



VBF Awareness Day Newsletter

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SPECIAL EDITION©

First Annual VBF Awareness Day A Huge Success

The First Annual Vascular Birthmarks Foundation National Awareness Day was held on May 15, 2004.



VBF Founder and President Linda Rozell-Shannon with New York Assemblyman James Tedisco raise awareness at a local McDonald's.

~Thanks to the hard work and generosity of VBF members, friends, and families our first Awareness Day was a huge success.~

The campaign, spearheaded by the Awareness Day Chairman Karla Pripke, and Executive Director Paige Salvador, included a host of volunteers

from the US and Canada, and raised over \$20,000.

Karla and husband Peter have a son, John, with Sturge-Weber Syndrome (SWS). The Pripke's have been active in bringing light to this rare disease.

Paige's son, Tyler, had a lower-lip hemangioma, and was the first child networked into treatment by the VBF.

Linda Shannon, Founder and President of the VBF, took over the grill at her local McDonald's Restaurant.

New York Assemblyman James Tedisco rolled up his sleeves and joined Linda and other volunteers in cooking and serving food; while raising funds for the cause, and spreading awareness in the New York area.

Linda also appeared, along with her daughter Christine, on local affiliate TV news programs. Christine was the inspiration for the formation of the VBF. She was born with a hemangioma on her lip, which led Linda on a mission to

research vascular anomalies and to later found the VBF.

Linda is proof positive of the impact a single individual can have on the lives of so many. The VBF has networked over 20,000 patients into treatment since 1995.

Life-Altering Surgery Sparks Awareness

Shortly after Aslynn Brown was born, a small red spot appeared on her head - a hemangioma. Slowly it began to grow. Like many children with hemangiomas, Aslynn's parents were advised to leave the growth alone, as it would involute and disappear on its own. Instead, it grew...



Growth caused strain on heart.

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until it covered most of the back of her head. The growth pushed her ear forward and caused it to “fold”.



Aslynn’s ear began to “fold” from weight of growth.

As it grew, the now enormous hemangioma required more blood to feed itself. As the growth diverted bloodflow, the strain on Aslynn’s heart was becoming increasingly life-threatening.

Paul and Jill Brown sought the help of Dr. Milton Waner, VBF’s Honorary Medical Chairman, who had pioneered surgery for hemangiomas and other vascular birthmarks.

The surgeries Dr. Waner performed were becoming world-renowned. Aslynn’s grandmother, Judy Brown, had searched the Internet and found the VBF website, where she learned of Dr. Waner’s groundbreaking surgical techniques. Many considered these surgeries “miracles”.

Up until this time, most doctors have been hesitant to operate on these growths, as excessive blood loss can result. While most doctors practice the “wait and see” approach when it comes to these types of birthmarks, Dr. Waner felt that early treatment and

removal of these types of growths was not only possible, but could act as a preventative measure for possible complications due to excessive growth; as well as being essential to the emotional and psychological well-being of patients as they became older and more aware of their condition.

In May of this year, Dr. Waner performed another one of his “miracles” and was able to remove almost all of the massive hemangioma in a single surgery.



Aslynn Brown after “miracle” surgery to remove a life-threatening hemangioma.

Today, Aslynn is healthy and happy, and has almost fully recovered from her surgery.

Inspired by her daughter, Jill Brown hosted an awareness campaign by holding a garage sale at her home in **Grimes, Iowa**. In addition, Aslynn and the Brown family were featured in articles by their local community newspaper, in the *New York Magazine* Best Doctors series featuring Dr. Waner, and are featured in October’s *Reader’s Digest*.

VBF Awareness events hosted by members across the United States and Canada

North Carolina Events

Betsy Lamb of Charlotte, North Carolina, hosted a yard sale and donation drive to support the VBF Awareness Day campaign. Her neighbors rallied to the cause and donated items for the sale.

Betsy said her inspiration is her son, Jeremy, who has a venous malformation on his face, and also “the help I got from the VBF website, which helped me with his diagnosis.”

Proceeds from Betsy’s yard sale netted well over \$3,000.

Florence Chavez of Shallotte, North Carolina, organized a neighborhood collection drive.

Her children Michael and Jennifer, who were assisted by their friend Lauren Sparks, canvassed their neighborhood collecting over \$100.

The children also received a \$20 donation from a patient at a local nursing home.

Florence’s son, Michael, has a venous malformation in his leg.

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South Carolina Events

Jackie Burke of Columbia, South Carolina, collected donations through Lakeside Outreach Ministries.

The generosity of the group helped to raise approximately \$1,000 toward funding VBF projects and programs.



