



Vascular Birthmarks Foundation Annual Newsletter 2015

Editors: Carla Mannix, Administrative Assistant, and Dr. Linda Rozell-Shannon, VBF President and Founder

2015 Vascular Birthmarks Conference and Clinic in California



Dr. Anton Hasso, Dr. Rozell-Shannon, Jade Riley and her Z Team

An estimated 300 people benefitted from our Annual Conference and Clinic in Newport Beach, CA.

Twenty experts in the field of vascular birthmarks donated their time to give families an accurate diagnosis and informal treatment plan, providing over 130 free clinic appointments at the Beckman Laser Institute in Irvine, CA. Clinic physicians included Dr. Francine Blei, Dr. Tatiana Belysheva, Dr. Kamiab Delfanian, Dr. Laura Findeiss, Dr. Anton Hasso, Dr. Kristen Kelly, Dr. Gregory Levitin, Dr. Martin Mihm, Dr. Stuart Nelson, Dr. Paula North, Dr. Teresa O, Dr. Srinivasan Paramasivam, Dr. Anna Leticia-Pinto, Dr. Robert Rosen, and Dr. Milton Waner.

VBF honored Dr. Paula North as the 2015 Physician of the Year. Dr. Anne Comi was recognized with the Michael W. Berns Achievement Award. The 2015 VBF Service Award was presented to Missy Scott, our esteemed website administrator.

More importantly, over 50 medical procedures were scheduled as a result of the Conference. The experience of Lindsay, a mother from Mississippi, was echoed by many of the families after the Conference.

I'm reminded how thankful I am. Thankful that my daughter Mary Vickery's hemangioma is located where it is. As I have been reading some of the kids' blogs that we met at the Vascular Birthmarks Conference last weekend, my heart aches for these families and the journey they are on with their vascular birthmarks. Some can be treated with laser treatments or surgeries, but some have no

treatment and have to be left alone. I met another mom who is a board member with the Vascular Birthmarks Foundation [Tiffany Ethington]. Her son, now 18, was born with a port wine stain. This is one birthmark that can't be completely removed. It covers half of his face. He is beautiful and unique. She took me under her wing the night before the conference started and it was such a blessing to me. God sent her for a reason. I was at ease when I talked to her. She told me about the emotions I would have throughout the day, and boy was she right! That evening, after our clinic appointments with the doctors, she walked me outside to hear the news about how Mary could be treated. To hear that she could AND would have surgery was such a relief, and also that I had found someone who would do it was such a relief. I was so happy! We promised to keep in touch and send updates. She will never truly know how much she means to me.

Mary's hemangioma was removed on Nov. 17th.

"To hear that she could AND would have surgery was such a relief, and that I had found someone who would do it was such a relief."

VBF managed to arrange for some fun, too. Jade Riley traveled with her two children from New Zealand to get advice for how to best treat her daughter's PHACES syndrome. After the conference, Dr. Anton Hasso, long-time VBF-network physician, took the family to some local theme parks. Also, the Robertson family from Oregon won the raffle for the Walt Disney World Resort vacation donated by the Antonelle family and Mickey Travels, which generated over \$2000 in much-needed funds.

While networking families with a vascular birthmark specialist is at the heart of VBF's services, many of the families express sincere gratitude for the emotional and social support given before, during, and after the Conference and Clinic.



See why Dr. Linda Rozell-Shannon 'Put On Your Birthmark' - page 6

Letter from VBF President



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

2015 has been an amazing year for VBF and for individuals affected by a vascular birthmark.

VBF celebrated its 21st year as the leading not-for-profit in the world serving families affected by Hemangiomas, port wine stains, vascular malformations, Sturge-Weber Syndrome and other vascular birthmarks and tumors.

We now have international chapters on all continents, except for Antarctica! We are receiving over 3.7 million hits each month on our websites and over 80,000 individuals have been networked into treatment since 1994.

Our **VBF iTEAM** (international team) has now been to Russia, India, and Israel and is heading to Italy in 2016. We are also presenting at an international conference at the Nicklaus Children's Hospital in Miami, FL in February 2016.

In September 2015, I was thrilled to present at the Grand Rounds Session at the Nicklaus Children's Hospital in Miami, FL for their monthly lecture series regarding Vascular Anomalies.



