so richly deserve it
health
happiness
and hope.

Dr. Felicia B. Axelrod
Dr Axelrod,
Dr A,
Felicia,
Savior,
Godsend,

THANK YOU

Thank you for the over 5000 years of FD life that you are responsible for.

Thank you for always being there no matter the time of day (or night).

Thank you for that feeling of safety that everything would be alright.

Thank you for the sense of relief that you provided just by walking into the hospital room.

Thank you for allowing us to be your "second" family.

The Wexler Family
To my darling grandson

Michael Brenner

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

Grammy

In Honor Of

MICHAEL BRENNER

LOVE,

NICK, PRISCILLA AND HAROLD
MICHAEL BRENNER

We Love you!

Aunt Adele & Uncle Paul
Cousin Danielle & Ethan

In honor of our beautiful daughters
&
With gratitude to the
Dysautonomia Foundation

Marsha, Jeff, Frannie & Natalie Cohen
In Loving Memory

DANIEL ALAN COHEN

From
Mara Cohen Marks,
Allan Marks & Family

In loving memory of
Rita and Leo Greenland

The Greenland Family
IN MEMORY

ANDREA LYNNE HAUBEN
FEBRUARY 2, 1984 – MARCH 21, 2009

FOREVER IN OUR HEARTS

The Hauben Family

In Loving Memory

ANDREA HAUBEN

Howard & Patti Hauben
H2 Events
In loving memory of Andrea Hauben

Jayne Lipman and Bob Goodman

IN HONOR OF

OUR CHILDREN

ADAM & JOSHUA KIETZ

WE LOVE YOU SO MUCH

MOM and DAD
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

LOVE, ALWAYS
TO OUR CHILDREN & GRANDCHILDREN

Amy & Michael
Barbara & Steve
Ronni & Philip

Zach
Alex, Becca, Emily
Adam, Josh
Brian, Jacob

Grandma & Grandpa
Anita & Stan
In memory of our precious
DONNA LYNN MICHAELSON

My dear Sam,

You have had quite an exciting year.
I am very proud of you.

Love,
Aunt Ruthie

Always loved
Never forgotten
In our hearts forever

Mom
Howard and Sheila
Chase and Spencer
and
All who knew and loved her
WE REMEMBER OUR FACEBOOK WARRIOR,
JEWELRY DIVA,
PAL, DAUGHTER
AND
ALL OF THE SMILES
AND
GREAT TIMES.

WE MISS YOU KID.

LOVE,

MOM AND DAD

MAGGY MILLER

1975-2009

In honor of Faye, Fred and Sam.

Marc I. Gross
and
Susan Ochshorn
IN HONOR OF OUR WONDERFUL GRANDSON

JACK MADDOX POSNACK

WHO NEVER CEASES TO AMAZE US.
WE LOVE YOU VERY MUCH
GRANDMA & GRANDPA POSNACK

TO BRIAN SOLOMONS

We are honored to be a friend of yours and your wonderful family.

You are a true inspiration to us each and every day.

We hope the coming year brings you the best of health and tremendous happiness.

Much Love,
Amy, Cliff, Julie & Katie Goldman
Dear Pete,

This has been an exciting year.

How nice it is that you, Peter, have had a successful art show.

Love you.

Grandma

From the proud family of the artist.
In Honor Of
All of Those Who Work So Hard
In the Fight Against FD

Tova and Howard Weiser

In honor of
Dr. Felicia Axelrod,
Dr. Horacio Kaufman
and the entire staff of the
Dysautonomia Treatment Center,

For their tireless efforts in bringing about
a better quality of life for
all those afflicted with FD.

The Wexler Family
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

In honor of

The Wexler Family

Susan and Jonathon Held
To Steven Wexler and Family,

Steven, we are so proud of the fine young man that you’ve become. Wishing you good health and happiness today and always.

Given with love from
The Bakers
The Edelmans
The Farbers
The Gewirtzs
The Heyligers
The Kravietzs
The Lisanns
The Osterlands
The Silvers

Dearest Lauren,

Yesterday, today and tomorrow.

Time moves on but you are not here to share the joys of life with us.

The family continues to grow and all we have is the memories of the past to share with them. The memories of your endearing smile, your love and your affection that lay deep in our hearts.

Yesterday, today and tomorrow. Forever we will think of you and forever we will miss you.

With much love,
Uncle Simon & Aunt Robin
Bracha & Oded
Chanoch & Ester
Yoel & Tali
Daniel & Yael
Cherut, Bat Shachar, Eitan, Hodaya, Ayala & Yosef
Dear Lauren,

Y our beautiful smile would warm the heart
Of all the lives you touched from the very start.

Y our brimming smile sent a message of love
From the earth down low to the heavens above.

Y our contagious smile was always there
Even when times were too tough to bear.

Y our endearing smile brought us all together
We cherish the memories of your smile forever.

With everlasting love & affection,

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

In honor of the

Adler Family

Caron & Steve Gelles

Bonnie & Russell Mannis
Morgan Asinowski

Morgan, 
Strength of Character has always defined who you are; A kind generous 
loving and funny young man who charms and befriends all those around 
you.

We love you, 
Uncle Bernie, Auntie Carole & Cousins Lauren, Alexandra, and Sydnee

IN TRIBUTE TO

DR. FELICIA AXELROD

WHO HAS DEDICATED HER LIFE AND HER CAREER TO 
MAKING LIFE BETTER FOR THE CHILDREN AND THEIR 
FAMILIES AFFLICTED WITH FAMILIAL DYSAUTONOMIA.

CAROLE AND RICHARD EISNER
In honor of

Dr. Felicia Axelrod and Dr. Horacio Kaufmann

For their untiring love and dedication.

On behalf of our family and all the dysautonomia families.

May you continue your work with the dedicated team at the center.

