

Vascular Birthmarks Foundation Annual Report 20th Anniversary Issue

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VBF 20th Anniversary Gala Celebration



Dr. Linda and Catalanotto family

2014 was a landmark year for VBF as we celebrated 20 years of helping families affected by vascular birthmarks. A celebratory gala was held Friday,

October 10, 2014, in New York City's Times Square at the Hudson Theater. Nearly 230 people joined us at this event as we relived our 20-year history.

Co-chairs for the event were Frank and Barbara Catalanotto and Dr. and Mrs. Robert Rosen. The Catalanottos were joined by their daughter Morgan who had a facial hemangioma and was networked into treatment by the VBF. Frank Catalanotto, former major league baseball player, hosts an annual golf classic to benefit the VBF. Dr. Rosen serves as a VBF Expert in vascular lesions in the arms and legs and is currently at the Lenox Hill Heart and Vascular Institute in New York. Prior to that, he served for 25 years as the Director of Vascular and Interventional Radiology at New York University Medical Center and in the Department of Radiology at Bellevue in New York. Dr, Rosen was also VBF's Physician of the Year in 2009.

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2014 VBF 20th Anniversary Vascular Birthmarks Conference and Clinic



Conference attendees

The 2014 VBF 20th Anniversary Conference was held Saturday, October 11th, at the Lenox Hill Hospital in New York City. An estimated 300 people attended

the event. Dr. Robert Rosen, Dr. Roy Geronemus and Dr. Gregory Levitin were chairs for the conference.

Physicians who are experts in the field of vascular birthmarks held clinic sessions where families received an accurate diagnosis and treatment plan, providing 150 free clinic appointments. Clinic physicians included Dr. Alejandro Berenstein, Dr. Francine Blei, Dr. Anne Comi, Dr. Kamiab Delfanian, Dr. Aaron Fay, Dr. Laura Findeiss, Dr. Roy Geronemus, Dr. Anton Hasso, Dr. Steven Kane, Dr. Gregory Levitin, Dr. Martin Mihm, Dr. Stuart Nelson, Dr. Paula North, Dr. Teresa O, Dr. Rafael Ortiz, Dr. Robert Rosen, Dr. Ignacio Sanchez-Carpintero, Dr. Stavros Tombris, Dr. Milton Waner, and Dr. Barry Zide.

Speakers at the event included parents and their children who were networked into treatment over the

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Letter from VBF President



VBF President/Founder Dr. Linda Rozell-Shannon and her daughter Christine

2014 was an amazing year of celebration for VBF. Specifically, October 2014, marked the 20th anniversary since I filed a New York State DBA (doing business as) form so that I could establish a charity that would help families affected by a vascular birthmark.

It was 8 months after my daughter, Christine, was diagnosed with a

hemangioma--a word I knew little about but one that would change my life.

The first business name I filed was Hemangioma Hotline. With much thought and consideration, our 501c3 was filed with the name The Hemangioma and Vascular Birthmarks Foundation and later amended to The Vascular Birthmarks Foundation (VBF).

No one could have predicted what would happen from 1994 until 2014. Just look at these stats:

- over 3,000,000 monthly visits on websites with chapters on 6 continents
- 75,000 children and adults networked into treatment
- over 500 families have been provided free lodging while seeking a medical opinion or treatment
- 15 conferences held
- over 400 conference scholarships awarded
- over 200 Day of Awareness events organized
- over 100 insurance appeals successfully challenged
- 12 new programs established (including our Ask/Accept Anti-Bullying campaign)
- 10 walk/runs completed
- 6 research projects funded
- 4 physician education grants distributed
- 8 college scholarships awarded
- 3 International Missions Trips completed with over 300 patients treated by our international team

We have also absorbed seven former vascular birthmark related organizations. And, one final statistic that I am most proud of is that we have facilitated the adoption of five international orphans with a vascular birthmark who were considered "unadoptable" into homes in the United States. We have exceeded all of our expectations! All of this has been accomplished on a bare bones annual budget with a bare bones staff. Think of what we could do with more!