Dr. Linda with Dr. Ana Duarte and Dr. Chad Perlyn in Florida

A huge breakthrough has occurred from my work with the American Academy of Pediatrics. A letter that we jointly worked on to urge insurance companies to cover the treatment of all vascular birthmarks was issued in February and again in July 2015. There has been a tremendous outpouring of praise for this letter, which was signed by Presidents of the following major medical academies: American Academy of Pediatrics, American Academy of Dermatology, Society for Pediatric Dermatology and the American Society for Dermatologic Surgery. The pediatric textbook used by all pediatricians is also being revised to include information on early treatment, and the Bright Futures handbook carried by all pediatricians now includes a review and referral when vascular birthmarks are present in an infant.

I am also thrilled to announce that I have outlined the first ever vascular anomalies [on-line course for physicians](#). Dr.

Francine Blei and Dr. Robert Rosen are co-sponsors of the implementation of the course as a CME-accredited program, along with the North Shore LIJ Health System, which has sanctioned the highest level of CME credits for the course.

For 2016, we are also working on a **Physician Portal** for doctors from around the world to share complex cases with our iTEAM. Our iTEAM will then review the case and respond to the physician regarding a suggested treatment plan.

Our **Annual Conference** continues to be our core focus for both family and physician education. We work all year to raise the funds to pay for families to attend our conference. We provide lodging, meals, and even waive our conference and clinic fees for families who cannot afford to pay. We are the only birthmark organization that provides this service.

Our **Ask/Accept** anti-bullying program is really taking off since we hired two social media experts: Lisa Bianchi and Crystal Hodges. They are "knocking it out of the ballpark" and our presence on all social media has quadrupled!

2016 is just around the corner. As we celebrate May as Vascular Birthmarks Awareness Month, we are asking vascular anomalies treatment centers around the world to participate in our **VBF Day of Awareness** Campaign by offering a free clinic. So far, we have 6 places throughout the world (New York, Miami, California, Boston, Berlin, and Israel) and are looking for more to join us. Stay tuned.

With your support, **VBF IS MAKING A DIFFERENCE !**
Without your support, we cannot exist.

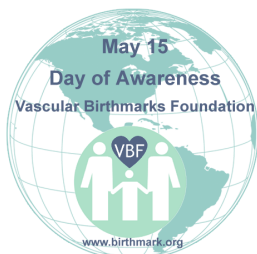
Remember VBF when you are making your annual charitable donation because, together, we can **MAKE A DIFFERENCE** in the lives of individuals affected by a vascular birthmark.

Make your annual donation today !



VBF - MAKING A DIFFERENCE
Together with the Families,
Board Members, Staff, Volunteers, and Donors

VBF 12th Annual Day of Awareness May 15, 2015



<http://www.birthmark.org/awareness>

2015 VBF Day of Awareness Events

- ❖ On May 15th, almost 30,000 people were reached and over 1,530 inspired members engaged with the stories and photos on our Facebook pages and affinity groups.

- ❖ Thank you to all the families who created personalized online fundraising pages and together raised enough to sponsor 10 families [\$5000] to VBF's Conference:
John J Brown III Joanmarie DiMirco
Misti Dixon Laurie Firstenberg
Alison Maddox Elizabeth Poon

- ❖ Lauren and Tony Sheehan of Illinois created a Bravelets bracelet page in honor of their daughter born with a port wine stain. \$10 of every purchase, over \$400, was donated to VBF.



- ❖ Board member Sharon Israel organized an *Alex and Ani Charmed by Charity* event in NJ on March 17 which donated 15% of all sales to VBF.

- ❖ Lucy Wang received a VBF college scholarship in 2014 and organized a fundraiser at a favorite BBQ spot in Wisconsin as her pay-it-forward event.

- ❖ Marisa Kalafer created 100 VBF keychains to sell and raise awareness as her bat mitzvah project.

- ❖ Kianna Smith of Trinidad and the Rogers Family of CA produced videos thanking VBF for networking them.



- ❖ Inspired by VBF's upcoming iTEAM trip to Italy, Lisa Lanza, who has a port wine stain, donated the proceeds and CD sales of her solo piano concert at the NW Maritime Center in Port Townsend, WA on Sept. 20th.

- ❖ Alana Kamins created www.artsialana.com to sell her artwork online and donate the funds to VBF.

- ❖ *Buddy Booby's Birthmark* book Read-Along events took place in Colorado, Iowa, Massachusetts, Michigan, and Texas.

Major Events Generate Funds to Advance VBF's Mission

- ❖ The 4th Annual *Olivia's Walk for Birthmark* organized by board member Andria Gottsabend and family was held on May 16th at Neshaminy State Park in Bensalem, PA and raised over \$8300.



- ❖ VBF's 1st Annual *Chasing the Cure* Golf Benefit was held in Troy, NY on Sept. 20, 2015. Organizer Kyla Manny named it in honor of her son Chase. It featured a dinner catered by the locally-renowned Old Daley Inn and raised over \$10,000.