Rochelle and Leo Goldberg
& Elliot

and

Shari & Josh Goldberg
In honor of our very special friend

Dr. Felicia Axelrod

who continues to give so much of her time and heart
to all of the lives that she touches.
Nobody does it better and with so much love.

With the greatest love and admiration,

Suzanne and Mort Marvin

Continued Success!

In Honor of
Dr. Felicia Axelrod

Love,
Barbara and Leonard
Steiner
To our handsome Mikey,

You’re always such a joy and pleasure, we’re so proud of all your efforts.

G-d bless you and your incredible siblings.

We love you so much,

Grandma Prissy

Grandpa Mike

In Honor of
Michael Baranoff

We adore you and we are so proud of you.

Love,
Auntie Kim, Uncle Eric, Priscilla, Sam, India and Lucie
To my very special brother

Michael Brenner

I love you,

Sarah

MICHAEL BRENNER

You are the best!

All our love,
Aunt Robin, Uncle Brian,
Cousin Alex and Cousin Maddie
We Love You
Frannie Cohen

Great-Uncle Herb
Cousins
Meredith, Marc
Sasha, Hudson
Pam, Dan
Gemma
Jill

In Loving Memory of My Sister

SHEILA BOLTIN

You were a special sister in every way.
I will always have you in my memories,
and most of all,
in my heart.

Your Loving Sister Judy
and the Fass Family
In Loving Memory of

Mollie Weill

Her love for her Grandson Scott was only matched by her desire to find a cure for FD.

She generously supported the Dysautonomia Foundation's research and treatment efforts throughout Scott's life.

She is in our thoughts every day.

The Fass Family

In Honor of

Scott Fass

Julius and Ruth Fass
In honor of

Judy, Steven and Scott

You're an inspiration to all of us!

Love,

Brooke, Jeremy and Luke

Congratulations to Scott Fass and his wonderful family.

You are all amazing, and we are fortunate to have you in our lives.

Love,
Sue & Jon
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 and
Benjamin Gordon
and
Edna Sydney

In Memory of Richard Gould
In honor of my two treasures
Gabi Jassie
and
Alexa Schweer

~
Grandma Lois

From the staff of:
The Operating Room
Anesthesia
Ambulatory Surgery
3 North
Engineering

We Support you Gabi,
and the entire FD Foundation!
OUR LOVE TO A MOST WONDERFUL YOUNG MAN:

EVAN REID KAPLAN

CONGRATULATIONS ON YOUR TURNING 17!

GRANDPA BOBBY & GRANDMA NANCY

Dear Josh,

We are honored to be a friend of yours and your wonderful, special family.
You are a true inspiration to us each and every day.
We hope the coming year brings you continued health and happiness always.

Love,

The Feldman Family
The Goodwin Family
The Handy Family
The Levine Family
The Messer Family
Marcia Levine
Ilyssa and Mark Silver
The Stern Family
With love to our grandson, Ezra Kress

The Kochman Family

We celebrate your 16th birthday, continually inspired by your spirit, love and courage.

Saba and Savta, Bill & Beverly Lebeau
DEAR SAM LANDAU,

WE LOVE YOU!

SUSAN AND ARNIE SCHARF
In Honor of

Sam Landau

IN LOVING MEMORY
OF

STEPHEN AND JERRY LINKER

JEAN AND STEVE ANREDER
In honor of

Jack Posnack

Who lights up

So many lives

Love, Lanie and Steven

In honor of our terrific cousin,

Jack Posnack,

and his loving and caring family.

Jessica and Steve Strauss
In Honor of

Jack Posnack

With Love from
Your California Cousins

Rebecca, Jonathan, Mimi, Lili and Liam

James David
Rader

November 11, 1964 – December 2, 1966

Love is not measured by
Time

Your Family
For Always and Ever
WITH LOVE & ADMIRATION
TO
BEN RAINER & ANNE,
DAVID, DANNY, JAKE

LOVE
GRAM / MOM / CAROL

IN MEMORY OF
EVINSKY
&
RICHARD DAVID

A DAY DOES NOT PASS
THAT WE DO NOT
THINK OF YOU!

LOVE AND MISS YOU,
LOREN & SETH
In honor of
Steven Wexler
and
Brian Solomons

Your courage and strength
are an inspiration.

Alyssa and Steven Ackerman

In Honor of
Brian Solomons
and
Steven Wexler

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

Joanie & Don Fisher
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

To Brian Solomons and
The Haberman Family

We send our very best to you and we solute your amazing efforts in supporting such a great cause.

Bonnie, Jason, David & Chad Spodek
To my amazing and talented cousin,

Pete,

whose wisdom, compassion and humor help keep me sane. And to his wonderful parents, David and Jennifer, and sister, Emily.

With love and appreciation.

John
SIMI STEINER

No matter what the circumstance for one thing you're renowned
Y our character is spit spot spic and span
Y ou're practically perfect in every way

Practically Perfect
S o people say
Y ou're practically perfect from head to toe
I f you had a fault it would never dare show
Y ou're so practically perfect in every way

B oth prim and proper and never too stern
W ell-educated yet willing to learn
Y ou're clean and honest your manner refined
E ven when you are ruthless, you're incredibly kind
Y ou suffer no nonsense and whilst you remain
there's nothing else you need to explain

Y ou're practically perfect in every way
P ractically perfect that's your forte
Y ou're so practically perfect in every way

N ot Temperamental.
N ot Grouchy or Gruff.
Y ou always stay tender when the going gets tough.
Y ou always read stories without a big fuss
A nd have no objections to playing monopoly deal with us.

E ach virtue virtually knows no bound
E ach trait is great and patiently sound
Y ou're practically perfect in every way.
(A pologies to Mary Poppins)

WE LOVE you!!!!!!!
M a and Zaidy

Thanks to Dr. Axelrod, the entire team
at the FD Treatment Center and the Foundation
for being part of what makes our little
miracles happen every day!

Brad and Susan Stillman
and Jacob, BENJAMIN, Gabriel and Naomi
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.