What does the future hold? We are currently working with the American Academy of Pediatrics (AAP) to establish and distribute guidelines for treating infants with a vascular birthmark. I have also drafted a letter to all insurance companies to require them to cover treatment. This letter has been submitted to the AAP, revised, and finalized. It will be issued in 2015. We are also preparing for our 4th international iTEAM trip to Israel. Last, but not least, we are seeking your financial assistance so that we can expand our staff to provide more services.

With your generous donations, we can all MAKE A DIFFERENCE!!!!

20th GALA||From Page 1

years, as a result of VBF. Dr. Linda Rozell-Shannon spoke on the foundation's growth and about some of her struggles and the accomplishments that made VBF what it is today. She took everyone back to the beginning of her journey when her daughter Christine Shannon was born with a large hemangioma on her lower lip. Dr. Linda was shocked that so little was known about her daughter's condition and that treatment options were almost non-existent. It became her mission not only to find answers for her daughter, but to help other parents who were searching for hope of treatment.

A highlight of the evening was a performance by Christine, who sang Leonard Cohen's *Hallelujah*. She was accompanied by Dr. Milton Waner and Madelaine Pizzarelli on guitar and Anna Joyce and Coco Bolinger as chorus. Dr. Waner was the physician who treated Christine as a child, and Anna and Coco also once had large hemangiomas and were networked into treatment by VBF.

VBF honored Dr. Martin Mihm as its 20th Anniversary Physician of the Year. Dr. Mihm's research has been instrumental in the field of vascular birthmarks. He serves as VBF's Co-Medical Director and Research Director. Dr. Roy Geronemus received the VBF's 2014 Humanitarian Award for his dedication to patients and families. Dr. Geronemus is the Director of the Laser & Skin Surgery Center of New York. Natalie and Brian Bolinger received the President's Award for outstanding service in fundraising for VBF for over 10 years. VBF Service Awards were presented to Wendy Olin, Jennie Drury, and Carla Mannix.

New York comedian Mike Stankiewicz, who has a port wine stain, entertained the crowd as the closing act.

Letter From AAP President to Dr. Linda Rozell-Shannon

For years, Dr. Linda Rozell-Shannon has been working to establish VBF Guidelines for Babies with Birthmarks to ensure infants born with or who develop a vascular birthmark receive an accurate diagnosis and treatment plan. She and Dr. Thomas McInerny, President of the American Academy of Pediatrics (AAP), have worked together over the past three years to bring her vision to fruition.

Below is Dr. McInerny's letter acknowledging Dr. Linda's efforts and reiterating one of our goals—early diagnosis and treatment.



AAP President Dr. Thomas McInerny

As President of the American Academy of Pediatrics (AAP) I have had the wonderful opportunity to work with Linda Rozell-Shannon, PhD for the past three years on educating the AAP's 62,000 members on the best ways to diagnose and treat vascular birthmarks.

I found Dr. Rozell-Shannon extremely *helpful in identifying* what

pediatricians needed to know about the latest scientific findings in caring for children with vascular birthmarks.

Together we were able to use the considerable resources of the AAP, including the leadership of the Academy's Section on Dermatology, to provide information to AAP members through various publications and newsletters. In addition, Dr. Rozell-Shannon advised me and the authors of a new AAP Policy Statement, to be published in 2015, on the diagnosis and treatment of vascular birthmarks. I am confident that this collaboration will lead to a significant improvement in how pediatricians treat children with these conditions.

It has indeed been a pleasure working with you, Linda. Best wishes for a happy new year, one with better care for children with vascular birthmarks. *Tom*

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VBF also offered support group discussions, as well as free dental clinics, daycare services, make-up sessions, and insurance sessions. Breakfast and lunch were also provided for all conference attendees and volunteers.

The 20th Anniversary Conference was dedicated to the Catalanotto Family in recognition of their continued support of VBF. Dr. Roy Geronemus and his staff from the Laser & Skin Surgery Center of New York provided free laser treatments to many conference attendees. Dr. Geronemus and his staff cleared their schedules for two days in order to provide these free treatments.

