2010 Annual Report

Built On Leadership, Vision, And Commitment To Find A Cure
**Our Mission**

To advance knowledge through research and to educate the medical, allied sciences, and lay community about Chiari malformation, syringomyelia and related CSF (cerebrospinal fluid) disorders.

The Chiari & Syringomyelia Foundation, Inc. is a national a 501(c)(3) organization committed to disseminating accurate and current information about treatments for and best practices surrounding the management of Chiari malformation (CM), syringomyelia (SM) and related CSF (cerebrospinal fluid) disorders.

Many recognized world-class physicians, scientists and professionals agreed to collaborate and form a superior Medical Research Board. The trusted and dedicated members of our Board of Directors and Board of Trustees include community and business leaders, educators, legal experts, families, and patients, who have been advocates in the CM/SM community for years. They have the skills and passion to create, fund, and direct programs and research that will change the lives of over one million families affected by CM/SM.
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Long Island Veterinary Specialists - Plainview, New York

Arnold Menezes, MD  
University of Iowa College of Medicine - Iowa City, Iowa

Miseo Nishikawa, MD, Japan  
The Chiari Institute - Great Neck, New York
With the holiday season upon us, we take the opportunity to reflect on what an extraordinary year 2010 was for the Chiari & Syringomyelia Foundation. Thanks to you and your generous gifts, we accomplished many of the goals we set for 2010, established many new and exciting events, and have set our sights on a productive and eventful 2011. I’d like to update you on the progress we made this year.

Regarding our fundraising efforts, our signature events continue to provide the much needed revenue for our regional education and awareness programs, even in these difficult economic times. Your generosity and support is inspiring has made our progress possible!

Our third annual Charity Ball, held on March 13, in Staten Island, New York, was a huge success, and on September 12, our third Race for the Cure at the Arlington Park Race Course near Chicago generated more excitement, awareness and funds. These two events raised over $280,000. 2010 also marked the second year that Board of Directors member Jim Feisthamel and his wife Mary Ellen have hosted the CSF Valentine’s Day Dinner Dance in Utica on February 13. The Utica Chapter’s, Kathe Pianella and Jerry Hitchcock hosted a dinner fundraiser in October, raising over $6,000 and Cathy Poznik, CSF Board member and Chapter Coordinator, organized and hosted the third Cleveland Hour of Hope Fundraiser, which raised over $12,000 for CSF.

We are also extremely proud of our newest and most ambitious event, the Night of Light Children’s Gala, held this past November in Washington, DC, which was a huge success. This magical evening included a royal guest list, international ambassadors, world-class physicians who treat Chiari and syringomyelia, and 100 philanthropic guests from around the world. We were most fortunate to have a distinguished group of patrons, including Nicholas, 14th Lord Fairfax of Cameron, Lord and Lady Malloch-Brown, The Honorable Christopher Burnham, and Mr. Randy Theken, whose presence made for an extraordinary evening. The money raised from this event will help directly fund our most ambitious research project to date, The CSF Project to Analyze the Prevalence of Chiari Malformation within the Autism Spectrum Disorder Population. Please click on the Night of Light page on our site to view photos of this wonderful event.

Our Strategic Planning meetings in 2009 and 2010 have truly paid off.

At the end of last year, I talked about our “wish list” which included establishing CSF chapters across the country, and continuing to further our cause with the National Institutes of Health. I am pleased to report that we made exceptional progress on each of these goals.

After the incorporation of our first four CSF chapters, located in Cleveland, Denver, Utica and Washington, DC, in 2009, I am very pleased to announce that we opened new chapters in 2010 in Seattle, WA and Raleigh-Durham, NC. Our Education and Awareness series continues to directly impact patients and families this year and included respected keynote speakers Dr. Allison Ashley-Koch, Dr. Ed Benzel, Dr. Judith Scheman, Dr. Ed Covington, Dr. Jan Dommerholt, Dr. Riad Dakheel, Dr. Robert Gerwin, Dr. Clare Francomano, and Dr. Richard Ellenbogen. CSF plans to continue opening additional Chapters throughout the country in 2011. For more information about our Chapter programs, visit our Chapter page.

In August, to continue spreading awareness, we were invited by Dr. Dominic Marino, member of CSF’s Medical Research Board, to attend the Hampton Classic Horse Show on Long Island, New York, to exhibit our corporate materials and to present information on Chiari malformation, syringomyelia, and CSF’s mission.