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

I love you a whole bunch.

Grandpa Phil
IN HONOR OF
STEVEN WEXLER

MICHAEL GORIN

To our Friend
STEVEN WEXLER

A REAL GEM!

With Love Always,
THE SOLOMON FAMILY
Deborah, Marc
Jordan & Eric
With great appreciation to David Brenner and the entire staff of the Dysautonomia 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 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 LOVING MEMORY OF**

**LAUREN ADLER**

Karyl, Asher, Lauren & Rebecca Miller

---

In Honor of Vivian and Gerald Adler
For all that they do.
- Joseph Rackman

---

In Honor of
Vivian and Gerry
Adler

Chani and Bennett
Salamon

---

In Honor of
Gerry, Vivian and Joseph Adler
- and in memory of -
Lauren Jamie

Susan and Bruce
Schneider

---

**In Memory of**

**Lauren Adler**

Debra and Howard Schub

---

**In memory of Lauren Adler**

Penina & Tommy Weinberger
In honor of Vivian, Gerry and Joseph Adler
And in memory of Lauren.

With love,
Sue and Arnie Wilson

In honor of Vivian and Gerry Adler
Geet & Hersh Wolf

Remembering Lauren Adler
Chanie and Howie Bryks

Morgan Asinowski Booster
Sonia Elisha and Sol Shimshi

In honor of
Dr. Felicia B. Axelrod and Dr. Horacio Kaufmann
IN MEMORY OF

DR. ROBERT F. PORGES

FOREVER IN OUR HEARTS,
VICKI, JOE, ERIN AND JESSE

Many thanks to
Dr. Axelrod
and all the doctors,
nurses, staff and hardworking parents
of The Dysautonomia Foundation.
Your work makes a world of difference.

Larry Eisenberg, M.D.

Thank you, Dr. Axelrod, for your continued
commitment and dedication to FD.

The Ross family

Philip Bach Boosters
Sol Brickner
Bonnie Schwarz

Michael Baranoff Boosters
The Ades Family
Calvin Haddad
In Memory of

Philip Bach

Jennifer Taylor Bell
Time Goes on but Memories Live Forever
Always in our Hearts
In loving memory of

Jennifer Bell

Home Care For Children

In memory of
Zoe’s and Sydney’s brother

ZACHARY

With love,
Steven, Naomi and Sam
In memory of a beautiful young boy,
ZACHARY BERG

WE LOVE YOU!
The Florida Gang
Marlene Chavin, Bonnie and Steven Schwartzbaum,
Adam, Alison, and David

GREGORY ASHER BRANDT

With Much Love and Great Pride
WE HONOR YOU
OUR DEAR GRANDSON

Grandma Fran and Grandpa Lenny

We Love you Gregory!
Aunt Cynthia, Uncle Jeff,
Emily, Melissa and Julie

We Love You GREGORY
All our Love,
Aunt Andrea, Uncle Lloyd, Shanna,
Alexander & Michelle and David

Love you, Cousin Michael Brenner!
Alyson, Craig, Eric, and Abigail

Michael Brenner Booster
Gail Wanger and Family
Michael Brenner
No one has taught us more about
Embracing life
Facing every challenge with courage
And the pure joy of hugs

We love you,
Mom and Dad

In Honor of
Michael Brenner

Sue and Aaron Mazurek

In Honor of

Michael Brenner

Linda and Bob Mazurek
FD Foundation and Researchers:
Keep up your amazing efforts! Thanks to your first screening process we have healthy daughters, Hannah and Carly who are now 16 and 14.

Gratefully,
Lisa and Kevin Bress

In Honor Of

Michael Brownstein, MD, PhD

Chairman, Dysautonomia Foundation
Scientific Advisory Board
WE LOVE YOU FRANNIE

FROM YOUR BIGGEST FANS,
UNCLE MICHAEL, AUNT ILONA,
ALEXANDER, ETHAN

BEST FRIENDS FOREVER
THROUGH THICK AND THIN
IN MEMORY OF
OUR BELOVED

MINDY, STEVEN AND LORI COHEN

Frannie Cohen Booster
Elaine & Michael Denenberg

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

Congratulations, Alexia, on completing your trilogy,
Steps of Life: Exceeding Boundaries. In admiration of your
inspiring courage and exemplary perseverance.
In Loving Memory of
Maximiliano and Lionel Donzis
Graciela, Carlos, Sebastian
Tracie, Sienna, Greyson
Hernan, Melissa and
Samuel Donzis

DEAR SCOTT,
YOU WILL ALWAYS BE
OUR #1 GUY.
WE LOVE YOU.

AUNT MARYON
ELENA, MATTHEW & JOSEPH

ANDREA, STEVE,
MARISSA & JONATHAN
SCOTT FASS:

YOU ARE ONE LUCKY GUY!

YOU HAVE THE VERY **BEST** SUPPORT SYSTEM!

YOUR FATHER, MOTHER, SISTER AND EXTENDED FAMILY LOVE YOU MORE THAN LIFE ITSELF, AND THEY KNOW HOW TO SHOW IT ALL THE TIME!

HOW LUCKY ARE YOU?

NEVER STOP ASKING THAT QUESTION; ESPECIALLY WHEN FISHING IN FLORIDA.

With our love,
Caren & Jeff Rosenberg.

---

In Honor of
Scott Fass
and his wonderful family.

With our love,
Sandy & Sandy
Our respect and admiration goes to all who dedicate themselves to the work of the Dysautonomia Foundation.

Sincerely

Elaine and Brian Rappaport
Dear Scott,

Your strength and your courage is an inspiration to us each and every day.

You truly touch the lives of everyone around you in such a special way.

You are sweet, kind, funny and sincere. We love you very much and wish you only the best in the upcoming year.

All of our love,
Rachel and Mark

Dear Scott,

You are an inspiration to us all.
Your will to succeed is second to none.
Continued health and happiness to you Scott.