8-year-old Abigail is the daughter of Michael and Jackie Burke.

Jackie's daughter, Abigail, has a venous malformation on her lip

Jackie also plans to distribute the VBF fact pamphlet to local hospitals.

Joy Hird of Conway, South Carolina, raised funds and awareness in honor of her daughter, Lydia. An article written by Joy was published in her church newsletter and an article also appeared in the local newspaper, Lydia's treatment for facial hemangioma has included steroids, laser treatments, and eye surgery. Lydia faces more surgery in October.

Jennifer Wylie of Gaffney, South Carolina, joined the VBF fact pamphlet campaign. Known as "Jinny" to her friends, she distributed pamphlets to medical professionals in her area. Jinny's son, Austin, has Sturge-Weber syndrome, and has port wine stain on his face and other areas of his body. Jinny also manages the CMTC discussion board for the VBF and the online support group for the SWSC.

Connecticut Events

Suzanne Walsh of Simsbury, Connecticut, raised awareness by having an article written about her daughter, Molly, in her local newspaper. Molly has a nasal tip hemangioma that was removed during recent surgery in New York.

Canadian Events

Cheryl Visentin of Ontario, Canada, collected close to \$600 in donations for awareness. Her daughter, Sara, had a hemangioma on her forehead, which was surgically removed. Sara also had hemangiomas on the back of her neck, chest, back and diaper area. Cheryl designed and distributed a pamphlet, which highlighted Sara's surgery and VBF Awareness Day.

Lise Daoust of Quebec, Canada, launched the first French-language website for vascular anomalies. Lise has

an arteriovenous malformation of the lip, and has dedicated her time in helping others with vascular birthmarks, and by networking with support groups and foundations. Visit her French-language website at:

<http://www.anomalievasculaire.org>

Rhonda Spuzak of Ontario, Canada, wrote an article for her local newspaper about her daughter Kenna. The story included information about VBF Awareness Day, hemangiomas, and Kenna's personal story of hemangioma growth on the top of her head.

Kentucky Events

Mother and son team, Tiffany and Glen Ethington of Lexington, Kentucky, did their part to raise funds and awareness for vascular birthmarks. Tiffany and Glen appeared on a local afternoon news program to talk about birthmarks. Glen has Sturge-Weber syndrome and a port wine stain on his face. Glen also organized an awareness campaign at his school, Maxwell Elementary. The students participated in "Hat Day", where they could wear a hat in school for a donation to the VBF. Glen and his classmates raised over \$700.

Michigan Events

Holly Gregory of Three Rivers, Michigan, sent out flyers and talked to people in

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her area to raise awareness and funds for VBF. Her son Jonny had two hemangiomas.

Mississippi Events

Marla Rutland, a teacher in Petal, Mississippi, coordinated a letter campaign to local businesses for awareness. In addition, she and her students held a car wash and sticker sale to raise funds for VBF.



Marla Rutland and students at their car wash for VBF Awareness Day.

The eighth-grade students at Petal raised over \$800 to help further physician education and to direct patients to the proper treatment. Marla's daughter, Marleigh, has a hemangioma on her eyelid.

Missouri Events

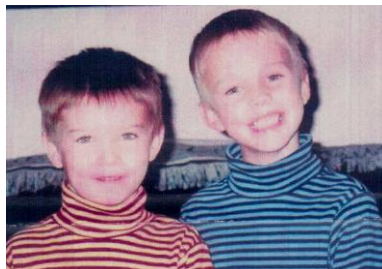
Elissa Rifkin of Clayton, Missouri, was inspired by her daughter Jacqueline ("Jaci") to raise awareness for the VBF. Elissa, VBF's first Clinic Rep., facilitated an interview with Dr. Susan Mallory, as well as a mother of a teenager with Sturge-Weber syndrome, for a local evening news program's Health Section. She also volunteers at the Birthmark Clinic at St. Louis Children's

Hospital, and had an article placed in their *Doctor's Digest* magazine. Jaci, now 14 years old, had a hemangioma on her nose and is undergoing reconstructive surgery. Jaci donated money from her Bat Mitzvah to the VBF.