Continued on following page
In addition to spreading awareness, research is a top priority for our organization and CSF is pleased to announce our sponsorship of the First Annual CSF Hydrodynamics Symposium in Zurich, Switzerland in July 2011. This sponsorship is made possible by a generous grant from the Monkton Institute. Under the guidance of CSF Medical Research Board member, Dr. Frank Loth, this engineering/physics symposium will be focused on the motion of cerebrospinal fluid. Approximately 20 to 30 invited speakers from around the world will present their research that involves either experiments or computational methods to better understand normal physiology and diseases related to CSF motion, such as Chiari malformation, syringomyelia and hydrocephalus.

CSF recently acted as a sponsor for Conquer Chiari’s 2010 Research Conference which was held in Chicago on November 11-12. This conference brought together top physicians and researchers involved with Chiari Malformation to share recent developments as well as collaborate for future care of this disorder. The sessions included a number of important and ground-breaking presentations that will hopefully lead to improvements in the treatment of Chiari malformation. A number of physicians from the CSF Medical Advisory Board participated and presented at this conference. CSF congratulates Rick Labuda and Conquer Chiari on this successful conference of which we were proud to be a sponsor.

Finally, we continue to move forward and develop our plans for the Bobby Jones Classic for CSF, which has been re-scheduled for April 2012, due to the current state of the overall economy. This tournament is made possible with the blessing of the Jones family, in particular Board of Trustees member Bob Jones IV, grandson of the legendary golfer. Please continue to visit our website for important updates on this groundbreaking event.

It’s been quite a productive year, as we continue to build a solid foundation and set our course for the future. Join the CSF community and stay up-to-date on upcoming news and events with periodic email updates. Just click on Sign Up Now on the left side of our site, add or update all of your information, to receive these CSF eNewsletters.

Please consider making a tax deductible contribution to CSF by donating online. Just click the Donate Online button and fill out the form. If you prefer to mail your gift, please send to:

Chiari & Syringomyelia Foundation, 69-39 Yellowstone Blvd. #216, Forest Hills, NY 11375

Thank you so much for your support of CSF! Have a healthy & happy New Year!

Paul J. Farrell
Chairman and Founding Member
<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
<th>Location</th>
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<tr>
<td>Chiari Meeting</td>
<td>January 6, 2010 - Canastota, New York</td>
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<tr>
<td>Greater Metropolitan Washington Area Chapter Meeting</td>
<td>January 19, 2010 - Lanham, Maryland</td>
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<tr>
<td>Valentine's Day Dinner Dance</td>
<td>February 13, 2010 - Utica, New York</td>
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<tr>
<td>Greater Metropolitan Washington Area Support Group Meeting</td>
<td>February 17, 2010 - Lanham, Maryland</td>
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<tr>
<td>3rd Annual Charity Ball</td>
<td>March 13, 2010 - Staten Island, New York</td>
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<tr>
<td>Greater Metropolitan Washington Area Chapter Education &amp; Awareness Program</td>
<td>April 20, 2010 - Lanham, Maryland</td>
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<tr>
<td>Think Tank Meeting</td>
<td>May 1, 2010 - Philadelphia, Pennsylvania</td>
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<tr>
<td>Cleveland Area Education &amp; Awareness Program</td>
<td>June 23, 2010 - Cleveland, Ohio</td>
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<tr>
<td>Greater Metropolitan Washington Area Chapter Education &amp; Awareness Program</td>
<td>July 20, 2010 - Lanham, Maryland</td>
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<tr>
<td>Greater Metropolitan Washington Area Chapter Support Group Meeting</td>
<td>August 11, 2010 - Lanham, Maryland</td>
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<tr>
<td>Hampton Classic Horse Show</td>
<td>August 29, 2010 - Bridgehampton, New York</td>
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<tr>
<td>3rd Annual Race for the Cure</td>
<td>September 12, 2010 - Arlington Heights, Illinois</td>
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<tr>
<td>Northwest Chapter Education &amp; Awareness Program</td>
<td>September 22, 2010 - Seattle, Washington</td>
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<tr>
<td>Carolinas Chapter Education and Awareness Meeting and Dr. Marcy Speer Garden Dedication</td>
<td>October 1, 2010 - Durham, North Carolina</td>
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<td>Utica Chapter Fundraiser</td>
<td>October 9, 2010 - Rome, New York</td>
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<tr>
<td>Greater Metropolitan Washington Area Chapter Education &amp; Awareness Program</td>
<td>October 19, 2010 - Lanham, Maryland</td>
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<td>2010 CSF Hour of Hope</td>
<td>October 28, 2010 - Twinsburg, Ohio</td>
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<td>Greater Metropolitan Washington Area Chapter Support Group Meeting</td>
<td>November 11, 2010 - Lanham, Maryland</td>
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<tr>
<td>Conquer Chiari Research Conference 2010</td>
<td>November 11, 2010 - Chicago, Illinois</td>
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<td>CSF Night of Light Children's Gala</td>
<td>November 13, 2010 - Washington DC</td>
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<tr>
<td>Greater Metropolitan Washington Area Chapter Support Group Meeting</td>
<td>December 16, 2010 - Lanham, Maryland</td>
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INDEPENDENT ACCOUNTANT’S REPORT

