



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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Letter from the Chairman



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

Letter from the Chairman *(continued from previous 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 the 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

2010 Calendar of Events

Chiari Meeting

January 6, 2010 - Canastota, New York

Greater Metropolitan Washington Area Chapter Meeting

January 19, 2010 - Lanham, Maryland

Valentine's Day Dinner Dance

February 13, 2010 - Utica, New York

Greater Metropolitan Washington Area Support Group Meeting

February 17, 2010 - Lanham, Maryland

3rd Annual Charity Ball

March 13, 2010 - Staten Island, New York

Greater Metropolitan Washington Area Chapter Education & Awareness Program

April 20, 2010 - Lanham, Maryland

Think Tank Meeting

May 1, 2010 - Philadelphia, Pennsylvania

Cleveland Area Education & Awareness Program

June 23, 2010 - Cleveland, Ohio

Greater Metropolitan Washington Area Chapter Education & Awareness Program

July 20, 2010 - Lanham, Maryland

Greater Metropolitan Washington Area Chapter Support Group Meeting

August 11, 2010 - Lanham, Maryland

Hampton Classic Horse Show

August 29, 2010 - Bridgehampton, New York

3rd Annual Race for the Cure

September 12, 2010 - Arlington Heights, Illinois

Northwest Chapter Education & Awareness Program

September 22, 2010 - Seattle, Washington

Carolinas Chapter Education and Awareness Meeting and Dr. Marcy Speer Garden Dedication

October 1, 2010 - Durham, North Carolina

Utica Chapter Fundraiser

October 9, 2010 - Rome, New York

Greater Metropolitan Washington Area Chapter Education & Awareness Program

October 19, 2010 - Lanham, Maryland

2010 CSF Hour of Hope

October 28, 2010 - Twinsburg, Ohio

Greater Metropolitan Washington Area Chapter Support Group Meeting

November 11, 2010 - Lanham, Maryland

Conquer Chiari Research Conference 2010

November 11, 2010 - Chicago, Illinois

CSF Night of Light Children's Gala

November 13, 2010 - Washington DC

Greater Metropolitan Washington Area Chapter Support Group Meeting

December 16, 2010 - Lanham, Maryland

Arlia & Associates CPA's LLP

Francesco Arlia Jr.

Certified Public Accountant

10 Jefferson Blvd. Staten Island, New York 10312

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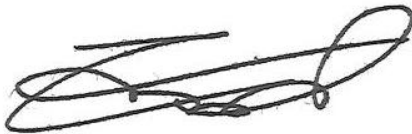
INDEPENDENT ACCOUNTANT'S REPORT

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

	<u>As of December 31, 2010</u>	<u>As of Dec 31, 2009</u>
ASSETS		
Current Assets		
Citibank Operating Account	\$ 185,757.76	\$ 93,590.83
Capital One Money Market	206,137.59	0.00
Citibank CD #4060	0.00	10,081.80
Citibank CD #4079	0.00	20,163.61
Citibank CD #4087	0.00	25,276.03
Golf Tournament Account	8,367.63	0.00
Total Current Assets	<u>400,262.98</u>	<u>149,112.27</u>
Other Current Assets		
Donation Receivable	0.00	22,000.00
Undeposited Funds	16,073.42	0.00
Total Other Current Assets	<u>16,073.42</u>	<u>22,000.00</u>
TOTAL ASSETS	<u><u>416,336.40</u></u>	<u><u>171,112.27</u></u>
 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	<u>416,336.40</u>	<u>171,112.27</u>
TOTAL LIABILITIES AND NET ASSETS	<u><u>\$ 416,336.40</u></u>	<u><u>\$ 171,112.27</u></u>

2010 Summary of Activities

Support and Revenue

Direct Public Support	46,272.00
Foundation & Trust Grants	44,600.00
Program Income	35,466.00
Special Events Income	417,968.00
Other Income - Interest and Refund	1,757.00
Total Support and Revenue	\$546,063.00

Expenses

Program Services	137,029.00
Management & General	63,680.00
Fundraising	103,619.00
Total Expenses	\$304,328.00

Net Income	\$241,735.00
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