New York Events

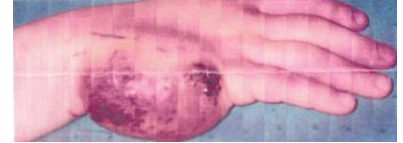
Ann Cioffi, VBF Parent Rep. from Troy, New York, helped to organize volunteers for the WMHT fundraiser in Schenectady. VBF members Linda Shannon, Charlotte Gallo, Mike Schaefer, and JoAnn Moretti joined Ann at the event. WMHT interviewed Linda Shannon on-air to bring awareness about vascular birthmarks and the need for better diagnosis and treatment. Ann's son Matthew, who has Klippel-Trenaunay syndrome, served as inspiration for her efforts. Ann also sold stickers at her favorite local hair salon, and participated in "Niska Day" at Niskayuna High School. Both events raised over \$60.

Lianne Chase of Albany, New York, called on friends, family and co-workers to help her celebrate Awareness Day. For her birthday on May 15, Lianne threw a party for VBF.



Brothers Cody and Casey Chase.

She emailed friends and colleagues a letter, including pictures and a proclamation by NY Rep. John E. Sweeney.



Vascular Malformation.

Both Cody and Chase have birthmarks; Cody has a vascular malformation on his hand, and Casey has small marks on his neck. Lianne's efforts netted around \$500.

Kim Riggi of Clifton Park, New York, hosted a birthday celebration for her twin daughters, Josephine and Sophia, for VBF Awareness Day. Thanks to the generosity of family and friends, they raised \$600.

Ohio Events

Julie Rose of Cambridge, Ohio, hosted "A Day of Awareness for children with Birthmarks".



Hannah Smith and Kennedy Rose play in the ball pit.

The mayor of Cambridge attended the event, and there was a variety of games and fun for the children.

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Several local businesses donated items for a “Chinese Auction”, as well as food and drinks for the event.

Julie had the help of Staci Smith and Wendy Curtis, and all are mothers of a child with a vascular birthmark. Their children, Kennedy Rose, Hannah Smith, and Tara Curtis served as the inspiration for the women.

Julie said, “Our three daughters had a wonderful time and thought it was ‘cool’ to have a birthmark because they got their own Day!” Plans are already underway for next year’s event.

Pennsylvania Events

Lily Mollencott participated in Awareness Day by handing out the VBF pamphlet to doctors’ offices in her area of Philadelphia, Pennsylvania. Lily was inspired by individuals living with vascular birthmarks.

Rhode Island Events

Ken and Carla Senus of Coventry, Rhode Island, held a “Dress Down Day” at the bank where Ken works. They raised over \$300 for awareness.

Melissa Barrett of Jamestown, Rhode Island, held a raffle to benefit VBF and to raise awareness. Melissa was also instrumental in bringing PGA golfer Casey Martin on Board for the VBF Special Event this

summer in Albany, NY. Melissa’s children sold candy, which was homemade by their grandmother, at the Special Event to add to their collection for Awareness Day. Together, the family raised over \$1,000. Melissa’s son, Jordan, has Klippel-Trenaunay syndrome.

Texas Events

Natalie Bolinger of Dallas, Texas, conducted a mailing campaign to family and friends, raising \$1,600. Natalie orchestrated the design of a three-fold, full-color brochure, telling about her daughter and the VBF Awareness Day. Natalie’s daughter, Nicole, had surgery to remove a hemangioma on her right cheek.

Virginia Events

Beth Eldridge of Vienna, Virginia, conducted a letter campaign to family and friends. Beth’s son, Benjamin, had surgery to remove a nasal-tip hemangioma, and he also has a lymphatic malformation on his chest.

Washington Events

Corinne Barinaga, Vancouver, Washington, is VBF’s Director of Informational Services. She distributed VBF pamphlets to medical professionals in her area. Corinne’s son, Nicholas has a segmental hemangioma on his head and is currently undergoing treatment.

Wisconsin Events

Jennifer Kalmon of Wisconsin Rapids, Wisconsin, sold stickers to family, friends and coworkers. An article about her son, Braden, appeared in her local newspaper. Braeden has a nasal-tip hemangioma. Jennifer’s sticker campaign helped to raise close to \$200 for VBF.

Corporate Donations

Thanks to Cadbury Schweppes Americas Beverages for their generous donation of \$5,000. The donation was made in honor of the Sturge-Weber Syndrome Community, in order to help further the cause of those with Sturge-Weber syndrome. Peter Priepeke, whose son John has Sturge-Weber syndrome, is employed by the company.

The Bemis Company, Inc. Foundation donated \$500 to VBF Awareness Day. Eric Emiliani is employed by Bemis-owned MACtac. Eric and wife Tara have a daughter, Taylor, with a hemangioma.

Congressional Record

The VBF would like to offer a special thanks to Congressman John E. Sweeney (R-NY) for reading into the Congressional Record a Resolution proclaiming May 15, 2004, VBF National Day of Awareness.