To the Board of Directors of Chiari & Syringomyelia Foundation:

We have compiled the accompanying statement of financial position – cash basis of Chiari & Syringomyelia Foundation (the “Organization”) as of December 31, 2010, and the related statement of activities – cash basis for the year ended December 31, 2010 in accordance with Statement on Standards for Accounting and Review Services issued by the American Institute of Certified Public Accountants. The financial statements have been prepared by the Organization on the cash basis of accounting, which is a comprehensive basis of accounting other than accounting principles generally accepted in the United States of America.

A compilation is limited to presenting information that is the representation of management in the form of financial statements. We have not audited or reviewed the accompanying financial statements and, accordingly, do not express an opinion or any other form of assurance on them.

Management has elected to omit substantially all of the disclosures ordinarily included in financial statements prepared on the income tax basis of accounting. If the omitted disclosures were included in the financial statements, they might influence the user’s conclusions about the Organization’s financial statements. Accordingly, these financial statements are not designed for those who are not informed about such matters.

Francesco Arlia, Jr., CPA

January 10, 2011
# CHIARI & SYRINGOMYELIA FOUNDATION

**Statements of Financial Position**

As of December 31, 2010 with Comparative Totals for December 31, 2009

## ASSETS

<table>
<thead>
<tr>
<th>Current Assets</th>
<th>As of December 31, 2010</th>
<th>As of Dec 31, 2009</th>
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<tr>
<td>Citibank Operating Account</td>
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<td>$93,590.83</td>
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<td>Capital One Money Market</td>
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<td>Citibank CD #4060</td>
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<td>Citibank CD #4079</td>
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<td>Citibank CD #4087</td>
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<td>Golf Tournament Account</td>
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<td>0.00</td>
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<td><strong>Total Current Assets</strong></td>
<td><strong>400,262.98</strong></td>
<td><strong>149,112.27</strong></td>
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</tbody>
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| Other Current Assets                          |                         |                    |
| Donation Receivable                          | 0.00                    | 22,000.00          |
| Undeposited Funds                             | 16,073.42               | 0.00               |
| **Total Other Current Assets**                | **16,073.42**           | **22,000.00**      |

**TOTAL ASSETS**                               | **416,336.40**          | **171,112.27**     |

## LIABILITIES AND NET ASSETS

| Net Assets                                    |                         |                    |
| Permanently Restricted Net Assets             | 210,853.44              | 85,853.44          |
| Unrestricted Net Assets                       | 205,482.96              | 85,258.83          |
| **Total Net Assets**                          | **416,336.40**          | **171,112.27**     |

**TOTAL LIABILITIES AND NET ASSETS**            | **$416,336.40**         | **$171,112.27**    |
# 2010 Summary of Activities

## Support and Revenue

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
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<tr>
<td>Direct Public Support</td>
<td>46,272.00</td>
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<tr>
<td>Foundation &amp; Trust Grants</td>
<td>44,600.00</td>
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<tr>
<td>Program Income</td>
<td>35,466.00</td>
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<td>Special Events Income</td>
<td>417,968.00</td>
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<tr>
<td>Other Income - Interest and Refund</td>
<td>1,757.00</td>
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**Total Support and Revenue**  
$546,063.00

## Expenses

<table>
<thead>
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<th>Description</th>
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<tr>
<td>Program Services</td>
<td>137,029.00</td>
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<tr>
<td>Management &amp; General</td>
<td>63,680.00</td>
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<tr>
<td>Fundraising</td>
<td>103,619.00</td>
</tr>
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</table>

**Total Expenses**  
$304,328.00

**Net Income**  
$241,735.00
Bobby Jones Society ($25,000 - $49,999)
  Jordan Family Foundation
  Michael and Denise Mikula, Excel Container

Platinum ($10,000 - $24,999)
  Doctors Community Hospital
  Mr. and Mrs. Paul Farrell
    Paul J. Farrell
    FTI Consulting, Inc
  Douglas and Karen Kindlon
  Lord & Lady Mark Malloch-Brown
  Richard Tripodi and Jane McKinney
  Bob and Toni Rumphrey