- ❖ Honorary Chairpersons Frank and Barbara Catalanotto hosted the Fifth Annual *Catalanotto Golf Classic* to benefit VBF on August 3, 2015 in Woodside Acres, NY. This year, they added the *First Annual FCF Celebrity All-Star Softball Game* on Sunday, August 2nd at the Bethpage Ballpark, home of the Long Island Ducks. Thousands of people gained awareness of VBF's programs and the Frank Catalanotto Foundation was able to contribute \$50,000 toward VBF's programs.



Alyssa Leto, who has a rare brain AVM, visits one of the ads on the Long Island Railroad platforms in August 2015.

[VBF] is a true advocate....Through trials and tribulations with insurance denials, they were able to provide me with valuable resources to finally receive approval for medical insurance coverage for my son.

-Rachel Lane, Texas

Dr. Linda's Advocacy with the AAP Results in Major Changes for Children with Vascular Birthmarks

Dr. Linda pioneered a letter signed jointly by the American Academy of Pediatrics, Society for Pediatric Dermatology, American Academy of Dermatology, and American Society for Dermatologic Surgery Association urging medical directors of insurance companies to approve timely evaluation and treatment of potentially problematic vascular birthmarks.

On July 8, 2015, after years of advocacy by Dr. Linda working with outgoing President of the AAP, Dr. Thomas McInerney, the current presidents of the AAP, SPD, AAD, and the ASDSA issued a letter that "call upon public and private payers, including health plans, to provide comprehensive benefits coverage and appropriate payment for evaluation and treatment of vascular anomalies."

This major accomplishment immediately began to help families around the country get insurance approval for medically-necessary procedures. Dr. Linda is currently working on other initiatives with the AAP to improve the lives of families affected by a vascular birthmarks.

Excerpt from AAP's clinical guidelines released in Sept. 2015

CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

American Academy
of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™



Diagnosis and Management of Infantile Hemangioma

LEAD AUTHORS

David H. Darrow, MD, DDS, FAAP
Arin K. Greene, MD, FAAP
Anthony J. Mancini, MD, FAAP
Amy J. Nopper, MD, FAAP

"Although many IH [infantile hemangiomas] can be observed without treatment, others will clearly benefit from medical or surgical intervention. It is important for pediatricians to keep abreast of

advances in IH management, because the types of intervention and the threshold for their use are likely to evolve. When complications are likely or the threshold for intervention is uncertain, referral to an experienced specialist or a multidisciplinary vascular anomalies center may be advantageous." (page e1092)

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ASK THE VBF EXPERTS service on our website www.birthmark.org allows parents to contact an experienced specialist directly.
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Making a Difference Around the World

Look at that first photo with the baby in her mother's arms. That picture is from June 2012 when the VBF iTEAM went to Russia. One of the families they met was Baby Guzal with a facial hemangioma and her mother. Dr. Linda refused to leave Russia without a plan to save Guzal. It did not appear there was any hope, but with GOD "all things are possible." The other photo shows a smiling Guzal in Dec. 2015 after four surgeries and numerous laser treatments with Dr. Tatiana Belysheva (above).

The doctors at the hospital where Guzal was born told her mother to "leave Guzal" because she would never be normal. The mom traveled a great distance (nearly a half day travel) from Moldova, a small country between Ukraine and Romania, in order to meet the VBF iTEAM in Moscow to save her daughter. A group of us joined together to save Guzal and give her a chance at a normal life. Hallelujah!

VBF is especially grateful to Olga Bachuk who was instrumental in bringing all the patients to Russia, and to Olga Ioffe Kasher and Tatiana Lazareva who raised significant funds for the treatments. Dr. Levitin skillfully removed the hemangiomas and discounted the surgeries. There were other donors, including VBF, who paid for some of the lodging and helped with airfare and the cost of each surgery. It was a major team effort!

People from all over the world pulled together to make a difference in the life of one precious little girl who a doctor told the parents to abandon. Every life is precious. Every child with a vascular birthmark deserves the right to have proper treatment.