Sponsors for the conference were Syneron, Pierre Fabre, Cynosure, Cutera, Terumo, the Vascular Birthmarks Center, Estee Lauder, and the Wicker Family.

VBF board members and volunteers provided assistance to patients and families during the conference and clinic sessions.

Annual Catalanotto Golf Classic

The Fourth Annual Frank Catalanotto Golf Classic to Benefit the Vascular Birthmarks Foundation raised over \$25,000 on August 4, 2014 at the Cold Spring Country Club in Huntington, NY. The event was cochaired by Dr. Rosen.

Frank and Barbara Catalanotto became VBF's biggest fans after Dr. Linda helped find a specialist to treat their daughter's hemangioma.

VBF Now Owns Birthmarks.com

At the VBF 20th Anniversary Gala, Michael Steffano announced his retirement from Birthmarks.com. VBF now supports the site and its popular Newsgroup.

Michael has a facial port wine stain (PWS), and he began an online diary in 1995 to document his condition and his search for treatment. This led to the creation of the Birthmarks.com website, a leading site for support and information on PWS.

He wrote, "I couldn't be more pleased to know that our mission will continue under the VBF and Linda's guidance." Thank you Michael, for your many years of service and for your outstanding work.



VBF 11th Annual International Day of Awareness May 15, 2014

Visit the VBF Day of Awareness website at: http://www.birthmark.org/awareness

2014 VBF Day of Awareness Events

❖ The Vascular Birthmarks Foundation 20th Anniversary Family Fun Day and Community Walk was held on June 8th at the Niskayuna Soccer Complex, Zenner Road, Niskayuna, NY. In addition to the community walk, there were bounce houses and Tumbling Tykes, DJ Krazy Keith, celebrity MC Joe Condon (B95.5), games and a prize wheel operated and donated by the Tri-City Valley Cats organization, a TCBY yogurt station, and hole-inone competition.

Retired Hall of Fame NFL football player Joe DeLamielleure was also signed autographs for kids. Joe played for the Buffalo Bills and Cleveland Browns and is a 6-time pro bowl selection, 6-time all pro, and member of the NFL's 1970 All-Decades Team.

The 2014 Birthmark Champion was Gabriella Thomas, a local girl whose parents found help through VBF. Gabbi was networked into treatment and had surgery to remove a large portion of a hemangioma located over her left eye. Gabbi has also received three laser treatments and has two more to go.

One event highlight was the helicopter golf ball drop. Numbered golf balls were dropped from a helicopter prior to the start of the event at a local golf course. The ball that landed in the hole or was closest to the hole was the winner of two round-trip coach class American Airlines tickets.

❖ The annual *Buddy Booby's Birthmark* Read-Along was held in locations around the country. The book's main character, a Galapagos booby bird with a birthmark on its beak, promotes tolerance and models generosity when granted one wish.

- ❖ A Charmed by Charity event held at the Alex and Ani store in Saratoga Springs, NY, on March 19 sent 15% of all sales directly to VBF. This event was organized for the second year in a row by sisters Tara Frazier and Kristin Krikorian. Tara's 3-year-old son Alec has a port wine stain birthmark.
- On March 22, Amanda Myers organized the Walk for Vascular Birthmarks in Huntington Beach Pier, CA.
- ❖ The 20th Anniversary Olivia's Walk for Birthmarks was held on Saturday, April 12th at Neshaminy State Park in Bensalem, PA. This is the 3rd annual walk organized by board member Andria Gottsabend.
- ❖ The Fourth Annual Frank Catalanotto Golf Classic to benefit VBF was held on August 4, 2014 in Huntington, NY, which included brunch, reception, and dinner buffet. The event was co-chaired by Dr. Robert Rosen.
- ❖ On November 14, Sharon Israel hosted an Origami Owl fundraiser to benefit VBF.
- ❖ On November 18, 2014, Evan Jones organized an 'Eat for a Change' event at the Chipotle Mexican Grill, 13348 Newport Ave, Tustin, CA, raising funds and awareness for VBF. Evan received one of VBF's \$1000 college scholarships.
- Miriam Karsh dedicated her bat mitzvah project to VBF by writing informative letters to Jewish baby groups around Silicon Valley in California.
- Families created personalized JoinMe fundraising pages in honor of their child and raised funds completely online to sponsor a family to the VBF Conference. Thanks to the friends and family of: Kaley Callicott Daniela DiMirco Carson Maddox Nakiya Reid