Love,
Geri, Harold, Jared
Cori & Lexi

In honor of Scott Fass
Your strength amazes us!
With love,
June, Chad, Rebecca and Sam Rosen

Dear Scott,

and Happiness
We wish you this and much more for the year to come.

Love,
Stefi & Craig
Sydney, Shani and Jordan
Daniel & Amanda

Scott Fass Booster
Virginia Sheflin
Judy Fettman Booster

www.famdys.org
facebook.com/famdys
twitter.com/famdys
youtube.com/famdys
**FD Researchers**

The Dysautonomia Foundation thanks our devoted researchers who dedicate themselves to the pursuit of a better life for all people with FD.

**Susan Slaugenhaupt, PhD and James Gusella, PhD**

*Discoverers of the FD gene* – their work has opened the door to new therapies, better understanding of the disease, and the possibility of a cure.

**Michael Brownstein, MD, PhD**

*Chairman of the Dysautonomia Foundation Scientific Advisory Board* – Mike’s tireless work in providing advice, leading conferences, seeking the help of outside experts and guiding research projects has been invaluable to our basic, translational and clinical research efforts.

**2013 FD researchers:**

Gil Ast, PhD  
Ioannis Dragatsis, PhD  
El-Cherif Ibrahim, PhD  
Joel Guttierrez, MD  
Adrian Krainer, PhD  
Frances Lefcourt, PhD  
Vaughan Macefield, PhD  
Carlos Mendoza-Santiesteban, MD  
Lucy Norcliffe-Kaufmann, PhD  
Susan Slaugenhaupt, PhD

---

**MAZEL TOV TO**

**JUDY AND MARC DREYFUSS** on the first anniversary of their marriage

**WE HONOR**

**JUDY AND HER FD COLLEAGUES**  
For meeting their challenges with courage and determination

**WE HONOR**

**DR. FELICIA AXELROD, DR. HORACIO KAUFMANN**  
**AND LUCY NORCLIFF-KAUFMANN**  
**AND THE ENTIRE STAFF OF**  
**New York University Dysautonomia Treatment & Evaluation Center**  
For their 24/7/365 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 therapies for the FD population

**WE HONOR**

**ALL OTHER SCIENTISTS**  
Funded by the Dysautonomia Foundation  
as we eagerly await the results of their research

**WE HONOR**

**THE FD FAMILIES AND THEIR FRIENDS**  
Who support efforts to improve the lives of those with FD

**Beverly and Ted Fettman**
In memory of Kathy Ann Fishman

David and Deena Fishman

IN LOVING MEMORY OF

ADAM GERSON

Jessica, Dan, Mary-Joan and Charles

Remembering Gregory Geister

Gale and Philip Davis

In Honor Of

FAYE GINSBERG

President of the Dysautonomia Foundation
In loving memory of our dear cousin
Felicia Gail Gold
And with gratitude to the devoted doctors
and staff of The Dysautonomia Foundation
From Joyce and Bern Saxe

Jamie Goldblat Boosters
Cousins Diane & Michael Busch
Karen and Rich Heller

IN HONOR OF OUR NIECE,
JAMIE
GAIL + MELVIN GOLDBLAT

In Honor of Daniel Goldstein
Dear Danny,
All the best for the new year.

Love,
The Green Family

Remembering Farah Goldstein
Brenda D. Fletcher

Remembering Jeffrey Aaron Horowitz
Andrew Grisafi
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

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
In loving memory of

Barbara A. Gould

Miriam K. Gould

Richard H. Gould

And with eternal gratitude

For all you were

Judith E. Gould

In Memory of

Richard Gould

In Memory of David Lee Greenfield

Dr. and Mrs. William Fogel
and
Mr. and Mrs. Alvin Greenfield
IN MEMORY OF

Robert Gross

Jason (now 38) + Kevin (now 31) + Lisa (now 31) = 100 years of knowing 3 incredible people...

You are the best!

We love you very much!

Mom & Dad
In Honor of

Jason, Kevin, & Lisa Gross

Our Wonderful Nephews and Niece and

Their Fabulous Parents, Bobbi and Bob

With All Our Love
 Bonnie & Bob

In Memory of

Evelyn and Rudy Brucks

Jason, Lisa and Kevin's Grandparents

They Loved their Grandchildren So Very Much!

In Memory of

Evelyn Brucks. Beloved Mother and Grandmother.
You will forever be in our hearts.

Wishing Jason, Kevin, and Lisa Gross a Healthy 2014.
filled with Happiness and lots of Laughter.
Love Always, Karen, Dave, Jake, Zac, and Drew

In loving memory of Diane and Michelle.

Love, Mom
In Honor Of

Ron Hauben

For his many years of service to the Dysautonomia Foundation

In loving memory of

Katherine Merle Irlen
1964 – 2006

Harvey and Barbara Irlen
Kevin and Anita Irlen
Steve and Jennifer Irlen
Thank you, Reni
for being you.
More than one life
has breathed easier
because you have lived

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

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.

We cannot wait to see what 2014 brings!
We Love Love Love you!
Mom and Dad

Gabi,
you continue to amaze us!

1. 21 college credits at Hunter College under your belt and counting!

2. You successfully completed your first ever summer internship!

3. You have mastered PROSE lenses--you go girl!

4. You continue to advocate for yourself at school, with doctors, with Access-A-Ride when necessary and at home!

5. You still ride the subway-alone!

Tamar Jacobs
Addy and Aurianne
A special special thank you to two pretty important people, My Aunt Roni and my Grandma Lois.

Aunt Roni raises money for FD by baking and selling cakes to her co-workers and friends. This year she had 30 orders for the holidays alone. Each cake was hand made by my Aunt Roni (with some help from my Cousin Alexa.)