Gold ($5,000 - $9,999)
  Aetna, Inc
  Dr. and Mrs. Edward Benzel
  BlueCross BlueShield of Illinois
  Mr. and Mrs. Steve Casper
  CSF Utica Chapter
  Bob and Janet Janess, inPLAY EVENTS
    Burt Jordan
    Daniel Kindlon
    Tim and Jane Kindlon
  Dr. Dominic Marino, Long Island Veterinary Specialists
  Metropolitan Neurosurgery Group
    Navistar
    Pro-Pak Industries
    The Integra Foundation, Inc

Silver ($1,000 - $4,999)
  George Amann, Unimac Graphics
  Dr. and Mrs. Simon & Nancy Archibald
  Frank Arlia Jr., Arlia & Associates CPAs LLP
  ATDC
  Dr. Paolo Bolognese & Dr. Allison Bloom
  Stephen A. Bou
  The Honorable Christopher & Courtney Burnham
  John & Joan Cleary
  Codman
  Carole Corcoran
  Leo and Debbie Deiger
  North Shore/LIJ Health System
  Gene & Bonnie Downey
  Sunny Downs
  William and Susan Doyle
  Dr. and Mrs. John and Suzanne Oro
  Douglas Dragon
  Dr. and Mrs. Richard & Sandy Ellenbogen
  John Esposito
  Dr. and Mrs. Timothy Farrell
  Paul and Patricia Farrell
  Five Star Sheets Dba Mid Corr LLC
  Five Star Transportation
  Elaine L Fontana
  Tom & Jerrice Fritzlen
  Fuchs & Roselli LTD
  Scott Harper
  Hartford City Paper
  David F. Hoffman
  Scott and Carla Janess
  Jeff and Julie Jessup
  Ben & Deb Waterman Johns
  Keybank National Association
  Jeff & Patty Kosty
Silver ($1,000 - $4,999)

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Gerald and Joan Kyle
Chulwoo Lee
Regis and Rebecca Luther
Manhasset Diagnostic Imaging, P.C.
James Mattiola
Eric and Kristin Maul
Medtronic Spinal and Biologics
Steve Merson
Alan Merson
Shane and Betty Mikula
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Mark and Laura Ruane
Scott and Stephanie Rumphrey
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Eli & Rachel Salzman
Scott & Melissa Sanders
Andrew & Sharon Schaefer
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Dion and Allison Sharp
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Richard & Mary Smith
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Truist Comprehensive Distribution
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Central National-Gottesman Fdn.
Douglas Wertheimer, Wertheimer Box Corp.
Richard and Amy Wickstrom

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Jim and Lisa Bolduc
Stephen and Denise Bongiorno
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Nancy Taylor Bubes
Michele Calbi
Ann M Caron
National City Corporation
James and Margaret Curtacci
Daniel and Judith Dolan
Edward Adam Dolan, DJJ Technologies
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Bill and Amy O’Donnell
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Matthew and Jen Schebo
Gloria Shafer
Raymond and Kathleen Skinner
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Solarsoft
Takeda Pharmaceuticals North America, Inc.
Twinsburg Dairy Queen
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Patrick and Lynda Weber
Mr. and Mrs. Doug Wertheimer
Bob Zuker
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John Aceto
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Mike & Donna Ambrose
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Ted & Donna Andregg
Dave & Carrie Andrews
Robert & Sharon Ansec
Patricia Aoki
Donald J. Applegate
Dave and Sue Arch
David Alan Arko
Floyd Volunteer Fire Department-Ladies Aux. Inc.
Clifford and Linda Aversano
Clifford M. Aversano
John Bacci
Stephen and Cynthia Baker
Matt & Susan Bard
Rich & Barbara Bard
LaVerne Barna
Stephanie Barry
Anne Barto
Shawn and Cynthia Bass
Donella Belleau
Mamie M. Bello
Gaspare Benanti
Mike Berlini
Rosemary Beutell
John & Sara Jane Billinger
Chris and Anna Bilton
Jennifer Bimberg
Duane & Carla Bishop
Nancy E Bollig
Dr. Paolo Bolognese
Sal and Lisa Bonella
Bonnie Heneson Communications, Inc.
Jim & Marie Bova
Carmen Bosson
Harlan Breger, Heart 'N Soul Foundation, Inc.
Walter & Maureen Brennan
David & Mary Bronza
Laura Brosten
Jimmy & Bettie Brooks