VASCULAR BIRTHMARKS FOUNDATION, INC
STATEMENTS OF FINANCIAL POSITION
DECEMBER 31, 2014 (Reviewed) AND 2013 (Audited)

ASSETS

	2014 (Reviewed)	2013 (Audited)
Current Assets		
Cash and cash equivalents	\$460,296	\$299,282
Prepaid Expenses	234	14,746
	-----	-----
Total Current Assets	\$460,530	314,028
Fixed Assets		
Property, Plant and Equip, Net	774	425
Other Assets		
Overpayment	16,805	-
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Total Assets	<u>\$478,109</u>	<u>\$314,453</u>

LIABILITIES AND NET ASSETS

Current Liabilities		
Accounts Payable & Accrued Expenses	\$3,293	\$248
Unearned Revenue	200,000	44,919
	-----	-----
Total Current Liabilities	\$203,293	45,167
Net Assets		
Unrestricted	269,816	264,286
Temporarily Restricted	5,000	5,000
	-----	-----
Total Net Assets	<u>\$274,816</u>	<u>269,286</u>
	-----	-----
	<u>\$478,816</u>	<u>\$314,453</u>
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VBF 2015 Physician of the Year
Dr. Paula North



Dr. North is an internationally-recognized expert in the pathological diagnosis of vascular anomalies. Her research uncovered some possible causes of infantile hemangiomas and contributed to the discovery of the genetic mutation behind Port Wine Stains and Sturge-Weber Syndrome. She is currently the Director of Pathology at

Children's Hospital of Wisconsin.

VBF iTEAM Supports Physician Education

VBF's iTEAM (international medical mission team) shared their collective expertise with over 115 physicians during a two-day Vascular Anomalies Conference at the Sackler Medical School in Tel-Aviv University, Israel on Feb. 18-19, 2015.

On Day 1, the VBF iTEAM, along with experts from Israel, presented the latest in the diagnosis and treatment of vascular anomalies. On Day 2, complex cases were presented by each VBF iTEAM member as well as by experts from Israel. The group discussed how these complex lesions can be effectively treated.

Dr. Moshe Lapidoth, Director of the Laser Institute in Israel, Co-Chaired the conference with VBF iTEAM member, Dr. Roy Geronemus, Director of the New York Laser & Skin Surgery Center of New York.



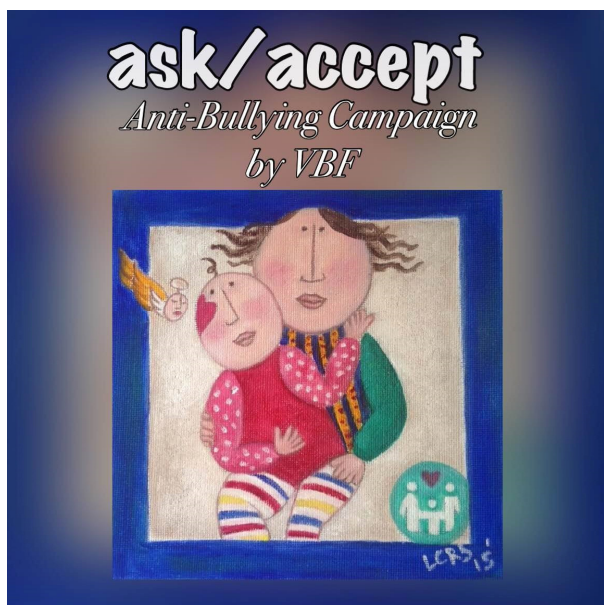
The VBF Israel Dream Team consisted of (l-r) Dr. Gregory Levitin, Child Life Specialist Leslie Graff, Dr. Francine Blei, Dr. Linda Rozell-Shannon, Dr. Roy Geronemus, Dr. Milton Waner, Dr. Teresa O, Dr. Aaron Fay, Dr. Robert Rosen, (not pictured) Dr. Stuart Nelson, Dr. Deborah Shatzkes, and Dr. Martin Mihm, Jr.

Dr. Mihm's presentation on his research regarding four new genes found in a Port Wine Stain generated excitement, as it could one day result in gene therapy to treat port wine stains.

VBF is very thankful for the VBF Israel Chapter Director, Vitali Varole. Vitali is the father of a little boy with a port wine stain. He successfully translated all of VBF's 24 key pages into Hebrew and is overseeing the VBF Israel Chapter website.

On February 16, 2016, a day before the 51st Annual Pediatric Postgraduate Course, the VBF iTEAM will present a special workshop in conjunction with experts from the Nicklaus Children's Hospital in Miami, FL.

In July 2016, the VBF iTEAM will head to Parma, Italy to participate in an international conference on vascular anomalies.



Dr. Linda's painting, "Birthmark Baby," will be on the cover of a new book on vascular and non-vascular birthmarks by Dr. Linda, Dr. Waner and Dr. Mihm.

VBF's Ask/Accept Anti-Bullying Campaign

VBF'S ASK/ACCEPT AWARENESS AND ANTI-BULLYING CAMPAIGN is a worldwide effort to encourage people to ask and then accept individuals living with a birthmark. For people with a vascular birthmark, Ask/Accept means "ask me about my birthmark," then "accept me as I am for who I am."