Lois Pepkin, also known as Grandma, or GMA, knits felted wool hats and handbags which she sells at the Artists Gallery in Virginia Beach, Virginia and donates all proceeds to FD. Not only does she raise money for FD, but my grandma, who has never spoken in public before, recently spoke about FD at two Temples (in Norfolk and Virginia Beach, VA.)

I love you!
Gabi

2014 High School Graduations

A shout out to my friends that have FD and who I love so very much.

Congratulations on your upcoming high school graduations. I know that we will all do great things! We will succeed! And that we will stay friends forever!

Frannie Cohen
Melanie Cohen
Sam Landau
Simi Steiner
Sarah Zucker

BFFs for ever!
Gabi
Thank you
Artist Gallery
of
Virginia Beach, VA
for your support in honor of
my Gabi.

Love,
Grandma Lois

Hi Mitchell,

Good Luck in 2014.

Bob and Judy Bier

IN MEMORY OF
ALISA ROBIN KALEY
NOV. 8, 1956 – JUNE 29, 1987
AND
LOUIS KALEY
MAY 2, 1927 – FEB 21, 1991
LOVE and MISSED BY ALL
ROZ KALEY, STEFANIE & STEVE LINAKIS
LAUREN & MATHEW, DARREN KALEY

No Tears: Life With FD

Gabi Jassie Boosters
Suzie Beizer, Ina Cohen, Francine and David Rothkopf
Sandy and Lew Stoll

Mitchell Joseph Boosters
Donna Aufiero, Lisa & Mark Campbell
TO **Evan**,  
THE TOUGHEST GUY  
IN THE FAMILY  
ALL OF OUR LOVE,  
MOM, DAD, MAX, & RACHEL

Happy 17th Birthday to  

**Evan Reid Kaplan**

Our hearts are with you

Roger and Linda Franklin
In Honor of

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
Dear Josh –
Keep up the good work!
We are so proud of you!
Love,
Your Connecticut Cousins

For Josh Kietz:
To a great family and a great young man.
With all of our love,
Rob, Barb, Josh and Rachel Rosenblatt

We love Josh
The Tortorellas
Josh,
You are doing amazing!

Patrice Dawn Brendan &
Owen

In Hopes of Finding a Cure!

Roman & Olga Koifman

Dear Josh,

We love you so much!!
Aunt Ronni
Uncle Philip
Cousins Brian and Jacob

Let's Go Giants!!!

To Josh Kietz
Accomplished Skier,
Amusement Park Thrill Seeker
and
Karate Master
You and your family inspire us every day.
Love,
The Settles

Dear Josh,

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

Josh Kietz Boosters

Bauman + Krasnoff LLP, Ana & Daniel Demeo
Nancy & Paul Halpern, Aunt Roselyn and Uncle Sol Koblick
Lois and Saul Levine, Steve Levy and Cheryl Shirley
Ellen and Craig Maiman, Julie Miller, Wendy & Sheldon Nussbaum
Alan and Lorraine Spector, Marcy & Mit Wanzer, Gloria Zapin

Josh,
So wonderful to hear about you still volunteering at the Cradle of Aviation.

You are amazing, and we love you!
Judy & Alan Friedman

Josh,
You are amazing, and we love you!

Ellen and Craig Maiman, Julie Miller, Wendy & Sheldon Nussbaum
Alan and Lorraine Spector, Marcy & Mit Wanzer, Gloria Zapin

Josh, 
Love,
and

Owen

Accomplished Skier,}

Uncle Philip

Cousins Brian and Jacob

Let's Go Giants!!!

To Josh Kietz

Rarely use you so much!!

Aunt Ronni

Uncle Philip

Cousins Brian and Jacob

Let's Go Giants!!!

To Josh Kietz

Accomplished Skier,

Amusement Park Thrill Seeker
and

Karate Master

You and your family inspire us every day.

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The Settles

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Amusement Park Thrill Seeker
and

Karate Master

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Love,
The Settles

Josh, 

}
Friends of Josh Kietz

Randi and Jonathan Altschuler
Laurie and Steve Block
Ken Damato
Lawrence Goldner
Jane Helfman
Sara and Wayne Kimbell
Ellen and Leslie Kreisler
Vivian and Myles Megdal
Robin and Brian Potash
Malva Rabinowitz
Debbie & Ezra Tuchman
Joanne Wolfe

In Honor of

Mitchell Kofsky

Dr. Albert Kofsky
& Sandra Kofsky

To our always smiling Hollie –

Minutes into Days,
Days to Months,
Months to Years
We will love you forever.

Jill, Jerry, Dale, Barry,
Lauren, John, Mindy, Amy,
Richie, Mia Hope, Nicole,
Kasey, Peyton, Sarabeth,
Jesse, and Jacob
With all our love to our grandson

Ezra Kress

You inspire us with your kindness, sweetness and acceptance.

We wish you a year of “A-okay”

health, happiness and fun.

We love you,

Grandma and Grandpa

Dear Ezra,

We have learned so much from you about appreciating every day things. Thank you for being the best teacher possible.

We love you!!

Love,

G.G., Aunt Sherry & Uncle Ira
To our A-OK cousin **Ezra Kress**: We love you very much and are so proud to call you our cousin.

Love,
Brian, Lisa, Matthew, Faith, Shayna, Ari, and Iggy

---

Happy Sweet 16, Ezra!
We love you!
Love,
Uncle Aryeh, Aunt Keren, Mimi, Caleb, Peabo, and Mookie

---

In Honor of Evan White and Ezra Kress.
David and Betty Roth

---

With Love to **Sweet Ezra**

From Your Cousins,
Renee and Hervey
IN LOVING MEMORY

OF

OUR BELOVED DAUGHTER

AMY JILL LEHRER

March 21, 1964

December 15, 1973

Kit & Don Lehrer
In Memory of our Aunt Bess
You are always in our Heart.
We will never forget you.