A Message from VBF President and Founder Linda Rozell-Shannon

In the 60's, Bob Dylan sang, "The Times They Are A Changin'," and that is the perfect title for what has happened in the world of birthmarks since my daughter Christine was diagnosed in February 1994. The times are a changin' ...for the better...for those affected by a vascular birthmark.

How appropriate that our First National Day of Awareness would be held the same year that marks 10 years ago when I began to fulfill the vision that God gave me to start a foundation, write a book, and raise \$1,000,000 for vascular birthmarks. On May 15, 2004, and for weeks before and weeks after, it was like a cloud rising up over the United States and Canada, as over 50 families told their stories and raised money to bring awareness to vascular birthmarks.

How exciting that the number of treatment centers has quadrupled in the past 10 years, mainly because of the efforts of VBF. We now have an international family support network and new programs springing up every day. Our partners include other birthmark support groups, and we continue to stretch out our arms to embrace any organization that provides informational resources and support to families affected with a vascular birthmark. Legislation is pending that will require insurance companies to cover treatment of birthmarks, and guidelines are before the primary medical groups to approve early intervention, all through the efforts of VBF and other birthmark support groups.

Our first National Day of Awareness was phenomenal, thanks to the efforts of VBF's Executive Director Paige Salvador, our Public Relations Director, Glenda Ethington, and our Awareness Chairman, Karla Priepeke. Also, many families helped all over the United States and Canada by conducting mini fundraisers and public relations campaigns. I can't wait to start next year's campaign. It will be another exciting time, and I hope we can double the number of stories that are told nationwide. Each time a story is told about a family dealing with a vascular birthmark, another child is helped because of the awareness. One day, one story, one step at a time...the times they are a changin', and you and the VBF are making this change happen.

Thank you to everyone who participated, and I look forward to you being a part of the 2005 campaign.

Linda Rozell-Shannon

Physicians Raise Awareness and Hope

The VBF would like to extend their thanks and gratitude to Dr. Milton Waner and Dr. Martin Mihm, Jr., for their support of Awareness Day. Not only do these doctors provide financial contributions to the foundation, they also devote their time and efforts to making life better for patients with vascular birthmarks. Each and every patient and their family receive unequalled medical care, as well as compassion and respect.

Dr. Waner, VBF's Honorary Medical Chairman, is an internationally recognized authority on hemangiomas and vascular malformations. He is currently the Co-Director of the Vascular and Birthmarks Institute of New York at Roosevelt Hospital. Dr. Waner has pioneered surgical techniques for the treatment and removal of vascular lesions.

Dr. Mihm, VBF's Research Director and Scientific Advisory Committee Chairman, is one of the founding members of the VBF. He also founded the Albany Medical Center Vascular Anomalies Program and the Massachusetts General Hospital Vascular Anomalies Program. He is the Director at both clinics. Dr. Mihm is responsible for having the World Health Organization Rare Tumor Institute classify a hemangioma as a "rare tumor."

The 2005 Second Annual Vascular Birthmarks Foundation Awareness Day

What's missing? You! The VBF would like to highlight your story in next year's Awareness Day Special Edition Newsletter. Please don't forget to sign and return the **Registration/Permission to Publish Form** for next year's Awareness campaign.

Don't miss out on this opportunity to have fun while raising funds and awareness, and helping to educate the public about vascular birthmarks. Each and every event is important. Fundraisers can be simple, but effective. Friends and families joined in the 2004 campaign by holding Easter egg hunts, car washes, birthday celebrations, and raffles. Others organized letter writing campaigns, newspaper articles, television appearances, and brochure and pamphlets distributions.

Plans are already underway for *The 2005 Second Annual Vascular Birthmarks Foundation Awareness Day*, and the VBF is ready to help you make your event a success. Let our Awareness Day Committee assist you in organizing and planning your 2005 event.

To receive your VBF Awareness Day Registration Packet, or if you require more information, fill in and return the form below; or write to Paige Salvador at: VBF, P.O. Box 106, Latham, New York, 12110. Please include your name, address, telephone number, and email address.

2005 VBF Awareness Day Registration Packet Request

Please send me a VBF Awareness Day Registration Packet.

NAME: _____

ADDRESS: _____

CITY: _____

STATE: _____ **ZIP CODE:** _____

TELEPHONE: () _____

EMAIL: _____

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

Doctor list and referral information

Ask-A-Nurse on website

PWS Conference in 2005 - Irvine, California

Family support and education

Physician education

Newsletter

Sturge-Weber Syndrome Community - <http://swscommunity.org>

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.



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