Lauren Vazquez

Fran Muscarella organized her annual event in NY in honor of her granddaughter Julia who was born with lymphatic and vascular malformations.



Fran and her brother

Make Plans to Join the 2015 VBF International Day of Awareness

YOU CAN MAKE A DIFFERENCE! Help us raise awareness and desperately needed funds. It's simple, easy, and fun! Go to the VBF website and click on the link "Create Your Own JOIN ME Fundraiser Page" for full details on how to create your page and start raising funds for VBF.

We have created a template that will enable you to create your own person fundraising website page in just a few easy steps! Tell your personal story and how VBF has helped you. You can even include photos if you wish. Once your page is completed, email the link for your fundraising page to family, friends and coworkers.

You can create your personal JOIN ME page to coincide with a special fund raising event such as a VBF Day of Awareness garage sale, car wash, dinner, walk/run, or even just a friends and family appeal where you will raise money to Sponsor a Family and send them to our conference for free – just because of your effort!

Contact Carla Mannix with any questions at <u>Carla@birthmark.org</u>. Please put "JOIN ME Page" in the subject line.

VBF 2014 Accomplishments

- VBF iTeam travels to India to educate, treat patients, and establish a clinic.
- VBF *Babies With Birthmarks Guidelines* adopted by American Academy of Pediatrics.
- VBF launches 504 Plan for students with birthmarks to receive accommodations in schools.
- VBF hosts 20th Anniversary Gala and Conference/Clinic in NYC.
- VBF assumes management of www.birthmarks.com website and newsgroup.
- VBF reaches milestone of 75,000 networked into treatment in 20 years!

Kiana's Journey Networked into treatment by VBF

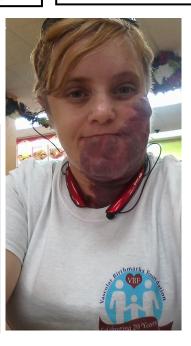




Kiana before treatment

Stories like Kiana's are the reason VBF advocates for early diagnosis and intervention.

Kiana today in her VBF Tshirt



VBF Awards Three Scholarships

VBF awarded a \$1000 scholarship to three college students who have or had a vascular birthmark.

Casey Matthews received the Frank Catalanotto Perseverance Scholarship.

Mallory Radtke received the Roy G. Geronemus Humanitarian Scholarship for her volunteer work.

Lucy Wang received the Martin C. Mihm Scholarship for her interest in pursuing a health career.

Each recipient agrees to organize a fundraiser to bring attention to the information and resources offered by VBF.

VASCULAR BIRTHMARKS FOUNDATION, INC. STATEMENTS OF FINANCIAL POSITION DECEMBER 31, 2013 (Reviewed) AND 2012 (Audited)

ASSETS

	2013	2012
	(Reviewed)	(Audited)
Current Assets		
Cash and cash equivalents	\$299,282	\$317,655
Prepaid Expenses	14,746	-
Total Current Assets	314,028	317,655
Fixed Assets Property, Plant and Equipme	ent, Net	
	425	485
	\$314,453	\$318,140

LIABILITIES AND NET ASSETS

Current Liabilities

Accounts Payable & Accrued	Expenses	
	\$248	\$18,741
Unearned Revenue	44,919	-
Total Current Liabilities	45,167	18,471
Net Assets		
Unrestricted	264,286	294,399
Temporarily Restricted	5,000	5,000
Total Net Assets	269,286	299,399
	\$314,453	\$318,140
	======	======

Appreciation for All Supporters

We wish we could recognize every donor, every volunteer, and every sponsor. Please know that we appreciate everything you do for VBF. Every contribution has impact and touches the life of someone who needs to hear that there is hope for treating an atypical birthmark.