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Tammi Lynn Brown
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Siegfried Buck
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Danel Burdo
Patty Burgess
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Matthew & Cassandra Caserta
Maro Carton, Inc.
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Turner Pain & Wellness Center
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Andy & Jackie Chenkus
Paul Ciempola
George Clark
Dolores Cleary
Mr. and Mrs. James Cleary
Julie E. Malanoski & William Cleary
Mr. and Mrs. Bud Cleary
Therese Cleary
Robert & Shirley Cleaver
Toccolana Club
Phil & Kelly Clunn
Susan Cobb
Barbara Coffee
Debbie Coleman
Steve Coleman
Coliseum Caterers
Consumer Flavoring Extract Company
Bruce and Dolores Cook
Dun & Bradstreet Corporation Foundation
Matching Gifts Program

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Carolyn Crusick
Lisa Ann Currall
William and Joan Cwinski
Martin Cyr
Margaret M. D'Avanzo
John Dalrymple
Matthew & Marylee Davis
Rita Davis
Robert Davis
Wilbur and Heidi Davis
Lawrence DeAngelis
Robert & Vita Debin
Crystal Allyn DeCarolis
Bill & Jose Delegram
Alice Denk
Bob Derasmo
Donald & Marie DeRoia
Edwin and Carol Devilbiss
Michael & Elaine DiCillo
Thomas Dirham
Charles Dobey
Ed & Mary Dolan
Mr. and Mrs. Thomas Dolan
Kent and Terry Dolenc
Matt & Lil Dolenc
Aleah R Dorsey
Stacy Driessen
Arthur & Dolores Driscoll
John Durdan
Eannace Funeral Home
Michael Elefante
Naji Elkhoury
Betty Jean Elliott
Susan A. Elliott
Joe Eskey
Andre Esposito
Paul & Jennifer Ettorre
Carl and Karen Evans
Nancy Evans
Richard & Angela Evans
Carol and Lester Fallon
Farm & Ranch Realty, Inc
Francis and Eileen Farrell
Frank Farrell
John Farrell
Kevin & Joanne Farrell
Peter Farrell
Carol Feather
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<thead>
<tr>
<th>Name</th>
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<tr>
<td>Joan Feisthamel</td>
<td>Glenn O. Harper</td>
<td>Amy Karides</td>
</tr>
<tr>
<td>Jean Paul Fekete, A La Mode Boutique</td>
<td>Thomas &amp; Elizabeth Hartmann</td>
<td>Louise Keen, State Street Jewelers</td>
</tr>
<tr>
<td>Marybeth Fell</td>
<td>Robert F. Heary, MD</td>
<td>John Kelly</td>
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<tr>
<td>Peggy Ferguson</td>
<td>Doug and Mimi Jones Hedwig</td>
<td>Maureen Kelly</td>
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<td>Drs. Mark and Carylee Adamushko-Fili</td>
<td>John D Heiss</td>
<td>Teresa Kemp</td>
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<td>Mr. and Mrs. Jim Finley</td>
<td>Lucille Hellyer</td>
<td>Michael Kerkhoven</td>
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<tr>
<td>Brian Fitzpatrick</td>
<td>Wilmer &amp; Donna Henninger</td>
<td>Peter &amp; Cynthia Kern</td>
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<td>Brian Thomas Fitzpatrick</td>
<td>Jonathan &amp; Brenda Henry</td>
<td>John &amp; Ellen Kerwin</td>
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<td>Elaine Fitzpatrick</td>
<td>Philip &amp; Dawn Henry</td>
<td>Keybank National Association</td>
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<tr>
<td>Gerald and Mary Anne Fitzpatrick</td>
<td>Barbara Hertz</td>
<td>Andrew Kindlon</td>
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<td>Thomas and Arlene Rodriguez- Fitzpatrick</td>
<td>Marianne Elizabeth Herzke</td>
<td>Karen King</td>
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<td>Martin Franklin</td>
<td>Paul and Barbara Hills</td>
<td>Robert Klockowski</td>
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<tr>
<td>Nicole Franze</td>
<td>Hilton Garden Inn Twinsburg</td>
<td>Doreen Konczos</td>
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<td>Gary and Deborah Friedman</td>
<td>Edward &amp; Denise Hlavacs</td>
<td>Matthew Kozak</td>
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<tr>
<td>Friends of Peter A. Caruso</td>
<td>Keith E. Hockman</td>
<td>Thomas B. &amp; Rosemary Kraft</td>
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<tr>
<td>Lisa Kay Funkhouser</td>
<td>Paul &amp; Sue Hodge</td>
<td>Dr. and Mrs. Roger Kula</td>
</tr>
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<td>FX Enterprises</td>
<td>Richard and Heather Hoffman, Jr.</td>
<td>Christopher Joseph Lach</td>
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<td>Jennifer Gale</td>
<td>Michael and Maria Chacon-Horn</td>
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