



Vascular Birthmarks Foundation

P.O. Box 106, Latham, NY 12110

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Editors: **Linda Rozell-Shannon, VBF President and Founder; Glenda Ethington, VBF Director of Public Relations; and Paige Salvador, VBF Executive Director**

*1,000,000 hits on our website monthly,
250,000 annual users and over 20,000
children and adults networked into
treatment...*

Your donations ARE MAKING A DIFFERENCE!!!!

By President and Founder,
Linda Rozell-Shannon

Wow! That's the only word I can think of to describe 2005 for VBF. Your donations over the past year have helped us hit an all time record high in accomplishments. Just look at what you have helped us to do this past year:

- ✓ Held our 2nd Annual Day of Awareness – Launched as an International event this year
- ✓ Presented VBF Founder/President with prestigious regional Jefferson Award

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Making A Difference

By Jill Brown

Paul and I thought we were out of options for treating our daughter's hemangioma.

We had been to several doctors who said there were no treatment options for a vascular birthmark as large and as complicated as hers. They were supposed to be the experts. So, we believed them and resigned ourselves to the fact that our daughter would have

her hemangioma and the health problems it presented, and we would just have to deal with it the best we could.

Paul's mother had come across the Vascular Birthmarks website and told us to check it out and see if there was something out there that could be done for Aslynn. I went to the site and read through all of the information, e-mailed people from the parent's list, and posted messages on the discussion board. I began to realize that our journey was far from over.



Aslynn Brown before and after surgery to remove a massive hemangioma

The real turning point came when Aslynn's heart began to deteriorate and I was starting to feel a sense of panic. I called Linda Shannon late one night in search of answers. I hung up from that phone call with a sense of relief I hadn't yet felt. Someone was in our corner and was going to stay there as long as we needed her.

Linda had such a passion for the work of the Vascular Birthmarks Foundation. She had me e-mail Aslynn's photos to her, got us

connected with Dr. Waner, and sent us down the path that we should have



taken from the start of our ordeal. This path meant a major life-altering surgery with Dr. Waner, and in the end a healthy, happy daughter and very grateful parents.

The old cliché that 'children don't come with instruction books' is true. We relied on the Vascular Birthmark Foundation to provide us with the information, the contacts, the resources, and the support that we needed to get through this difficult time.

Their theme, '**We are making a difference**' couldn't be more accurate. For us, it was all the difference in the world.

VBF President and Founder Receives



Left to right -
Senator Hilary
Rodham-
Clinton,
Christine
Shannon, and
Linda Rozell-
Shannon

Jefferson

Award

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JEFFERSON| From Page 1

On June 21, 2005, New York Senator and former First Lady Hilary Rodham-Clinton presented VBF President and Founder Linda Shannon with the prestigious Jefferson Award.

The Jefferson Award was implemented in 1972 when Jacqueline Kennedy Onassis, along with U.S. Senator Robert Taft, Jr. and Sam Beard, founded the American Institute for Public Service with the intention of establishing a "Nobel Prize" for public and community service

Due to her tireless efforts and commitments to individuals with vascular birthmarks, Linda Rozell-Shannon was selected as a local winner in Albany, NY, of the Jefferson Award, where she received a Jefferson Award medal. Linda was also selected as one of the 15 representatives to be sent to the national ceremony in Washington DC.

Linda's inspiration for VBF, her daughter Christine, accompanied her to the ceremony.



VBF Launches Kids Who Care

The Vascular Birthmarks

Foundation is proud to announce the establishment of VBF KIDS WHO CARE®, a program created by VBF Founder and President Linda Rozell-Shannon that is geared toward school-aged children K-12.

To head this program in a positive direction, the VBF is launching the VBF Kids Who Care - Birthmark Awareness Campaign. This campaign began on September 1, 2005 and will culminate on VBF Awareness Day, May 15, 2006.