Marc, Brett, Brooke

To Our Sweet Angel
Rebekah Jana Lieberman
From your loving parents,
Shiloh and Lynn

Sam Landau Boosters
Betsy and Ken Friedrich, James Lieber, Bella Masliah
Kari Nicolaisen and Charles Rubenstein

Erica Levit Booster
Francine & Bruce Adler and Family

In Loving Memory
Of
Stephen Linker
and
Julian Linker

Phyllis & Susan
IN LOVING MEMORY

OF

MORRIS RAPPAPORT
ANNA RAPPAPORT
NORMAN RAPPAPORT
LEO LINKER
LILLIAN LINKER
DAVID LINKER

IN LOVING MEMORY

of

STEPHEN LINKER
and

JULIAN LINKER

BETTY and ED SMITH
In memory of

Arthur Lipson

In honor of our dear friend

Shelley Lipson

and in memory of her beautiful daughter

Elaine

and her beloved husband

Arthur

We love you,

Wendy and Steven Kravitz
Remembering Stephen Linker  
Dr. & Mrs. Daniel Kornfeld

Remembering Elaine and Arthur Lipson  
Connie and Jerry Stern

No Tears: Life With FD

When I was born, everyone said people with my condition don’t live very long. As I got older, they told me all the things I couldn’t do!

But I proved them all wrong. I’ve come this far and I’m not gonna give up!

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XL SCREW CORPORATION

Fran and Bob Sachs  
Corrie, Scott, Mackenzie & Brody Delevitt  
Amy and Chris Etten

Supports the Work of Dysautonomia Foundation, Inc.  
In Loving Tribute to Sophie Meyers

XL SCREW CORPORATION
195 Schelter Road  
Lincolnshire, IL. 60069  
847.383.2300  
847.383.2345- FAX
In Memory of

Pearl Ginsburg

Beloved Wife, Mother & Grandmother

Mark & Sue Hamilton

Our hero Samantha Myers, tireless in raising awareness of FD and raising funds for research.

We love you Sam!

Barbara and Max

Sam reading 
Secrets of a Hollywood Life (and keeping it secret!) in Washington Square Park

In honor of Rebecca Newman and the entire Newman Family.

Wendy Leibowitz

Samantha Myers Boosters

Barbara Abrash 
Jess and Madeline Benhabib

Rebecca,

We love you so much!

Aunt Florrie, Steve, Barbara, Sue and Rich
In Honor of Our Wonderful Grandson Dovi Porush

Dovi lights up our lives in a million extraordinary and very special ways.

His gorgeous smiles, his twinkling eyes, his engaging laughter, his kindness, his generosity all combine to create the amazing person Dovi is.

Dovi is our role model. From him we have learned courage, gratitude, patience, humility, and sensitivity.

We love you so much Dovi!!

All our love, Savta and Zeidy Barg
In honor of
Jack Jack and Michael
The Posnacks and The Bergenfelds
The Suttons and The Baranoffs
&
All the families who live with this challenge.
We pray with you for a cure ... SOON.

Linda Gitter Gerstley and Jim Gerstley & Family

Jack Posnack Boosters

The Ripps Family
Sylvia and Gary Zuckerman

WITH DEEP GRATITUDE TO:
THE DYSAUTONOMIA FOUNDATION INC.
DRS. AXELROD, DITCHEK AND KAUFMANN
LUCY NORCLIFFE-KAUFMANN, PhD

For their dedication beyond the call of duty.
May they have much success in all their endeavors.
THE PROFESORSKE FAMILY
TO HONOR OUR VERY FIRST GRANDCHILD

EVAN DAVID RACKSON
WHO HOLDS A VERY SPECIAL PLACE IN OUR HEARTS

BRIAN PAUL RACKSON
WHOM WE ADORE

ALYSON MICHELE RACKSON
THE SWEETEST GRANDDAUGHTER WE ARE SO PROUD OF AND

FRAN AND ALAN RACKSON
WHO HAVE CREATED THE MOST WONDERFUL KIDS IN THE WORLD!!!

With All Our Love – Always,
GRANDMA TAFFY & GRANDPA HY

In honor of

Fran and Alan
the best parents
and

Evan David Rackson
# 1 son
and

Brian and Alyson
the kid brother
and
the kid sister

All my Love
Aunt Hannah
For our Dear Cousin

Evan Rackson,
and his parents Fran and Alan

We wish you the miracles of Health, Prosperity, and Joy. And we thank you for continuing to teach us about devotion, courage and love.

Kay and Richard Cowan
Ronnie and Joe Ron Getz

---

In Memory of Rachel Reich

Marea and Jeff Kahn

---

Evan Rackson Booster
Gloria and Harold Cohen

Ben Rainer Boosters
Joan Lyons
Herbert Weissman

Lanie Roebuck Boosters
Caroline and Robert Kanner
Minda and Joel Teicher

---

In honor of

All who face the challenges of FD

and

In memory of

All who so dearly touched our lives
In Loving Memory of

Evan Rosenthal

Your compassion, kindness and courage we remember with love. You are always in our hearts.

Joan and Henry Kazer
Debbie and Howard Hagen
Susan and Stephen Klein
Stephanie Greenberg
and Dan Powers
and our families

You are loved beyond words and missed beyond measure!

Love, Mom, Pop, & Samara
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, Bob, and Daniel Powers
Julie and Joshua Lurie

In honor of

Justin Sachs
Grandma Olson’s wonderful boy

In memory of my dear friend
Diane Bonow Sernovitz
& In honor of
Daniella Rena
You are always with me, Shari and Sally.
Lovingly, Andi

Sam Sernovitz Boosters
Debby and Robby Cohen
Aunt Linda Sall
I want to thank Dr. Axelrod for helping me overcome my health issues and being able to live a great life.