Dr. Linda and Crystal Hodges, VBF's new Ask/Accept Campaign Manager, called for individuals around the world to submit video clips supporting the Ask/Accept campaign. The clips were compiled into amazing videos now available on VBF's [YouTube channel](#).

In 2016, Crystal hopes to encourage people to follow the example of Dr. Linda who demonstrated how one could "Put On Your Birthmark" as a show of support. At VBF's Annual Conference, Makeup expert Kimberly Heintzman put a birthmark on Dr. Linda's face. Dr. Linda was able to experience the comments and stares that people with visible birthmarks often get. The kids at the Conference loved that she looked like them for the day!



Dr. Linda (left) wears a vascular birthmark during VBF's Annual Conference.

Crystal Hodges (right) has the common purple spots called purpura that appear after a laser treatment for Port Wine Stain.

How VBF Makes a Difference

John and Jackie Keating are overjoyed with the help and guidance of VBF's network of staff and doctors. One of their 5-month old twin daughters had a problematic and ulcerated hemangioma. They tried oral medication and laser treatments for months but saw no relief. Baby Madelyn showed no signs of improvement.

Madelyn's parents knew they had to find someone else who could help. Through Facebook, Jackie began corresponding with Dr. Linda Rozell-Shannon, President of the VBF, who referred her to one of VBF's surgical experts. Within three weeks of initial contact, in a single outpatient surgery, the surgeon was able to remove the entire hemangioma. Baby Madelyn was a new baby and her family was overjoyed with the results. The holidays were a time of great joy and celebration.

The Keating family is ONE of the thousands of families VBF has networked into treatment this year.



If you are curious about his condition or have any questions about his birthmark, please feel free to ask us, and please accept my brother for the loving and silly boy he is, birthmark and all.

-Jaxon's older brother
in VBF's ASK/ACCEPT1 video

Our new Social Media Coordinator
Lisa Bianchi invites you to follow, like,
engage, and share your stories.

Stay up-to-date and involved!

VBF is Making a Difference!



Facebook: <https://www.facebook.com/VascularBirthmarksFoundation>

Ask/Accept on Facebook:

<https://www.facebook.com/AskAccept/>

Instagram: @VBirthmarks

Twitter: @VBirthmarks

We're also on LinkedIn and Google+.

VBF Awards \$4000 in Scholarships

VBF's Scholarship Program is an important outreach to support young adults living with a vascular birthmark. It is a way to celebrate their accomplishments and triumphs.

Alyssa Leto received VBF's Frank Catalanotto Perseverance Scholarship for her studies at Brown University.

Cassie Nadon also received a Frank Catalanotto Perseverance Scholarship toward her freshman year at University of California, Riverside.

Kimberly Chan of New Jersey received VBF's Martin C. Mihm Health Career Scholarship to support her pre-med studies in Interdisciplinary Chemical Sciences at the University of Michigan, Ann Arbor.

Marion Wood of California received VBF's Roy G. Geronemus, MD, Humanitarian Scholarship. She is majoring in biology at San Francisco State University.

Each recipient agrees to host a 'pay-it-forward' event to raise awareness and funds. Applications for 2016 Scholarships are available on our website and accepted until July 1st.

New Programs Announced for 2016

- ❖ *A Foundation in Vascular Anomalies*, the first ever comprehensive online course for physicians to gain knowledge in the diagnosis and treatment of vascular anomalies.
- ❖ An online Physician Portal where doctors can submit cases confidentially for review and comment.
- ❖ Free consultation clinics around the world to mark VBF's International Day of Awareness in May 2016 "Changing Lives – One Mark At A Time"
- ❖ Ask/Accept Anti-Bullying Campaign to "Put On Your Birthmark"

Buddy Booby's Birthmark Book Read-Along



Every year, children are inspired by the story of Buddy, a booby bird in the Galapagos Islands born with a stain on his beak.

Schools, libraries, hospitals, and faith and community groups read the book during VBF Day of Awareness events held every May to promote compassion.

Buy or gift a copy on www.birthmark.org today.



Paige Parrish reads the *Buddy Booby's Birthmark* book to children at VBF's Annual Conference.

Mission: The Vascular Birthmarks Foundation networks families affected by a vascular birthmark, tumor, or syndrome to the appropriate medical professionals for evaluation and/or treatment, provides informational resources as well as sponsors physician education, mobilizes medical missions trips, and supports research and programs that promote acceptance for individuals with birthmarks.