KWC helps teach children the spirit of community service, and the rewards of charitable giving, while raising awareness and the much-needed funds. This program is perfect for schools that promote courage and confidence and helps teach children to respect and support other children who are different in any way.

This campaign is not limited to school participation only. Individuals or parents can take advantage of the KWC/DIY campaign by hosting a fundraiser of their choice. While the goal of these fundraisers are to coincide with VBF Awareness Day campaign, individual fundraisers can be held at any time during the year, and can encompass a wide variety of events.



Glen Ethington sells bracelets at the 2005 PWS conference.

Glen Ethington, VBF's first Kids Who Care participant, kicked off the campaign by selling bracelets at his school, and at the 2005 Port Wine Stain Conference. Glen has Sturge-Weber syndrome and a facial port wine stain.

Saige Cavayero, who had a facial vascular birthmark and is undergoing reconstructive surgery, inspired the Kids Who Care Bracelet campaign. Saige designed the bracelets for her 2005 VBF Awareness Day event.

VBF invites your child and local school to join us in this groundbreaking endeavor, because *kids with vascular birthmarks do care*.

For more information contact Tiffany at tethi@insightbb.com.

2006 VBF 3rd Annual Awareness Day Goes International



Please join us for our 2006 VBF 3rd Annual Awareness Day campaign.

This international grass roots campaign began in 2004, allowing participants all over the world to conduct their own personal fundraiser, and to tell their story. These are the stories of how a vascular birthmark has affected the lives of individuals and families. In doing so, these participants raised both awareness and desperately needed funds, which will help the VBF continue its important work of giving hope and changing lives for the better.

Members around the world hosted events for the 2005 VBF Second Annual Awareness Day. Over 70 families, from Canada to Brazil, held fundraisers and

awareness campaigns to benefit children and adults with vascular birthmarks.

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The events were all successful and most appreciated by the VBF, and were as diverse and imaginative as an E-Bay Celebrity Auction - to a young girl who sold her toys and clothes.



Elizabeth Peters' and "Wall of Fame". She and family sold VBF stickers, which were placed on the wall with the donor's name.

If you have any questions or need more information on how to organize your fundraiser, visit the VBF website, or please call our Awareness Day Director, Paige Salvador at 877-823-4646 or email her at: BASPASTS@cs.com (reference Day of Awareness).

VBF Announces 2006 International All Birthmarks Conference in Boston

VBF is proud to announce the first-ever All Birthmarks Conference. The event will be held in conjunction with Dr. Martin Mihm and the Massachusetts General Hospital in Boston, Massachusetts

This conference, a longtime dream of VBF President Linda Shannon, will highlight all types of vascular birthmarks, as well as the associated syndromes and related conditions. The conference is intended to be all-

inclusive and will create an atmosphere of a "reunion".

Families, support groups, foundations, physicians, and group/organization leaders will be invited to attend. The goal is to provide information to families and patients, and to help facilitate the gathering of accurate and timely data. This will help to ensure that all those involved in the vascular birthmark community are distributing correct and vital resources, and families and patients are no longer subjected to conflicting information.

To help in this process, the conference will include a leadership meeting – consisting of the presidents, founders, and organizers of vascular birthmark related groups. World-renowned physicians, who are the trailblazers in the field, will also participate in the meeting

More details will be released, as plans for the conference finalize. Please check the VBF

website for updates.

VBF Partners with BLI for Bi-Annual PWS Conference

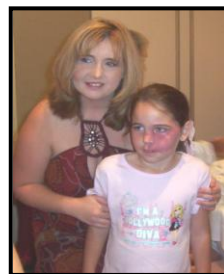
Due to the huge success of the VBF 2005 Port Wine Stain Conference, the VBF and the Beckman Laser Institute (BLI) have partnered to make this a bi-annual event. Taking place in California, the 3rd VBF Port wine Stain Conference will be held in 2007, and will alternate every other year with the VBF International All Birthmarks Conference.