-Andrew Sigman-

In honor of my nephew, Andrew…
Who continues to amaze me with his patience and kindness to all.
He is my inspiration.
Love you always,
Aunt Marsha

Wishing Dylan Singer and his family a year of ease and a healthier one than last year!
Dylan’s smile is infectious and there is more behind his eyes than we’ll ever know.
Love, Aunt Risa, Uncle Dave and the rest of the Altman crew

We love you Kyra!
Your love of life impacts on everyone.

Love, Cindy, Peter and Emily
(Pollack/Purchia)
We support the Slive Family
in their efforts to cope with and conquer FD.
Sue & Jerry Weinstein

Kyra Slive Boosters
Bea Kellerman
Marlene Brown and David McMillin

Dearest Brian,

Your courage is our inspiration.

Love,
Mom + Dad
In Honor of

Brian Solomons

Our hope is for a cure.

Penny and Perry Berger

In honor of

Brian Solomons

and

Steven Wexler

We are proud to support the research effort.

Mitchell and Adela Kahn

&

Family
In Honor of Brian Solomons
and the Foundation’s dedication to finding a cure

Mark & Joan Haberman

We admire his spirit and tenaciousness and we love his blazing smile. To more days at the beach!

the Bochners and the Goldsmiths

In support of Sheryl and Scott Haberman to this very worthwhile cause.

June and Michael Cohen

In Honor of Brian Solomons
Andrea and Jeffrey Lomasky
In honor of
Scott and Sheryl Haberman
Jeffrey and Laurie Goldberger
Paul and Karen Wexler

Best of luck in finding a cure, and keep up all the great work you do!

Cathy and Jonathan Miller

In honor of
Brian Solomons and family

with best wishes for a happy and healthy new year.

Love,
The Siskind Family

In honor of
Brian Solomons and family

we are proud to support the research effort.

Ilene & Paul Pearlman
& Family

We salute your efforts to improve the lives of those living with dysautonomia.

Toby and Josh Werber
In Honor of Brian Solomons

Lisa and Lon Goldstein and Family

Friends of Brian Solomons

Richard Allerton
Robin and Michael Cantor
Susan and Bruce Cohen
Lowell and Fern Kwiat
Todd and Staci Sycoff

Brian Solomons Boosters
Michelle and Lennert Gruszecki, Chester Kirschenbaum
Loretta and Morton Laurence, Jack Solomons

In honor of

Sheryl Haberman
In Honor of

Peter L.
Sonenshein,
Our Big Man

With much love
from Aunt Gail,
Uncle Linc, Dina,
Adam, Jenna,
Samantha and Jack

In honor of the artist

Peter Sonenshein
David and Gail Hofstein

Celebrating
PETER SONENSHEIN
Our “other son” and amazing friend!
With Love from,
Debi, Ron, Andrew and Deanie Hoxter

In honor of Peter Sonenshein & Family

Ellen and Steven Wolf & Family

Friends of Peter Sonenshein

Mary Hummel
Jane and Bernard A. Mason
Susan Tachau & Mark Anderson
Karal Taylor
Betty-Ellen and Michael Wolf

Peter Sonenshein Boosters
Lisa and Joe Becker, Randi Berman, Andrea Meyers
Laurie and Phillip Rubin, Shelley and Peter Sereni
With great appreciation
to the South Florida chapter
of the Dysautonomia Foundation.

In Memory of

FAYE LAGER

FOUNDBING MEMBER AND PRESIDENT OF
THE SOUTH FLORIDA CHAPTER OF THE
DYSAUTONOMIA FOUNDATION.

Dear Simi: we are delighted to see you
growing to be a wonderful young woman!

Grandma & Grandpa Steiner

YOUR PROGRESS – YOUR SMILING FACE
YOUR WONDERFUL WAYS
BRIGHTEN OUR HEARTS AND OUR DAYS
WE LOVE YOU
SIMI

Aunt Chava Sternfeld
Cousins Earl & Debbie Sternfeld & Family
Cousins Brenda Kahn & Family
Cousins Miriam Sara & Yitzchok Rosenberg & Family

Roxanne Stein Booster
Samuel & June Stein

Simi Steiner Boosters
Emilia & Boris Dragunsky, Carl Steinhart

Benjamin Stillman Boosters
The Margolis Family

IN LOVING MEMORY OF

BRYAN SUNDERLAND

Chet, Sheila, Michelle, Steven and Kim Hasday
Steve,

The way you face each day with courage and optimism inspires us both.

We love you,
Stef and Bryan

Best wishes to our hero

Steven Wexler
and the entire Wexler family

With love,
Amy, Michael, Ethan & Samantha Kopelman
"Did you know Steven's my hero? 
There ain't nothing to hold him back. 
He wakes up every day with a smile on 
his face,

it's true
And Steven's my friend......"

We love you, Steven !!!!!!!

Love,
The Diton Family
Lori, Eric, Alyssa & Adam
In Honor of

Steven Wexler

Best Wishes
For Continued Success
To
The Dysautonomia Foundation

FRANK & HELEN MCGRAIL

GOOD LUCK

IN YOUR
SEARCH FOR A CURE

118 ANDALUSIA WAY
PALM BEACH GARDENS, FL 33418
561-249-3500
www.PaperAndInkGraphics.com
STEVEN WEXLER…
YOU ARE AN INSPIRATION TO ALL!
ROBERTA & JOHN ADOMOVICH

To Steven and his family
We’re always thinking of you.
We admire your courage, strength and warmth always.

Pamela, Bruce, Zachary and Jake

With Warm Wishes!
Deborah & Joel Brooks

Joining forces to help your neighbors.
That’s Better thinking. Together."
Ellen and David Field

God Bless all with Dysautonomia and their families and loved ones and friends.

Have a Happy, Healthy, Joyous Year.

Always in my prayers.

Sincerely,

Angela Gustavson

We Are All Very Grateful for the ground breaking work of the Foundation.

Home Care For Children

In honor of

Steven Wexler

From

The McGuffog Family
We sincerely hope that science will prevail and overcome this disease of FD.
Our prayers are with you, Karen and Paul.
Usha and Shash Patel

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

Steven, You are awesome!
Love - The Segal Family

Steven you are an inspiration to us all.