VBF iTEAM Visits India

VBF is very proud of its second iTEAM, a group of doctors who donate their time to share knowledge, skills, and free treatments in another country. This year, the iTEAM spent February 3-7 in Delhi, India and gave free treatments to more than 30 individuals.

The iTEAM also presented at the VAICON-2014 conference to share the latest developments in the management of vascular birthmarks with local doctors.

Many thanks to the volunteers and speakers, which included: Dr. Linda, Dr. Cindy Bae, Dr. Francine Blei, Dr. Roy Geronemus, Dr. Leslie Graff (our Family Life Expert), Dr. Gregory Levitin, Dr. Kavitha Reddy, Dr. Bob Rosen, and Dr. Amit Sharma. In addition, VBF appreciated the assistance of Jennie Drury, PA to Dr Rosen, and Dr. Geronemus's nurses Katie Freehan and Wendy Olin.

VBF would like to acknowledge our hosts and partners in India:

- Medanta
- Medicity Hospital
- the VAICON-2014 Conference team consisting of Dr. Rajiv Parakh (Chairman), Dr. Ramneek Sodhi, and the chief of conference secretariat, Utsav Sharma

Our next step is to fund the training of one doctor from India who will spend two weeks in NYC training with our experts. Upon returning to India, he or she will be able to provide the services needed to families affected by a birthmark.

	~ Volunteer Response Form ~
Check all that apply and fill in contact	information below. I would like to volunteer
TO RAISE AWARENESS: on	lline with printed materials with a speaker or Read-Along
Description:	
TO RAISE FUNDS: online	fundraiser/sales solicit business donations organized event
Description:	
You may also Register Your Action	on online at www.birthmark.org/awareness/
	~ Tax Deductible Donation~
	or Honor of:
Check or Money Order enclose	ed payable to VBFMasterCardDiscoverAmerican Express
* -	
	Amount of Donation: \$
_	
	~ Contact Information ~
Name:	~ Contact Information ~
Street Address:	~ Contact Information ~
Street Address:	~ Contact Information ~
Street Address: City: Home Phone Number: ()	~ Contact Information ~ State: Zip Code:
Street Address: City: Home Phone Number: () Email:	~ Contact Information ~ State: Zip Code: Cell: ()

Return this form to VBF, PO Box 106, Latham, NY 12110 Phone: 877-VBF-4646 www.birthmark.org/contact

VBF is a fully approved not-for-profit. Federal Tax ID 16-1515227 We Are Making A Difference



VBF 20th Anniversary 2014 Physician of the Year Martin C. Mihm, Jr., M.D.

Dr. Martin C Mihm, Jr. has been instrumental in the foundation and success of the Vascular Birthmarks Foundation (VBF).

Dr. Mihm serves as Co-Medical Director and Research Director for the VBF. He also assisted Dr. Linda Rozell-Shannon in the early formation of the VBF. His dedication to patients and to the research of vascular birthmarks is unequaled. He has traveled extensively worldwide to share his findings with physicians and the international medical community.

While Dr. Mihm's accomplishments are too numerous to list completely, he is most notably the founder of the Albany Medical Center Vascular Anomalies Program and the Massachusetts General Hospital Vascular Anomalies Program.

On behalf of members of the VBF and the families and patients he continues to serve, we extend a heartfelt thanks to Dr. Mihm for his hard work and sacrifice over the years.

VBF is proud to name Dr. Martin C. Mihm, Jr. as the 2014 VBF Physician of the Year, in honor of the VBF 20th Anniversary.



VBF P.O. Box 106 Latham, NY 12110 (877) 823-4646 www.birthmark.org



Buddy – VBF's Official Mascot Join the Buddy Booby Read-Along