The Surgery Laser Clinic located at the Beckman Laser Institute is the world's first dedicated center for research and treatment using lasers and light. Since 1986, their specialists have performed more than 25,000 laser procedures. Dr. J. Stuart Nelson is the Associate Director of the BLI Medical Clinic and the Medical Director of the Surgery Laser Clinic.

More announcements will be made regarding this exciting news, so please check the VBF website for further updates.

Conference Notes By Amber Wilson

The 2005 Vascular Birthmarks Foundation Port Wine Stain Conference went off without a hitch on October 7-8, in California.



This Kay Lewin (left) traveled from England, pictured with Moranda Reynolds of California.

conference, entitled Port Wine Stains- Past, Present and Hope for the future, drew attendees from Canada, England, Mexico, Alaska, Texas, Massachusetts, and a scattering of other states. Patients and their families came together to learn about the new research and treatments available for PWS.

Friday night everyone came together for opening remarks by Linda Rozell-Shannon, VBF President and Founder, and Michael Steffano, Founder and Administrator, Birthmarks.com.

This ceremony included surprise presentations to Glenda Ethington for being VBF's 2005 Service Award recipient,

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and Dr. Nelson for being VBF's Physician of the year- a great honor to both of them. Linda was presented with a beautiful quilt made by Pat Cason who has family member with a birthmark. The night ended with a party celebrating Bithmarks.com's tenth birthday

Saturday morning was filled with doctor presentations on research being done relating to birthmarks. Dr. Mihm spoke about pathology and why it is important for treatment, Dr. Nelson, on why PWS is difficult to treat and what can be done to improve therapeutic outcome, Dr. Waner, on classification and surgical management of PWS; Dr. Comi on Sturge-Weber Syndrome diagnosis and treatment, Dr. Delfanian on Klippel-Trenaunay diagnosis and treatment, and child life specialist Leslie Graff on the psycho-social effects of living with a PWS.

After the very informative presentations, clinic appointments at the Beckman Laser Institute began. In less than five hours, two teams of doctors were able to see 58 patients thanks to scheduling by Linda.

Team A consisted of Dr. Waner, Dr. Delfanian, Dr. Levitin and Dr. Fay. Team B was made up of Dr. Comi, Dr. Nelson, Dr. Hochman and Dr. Kelly.

While the clinic appointments were going on at the Beckman Laser Institute, the hotel was busy with discussions by Leslie Graff regarding the emotional aspect of living with a vascular birthmark, and sessions with local makeup artist Stacey Craven. Stacey showed patients how to cover up their birthmarks by using Smart Cover cosmetics.

This conference was made possible with help from the following people and organizations: Vascular Birthmarks Foundation, Dr. J. Stuart Nelson, Medical Director of the Beckman Laser Institute; Dr. Bruce J. Tromberg, Director, Beckman Laser Institute; UCI Research Associates, Candela Corporation, Pat Beckman, Kasper Foundation, Beckman Laser Institute, Inc., Mary Roosevelt, Dr. Roy Geronemus of the Skin Surgery Center of New York, Stacey Craven, and Nancy Roberts of Smart Cover cosmetics. Thank you to the Fairmont Newport Beach Hotel for housing the conference guests.

VBF Annual Mini-Fundraiser Highlights By Paige Salvador



Jason Gough of WNYT News Channel 13 Albany, NY, Paige Salvador VBF, and NY Assemblyman James Tedisco

Saratoga Polo Event

On August 5th 2005, VBF celebrated its 5th Annual Summer Event

Fund Raiser at the Polo

Grounds in Saratoga Springs, New York.



Over one hundred friends of VBF enjoyed polo, hors d'oeuvres, live music from the Saratoga Youth Orchestra, dinner and a silent auction, raising \$10,000.

An unexpected surprise came this year when VBF guests had the opportunity to meet and speak to

VBF Board Members at Polo Event

John Walsh of *America's Most Wanted*. John is a Saratoga summer resident and a tireless advocate for victim's rights and missing children.