Debbie and Andy Veasey
IN MEMORY OF OUR BELOVED SON
HOWARD LAWRENCE GOLDSTEIN

IN MEMORY OF OUR BELOVED SON
HOWARD LAWRENCE GOLDSTEIN

In Honor of the Wexler Family
From The Byron Family

IN MEMORY OF OUR BELOVED SON
HOWARD LAWRENCE GOLDSTEIN

Best Wishes to
Paul and Karen Wexler
Bob Carney and Heide Kahme

Laurie & Flatow, P.C.
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Our Sincere Gratitude to the Wexler Family and everyone at the FD Foundation for their hard work and tireless efforts.

The Gropper Family

Dear Steven,

You are special. Your accomplishments are very praiseworthy. We are very proud of what you have done and what you will continue to achieve.

Best Wishes Always

Monty and Florentina Jacobson

Ellen & Jonathan Kessler are proud to support Karen & Paul Wexler and their family along with the Dysautonomia Foundation in all they do to improve the lives of FD patients and their families.
Steven
Wishing You Lots of Happiness in 2014!!
Leslie Kravetzky

With Admiration & Love for Steven Wexler & His Family
May their efforts continue to Be successful
Love,
Gloria Margolin

In Honor of the Wexler Family
Eric and Rhonda Moore

In honor of
Steven Wexler and Family
Karen, Paul, Stefani and Bryan
Ilene Rosenzweig

Best Wishes To

Steven and the Wexler Family

Larry & Judith Witmer

Steven Wexler Boosters

Anita and Jacob Avidon
M. M. Braun
Cori Wells Braun
Mr. & Mrs. Lawrence Ciccarelli
Rosemarie Davitt
Cindy Elan-Mangano
Gail and Mark Fialkov
Paul Gianguercio
Susan and Michael Goldberg
Alycia and Robert Gramling
Dr. and Mrs. Michael Halzel
Annette and Seymour Hoffman
Clifford Kane
Neil G. Kanner

Roberta and Marvin Kanofsky
Lillian Lefkin
Andrea Lewis and Marc Tarras
Piper Lutbak
Cindy and John Mangano
Ellen & David Mandel
Bryan Meckley
Mr. & Mrs. Jeffrey Nackenson
The Padell Family
Helen and Alvin Plotkin
Bernice and Harold Reisman
Diane and Arnie Simon
Mark Tobin
Yermanok Family
Friends of Steven Wexler

Meryl and Stewart Ain
Renee & Harold Bernstein
John Buckley
James Campbell
Pat Carroll / BlackRock
Damian Clarke
The Chipman Family
Robert Colotti
/ Rip-Out Artists
Matthew D'addario
John DeBonis
Rust DeBonis
Heidi and Jeffrey Dorf
Ellen and William Enco
Ruth Fialkov
Wendy & Joe Freeman
JoAnn Medigobch
Heinish
Jed Kanner
Jean and Herbert Kaplan
Jill and Brian Lacks
Fay and Steven Leicht
Jahn Levin
Annette Lippin
Millie Meck
Miss Sue's Nursery School, Inc.
The Peters Family
Poseidon Swimming Pool Corp.
Richard Radutzky
Roni and Jim Rathgeber
Leslie & Michael Rosenberg
Minette & Marvin Rothenberg
Budd Scheffler
Bernice Shanes
Carl Shechter
Barry Sigel
Tanglewood Corp.
Brad Tolkin
Doreen M. Yoo

Remembering Fanya and Adolph Ware
Minda and Joel Teicher

Howard Weiser Booster
Stephen M. Flatow

No Tears:
Life With FD

In Loving Memory of
Michael Zauder
Helene Braver
Sam & Lorraine Vogel
In Memory of

Michael Zauder

Remembering Brett Zinman
Joan Zinman

Dear Sarah Zucker,

Congratulations on your High School Graduation!

Love,
Mom, Dad, Josh,
Larry & Kiva
In Honor of Event Chairs

Tova Cohen
Shira Falk
Jessica Raab
Sarah Strongin

For their hard work and dedication to the 3rd Annual Walk for FD
New York, NY
March 10, 2013

In Honor of Event Coordinators

Sydney Sirota, Lexi Sirota and Ally Kaplan

and the

Sirota, Kaplan and Fass Families

and Special Thanks to

Scott Fass

For their outstanding efforts in the 8th Annual Bowlathon FD Fundraiser
Long Island, New York – April 14, 2013
In Honor of Event Chairs

Paul Wexler
Adam Posnack, Steve Fass
and Paul Sunderland

For their hard work and dedication to the
17th Annual FD Golf Classic
Glen Oaks Club, Old Westbury, NY
May 13, 2013

In Honor of Event Chairman

Gregg Meyers
and the
Meyers Family

For their hard work and dedication to the
10th Annual Chicago FD Golf Classic
Briarwood Country Club,
Deerfield, Illinois
July 29, 2013
In Honor of Event Co-Chairs

Lisa and Jeff Newman, Lisa Rudley and Melissa Slive

Thank you for your hard work and dedication to the

10th Annual Tour de Foliage - FD Cycle Tour

Pace University, Pleasantville, NY
September 22, 2013

Dysautonomia Foundation’s

2014 Events

- FD Research Conference
- Walk For FD - NYC
- FD Day
- Long Island Golf Outing
- Chicago Golf Outing
- Tour de Foliage - FD Cycle Tour

For details on these events and news about the Foundation and the FD community, check our web site, join our Facebook Page, follow us on Twitter, and see our videos on YouTube!

www.famdys.org
facebook.com/famdys
twitter.com/famdys
youtube.com/famdys
To all who contributed to the 2013 Journal

THANK YOU!

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

Dysautonomia Foundation, Inc

www.familialdysautonomia.org