Our Honorary Chair, NY State Assemblyman James Tedisco was on hand to speak to our guests and to offer his continued support. Assemblyman Tedisco has been a loyal supporter of VBF and its work and we are grateful to him.

This year's co-chairs, Maxine Baron and Elysa Baron, did a wonderful job in creating this success. The success of the polo event is a cooperative effort and we extend our thanks to all those who donated and attended

For more information, contact Paige Salvador at 518-209-6915.

NAPM Event

On December 3, 2004, the National Association of Purchasing Managers, Eastern New York Chapter, hosted its second Annual Silent Auction

Fund Raiser and VBF was its recipient. The dinner and auction took place at the Comfort Suites in Clifton Park, NY

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Our very special guests included Frank and Barbara Catalanotto and their children Morgan and Camdyn.

Frank plays professional baseball for the Toronto Blue Jays and he and his wife Barbara are VBF's Honorary Chairpersons. Frank and Barbara became supporters and friends of VBF when they contacted Linda Shannon regarding their daughter Morgan's hemangioma. We are grateful for their continued support.

Benita Zahn of WNYT – Albany, New Channel 13 was also on hand to host the event. She has been an advocate and supporter of VBF for years and her presence at our events makes them special.

In addition, Dr. Martin Mihm, Jr. was honored for his significant contributions to VBF. Dr. Mihm resides as VBF's Research and Scientific Advisory Committee Chairman and is a founding member.

We thank NAPM and its members who gave generously of their time to raise funds to further the work of VBF. This event raised \$5,000 for VBF.

SWSC Launches Canadian

Branch

VBF's first branch, The Sturge-Weber Syndrome Community (SWSC), launched its first chapter, SWSC Canada. Tom Gilbert serves as the Director, along with Co-Director Chantal Pichette (Tom's wife). Stephen Hawkins and Tabitha Dunphy (Stephen's daughter) serve as Assistant Volunteers.



Tom Gilbert and Tabitha Dunphy of SWSC Canada

Both Tom and Tabitha have SWS, offering a special insight

regarding the disease, and they serve as inspiration for others living with SWS.

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- ✓ Partnered with Eastern New York Chapter of National Association of Purchasing Managers to hold a December 2004 Silent Auction. Honorary Chairs Frank and Barbara Catalanotto were on hand to meet and greet attendees. Frank plays for the Toronto Blue Jays.
- ✓ Launched SWSC Canadian Chapter
- ✓ Launched VBF Kids Who Care
- ✓ Partnered with Beckman Laser Institute for 3rd PWS Conference with a commitment for 2007
- ✓ Announced 2006 ALL BIRTHMARK TYPES International Conference in Boston in October 2006
- ✓ Established Ask the Experts corner
- ✓ Held our annual Polo Event in Saratoga, New York
- ✓ Launched VBF Latin America

- ✓ Created the VBF We Care Bear as an on-going fundraiser for VBF. Over 500 bears sold in six months.
- ✓ Published VBF Birthmarks Brochure
- ✓ Attended National Institute of Health conference on vascular birthmarks
- ✓ President/Founder begins doctorate work on birthmarks to further the cause
- ✓ VBF Orphans With Birthmarks networks second orphan
- ✓ Published and posted numerous medical journals and parent resources on website
- ✓ Update website to be more user friendly and to provide more resources for families

So, what's left to do in 2006?
Plenty.

- ❖ We still need to get legislation passed that will require insurance companies to cover the treatment of children with vascular birthmarks.
- ❖ We also need to work directly with the primary medical insurance corporations in the United States so that they can have a better understanding of why so many of our families need out of network referrals.
- ❖ We have several physicians waiting to come to the United States to train in the diagnosis and treatment of vascular birthmarks. Due to a lack of sufficient funds, we have not been able to award any physician education grants in two years.
- ❖ We need to sponsor research and Dr. Mihm and his team are eagerly waiting to do with proper funding.
- ❖ We will be launching VBF Australia, VBF New Zealand and VBF Asia in 2006. We are ALMOST on every continent!
- ❖ We need funding to help with our 2006 International All

Vascular Birthmarks Conference so that we can keep the costs down to a bare minimum for families attending from around the world.

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We are expecting over 200 families to attend this conference.

- ❖ We need a marketing team that will help get the word out about VBF and especially about vascular birthmarks.
- ❖ We need to coordinate our 2006 International Day of Awareness. Only your help can make 2006 the best year ever. We would like 100 families participating from around the world in our DOA event. If you have not signed up yet, you can do it by

filling out the enclosed registration form.

- ❖ We need you to get involved. Become a parent or adult rep.
- ❖ Join our fund raising team or become a Kids Who Care coordinator in your child's school district. You can read about this later on in this issue.
- ❖ We need to design and distribute specialty brochures and booklets are various birthmark syndromes for all of our sub-specialty groups and conditions that we work with.
- ❖ We need your annual donation. Every donation enables VBF to help families all over the world affected by a vascular birthmark. You know and you can read in this issue how every dollar has a

place and every dollar is making a difference. We are not the type of charitable group that just collects money and has no new accomplishments each year.

We have grown over the past 11 years to be the leading not for profit in the WORLD for children and adults affected by a vascular birthmark. Your donations helped us to achieve that status and your continued financial support will help us to keep making a difference!

THANK YOU, for your past donations, and for the donation that we hope you will make this year!

**Vascular Birthmark Foundation
11/03/05 Profit & Loss
Accrual Basis January through December 2004**

INCOME

Contributions Income

Restricted	12,083.55	Net Ordinary Income	8,950.13
Unrestricted	98,187.00	Net Income	8,950.13
Total Contributions Income	108,290.99		
Interest Income	173.25		
Total Income	108,484.24		

EXPENSE

Gross Pay	7,100.00	Interest Expense	
Net Pay	275.85	Finance Charge	14.39
Payroll Tax Expense	848.32	Interest Expense - Other	54.85
Bankers MasterCard	0.00	Total Interest Expense	88.34
Paychex Expense	259.76	Licenses and Permits	85.00
Workers' Comp	7.56	Miscellaneous	500.00
FICA Payroll Tax Expense	105.40	Office Supplies	1,267.47
MEDICAD Payroll Tax Expense	24.65	Payroll Expenses	0.00
Advanta Bank Corp	0.00	Postage and Delivery	5,122.39
Milton Event Expense	86.60	Printing and Reproduction	6,199.88
Gala Expense	15,918.20	Professional Fees	
Conference expense	4,054.61	Accounting	1,395.00
Database conversion	1,702.80	Consulting	42,940.00
Internet Expense	749.00	Total Professional Fees	44,335.00
Office Equipment	43.28	Telephone	4,356.96
Amortization Expense	620.00	Travel & Entertainment	
Bank Service Charges	1,175.43	Travel	406.29
Contract Labor	0.00	Travel & Entertainment - Other	805.86
Contributions	2,125.00	Total Travel & Entertainment	1,212.15
Insurance	1,791.16	Uncategorized Expenses	0.00
		Total Expense:	\$ 88,514.11

VBF Donor/Fundraiser Registration Form

I would like to host the following VBF Fundraiser (Check all that apply):

Kids Who Care _____

Awareness Day _____

Other Fundraiser _____ Fundraiser type _____

~DONATION – Make Your Annual Tax Deductible Donation~

*Please fill in contact information below

I would like to make the following donation to:

____ Vascular Birthmarks Foundation (VBF US)

____ VBF Australia

____ VBF Europe

____ VBF Israel

____ VBF Latin America

____ VBF New Zealand

____ Sturge-Weber Syndrome Community

____ SWSC - Canada

*Contact Information

Fill out form where applicable:

Full

Name: _____

School Name: _____

Street Address: _____

City: _____ State: _____ Zip Code: _____

Principal: _____

Home Phone Number: (____) _____ Work: (____) _____

Email: _____

Number of Students participating: _____

Please check the box next to your campaign choice.

VBF Kids Who Care/Pennies for a Purpose – Individuals/Students can host a penny collection drive. Wrappers will be provided. Please exchange the pennies for cash and mail a check or money order in the self-address stamped envelope.

VBF Silicone Bracelets – VBF bracelets are embossed with “VBF Kids Who Care”. Bracelets will be sent in volumes of 50.

VBF We Care Bears – Birthmark Buddy We Care Bears are embroidered with the VBF logo. We can send you one bear to use to take orders for and when you are finished taking orders and collecting the money for the bears, we will send you the full supply.

DIY - Individuals/Students can host their own “Do-It Yourself” fundraiser (lemonade stand, car wash, garage sale, bake sale, etc.).

Type of DIY fundraiser (yard sale, auction, etc.): _____

____ DIY - Awareness Day _____ DIY – KWC _____ Other _____

For all fundraising campaigns: Please send in the money you collect as a check or money order made out to VBF, and send in the self-addressed stamped envelope provided for your convenience. Send monthly or at the end of your campaign. VBF, P.O. Box 106, Latham, NY, 12110

Individual Purchases - I would like to purchase the following items:

VBF Silicone Bracelet - \$3.00 Ea.

Adult size _____ #Youth size _____ Total Amount: \$ _____

VBF We Care Bear - \$20.00 Ea.

Bears _____ Total Amount: \$ _____

2003 PWS Conference 4-Part Video - \$29.99 Ea. + \$5.00 S/H

#2003 Conf. Video _____ Amount: \$ _____

2005 PWS Conference 3-CD Audio Series – Donation of \$49.99 Ea. (\$30.00 Ea. is tax deductible).

#2005 PWS Conf. CD _____ Amount: \$ _____

KWC: Contact Tiffany Ethington at (859) 272-3857 or Email: tethi@insightbb.com

For KWC, return form to: VBF/KWC, P.O. Box 24890, Lexington, KY 40524-4890

Awareness/General Fundraisers: Contact Paige Salvador at (856) 234-2126 or Email: BASPASTS@cs.com

For Awareness Day or General Fundraiser, return form to: VBF/Fund, P.O. Box 106, Latham, NY 12110

____ I am interested in attending the 2006 VBF All Birthmark Conference in Boston.

____ Please remove me from your mailing/email list (address above).

____ I would like to become a VBF Parent Representative. Please send me more information (address above).

VBF is a fully approved not-for-profit. Federal Tax ID 16-1515227

DONATION – CREDIT CARD/CHECK/MONEY ORDER

Amount of Donation: \$ _____

Name on Credit Card: _____

Type of Credit card

____ VISA _____ MasterCard

____ Discover _____ American Express

Credit Card Number: _____

Expiration Date: _____

____ Check or Money Order: payable to VBF (memo branch)

Mail to: VBF, P.O. Box 106, Latham, NY 12110

THE VBF IS WORKING FOR YOU

The VBF has networked over 20,000 patients into treatment since 1995

Helped to establish nine VB clinics

Website and Discussion Group

Annual Newsletters/Day of Awareness Newsletter

Doctor list and referral information

Ask the Experts/Ask-A-Nurse on website

2005 PWS Conference - Irvine, California

Family support and education/Physician education

VBF Branches – Israel/South America/Europe/New Zealand

Sturge-Weber Syndrome Community/SWSC Canada

VBF Program - VBF Awareness Day/Babies with Birthmarks/Orphans with Birthmarks/Kids Who Care

Mission Statement

The Vascular Birthmarks Foundation is an international charitable organization that provides support and informational resources for individuals affected by hemangiomas, port wine stains, and other vascular birthmarks and tumors, while sponsoring relevant research and promoting physician education.



VBF

P.O. Box 106

Latham, NY 12110

(877) 823-4646

www.birthmark.org

