



# Vascular Birthmarks Foundation Annual Appeal

VBF, P.O. Box 106, Latham, NY 12110

Publisher: **VBF** Volume No.: **10 Fall/Winter** Issue No.: **5** Date: **December, 2006**

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## Joon – VBF Orphans With Birthmarks

By Christine Buckley-Clement

Welcome to the story of our Journey to Joon! We are Phil and Christine Clement in Lincolnville, Maine. And this is a little glimpse of the amazing path that has brought us to this sweet little boy!

We first laid eyes on our "Joon-bug" in September 2005. We found him on [www.RainbowKids.com](http://www.RainbowKids.com) and his darling little face just tugged



Joon's hemangioma wrapped around the back of his head.

at our heartstrings! His brief profile stated that he was in Asia and that his special need was hemangioma. He was just a year old.

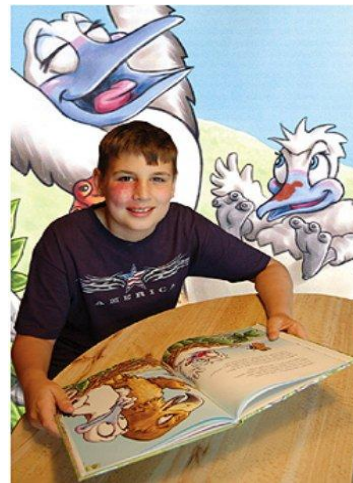
Phil and I kept telling ourselves it was too soon to consider adding another child to our family of six (then Phil and myself plus Sam-19, Matt-14, Sophia-5 and Lilianna-1).

After all, we were still paying off the adoption loans for Lilianna (JiangXi, China) and still trying to sort out our crazy work schedules and childcare.

-See JOON Page 5-

## VBF's New Mascot - "Buddy Booby"

By Donna Ducker



Evan and Buddy Booby- Photo by Steve Hopkins, Kingston Times

In 1994, Evan Ducker was born with a port-wine stain on his face, a love of animals, and an inquisitive, compassionate nature. At the age of 4 ½, he asked his mother, Donna, to read him a children's book featuring a character with a birthmark. When she couldn't find one, Evan decided to create his own--and he had some pretty big ideas.

Evan wanted his story to appeal to other kids with birthmarks, and he wanted it to teach people *without* birthmarks, what it's like to live with one. In addition, he wanted to teach others about endangered species--a passion he learned watching TV's *Animal Planet*. The Ducker's began a seven-year journey, which eventually led to their writing and self-publishing Evan's story, *Buddy Booby's Birthmark*.

-See BUDDY Page 6-

**The Hemangioma and Vascular Birthmarks Foundation, Inc.**  
**Statement of Financial Position**  
**December 31, 2005**

**ASSETS**

Cash and cash equivalents	\$ 168,655
Investments	830,540
Property and equipment	1,648

**TOTAL ASSETS** \$ 1,000,843

**LIABILITIES**

Unearned Revenue	\$ 982,000
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**TOTAL LIABILITIES** 82,000

**NET ASSETS**

Unrestricted	17,195
Fixed Assets	1,648

**TOTAL NET ASSETS** 18,843

**TOTAL LIABILITIES AND NET ASSETS** \$ 1,000,843

**The Hemangioma and Vascular Birthmarks Foundation, Inc.**  
**Statement of Activities**  
**For the Year Ended December 31, 2005**

**UNRESTRICTED NET ASSETS**

Grants	\$ 40,000
Program income	61,429
Fund raising	30,728
Contributions	25,288

**Investment income**

Interest income	2,370
Dividend income	917
Unrealized investment appreciation	1,901

**Miscellaneous** 893

**TOTAL UNRESTRICTED REVENUES AND GAINS** 163,526

**EXPENSES**

Program services	122,444
Management and general	17,668
Fund raising	35,978

**TOTAL EXPENSES** 176,090

**DECREASE IN UNRESTRICTED NET ASSETS** (12,564)

**NET ASSETS AT BEGINNING OF YEAR** 31,407

**NET ASSETS AT END OF YEAR** \$ 18,843

Note: The VBF underwent a first audit and received the highest grade.

**WE NEED YOUR HELP  
PLEASE SEND YOUR DONATION  
TODAY!**

What a year. We have our first mascot, Buddy Booby from the Galapagos Islands, we got to meet Joon (one of our Orphans with Birthmarks) at our conference in Boston, we are funding major medical breakthrough research, we have expanded our list of Ask the Experts, added new international chapters in India, Canada, New Zealand and Australia and continue to receive over one million hits on our website each month.

We had our first financial audit and received the highest rating. We take it very serious to be good stewards of the money you donate to VBF.

Your annual donation has enabled us to continue to make progress. Without you, there would be no progress. You may think that your donation does not matter, but it does. Every dollar we raise matters and every dollar makes a difference. The funds we collect help network children into treatment, offset costs for conferences, support our 9 international websites, fund research, and help us run the day-to-day activities for VBF, including our Day of Awareness campaign. No financial donation is too small. The following quote appropriately embodies this concept:

*If you think you are too small to be effective, you have never been in bed with a mosquito. ~Betty Reese*



Linda Rozell-Shannon and First Lady Barbara Bush at a recent event.

Be a mosquito and help VBF by sending us your annual financial donation, or by participating in our Day of Awareness Campaign, or by participating in the 2007

Read-a-Thon, or by doing ALL of them. There are many opportunities for

you to be a mosquito for VBF. Please make a decision today to send VBF your annual donation.

***Linda Rozell-Shannon, VBF President and Founder***



**VBF 2006 Physician of the Year  
Aaron Fay, M.D.**

Aaron Fay, M.D., is a Clinical Associate in Surgery at Massachusetts General Hospital. He received his medical degree from Columbia University in 1993.

His current academic practice is limited to eyelid, orbit, lacrimal, and facial reconstruction, and also includes a minor component of cosmetic facial surgery (special concentrations in clinical treatment of vascular lesions of the eyelid, face, and orbit, as well as laser treatment of lacrimal obstructions).

Dr. Fay is interested in eye conditions related to vascular tumors such as hemangiomas, glaucoma related to Sturge-Weber syndrome, lymphatic malformations, and tissue hypertrophy in Port Wine Stains.

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**VBF 2007 Conference**

VBF is excited to announce that our 2007 Conference "Research Holds the Key" will be in Irvine California the weekend of October 19-20, 2007. Save the date. We are currently working with the conference Chair, Dr. Stuart Nelson, to provide the best agenda, speakers, and options for all attendees. We know that we will be announcing some major research findings at the conference and will of course have the latest information regarding the diagnosis and treatment of vascular birthmarks. Keep checking on the VBF website at [www.birthmark.org](http://www.birthmark.org) for registration information and for a list of guest speakers.

**The VBF 2006 All Vascular Birthmarks  
Conference “Research Hold the Key”  
By Paige Salvador**

The Vascular Birthmarks Foundation along with Dr. Martin Mihm, Jr., Massachusetts General Hospital, Candela and Cynosure sponsored VBF’s fifth conference on October 27 and 28 in Boston at the Hilton Boston Logan Airport. Attendance totaled around two hundred. This was VBF’s largest conference to date and featured many unique opportunities and events.

Friday evening’s welcome reception began casually with hors d’oeuvres and a chance for old friends to get reacquainted and new friends to meet. Guests in attendance came from as far away as Australia, South America, Europe, Canada and some from right around the corner in the Boston area. After socializing, the attendees gathered to hear opening remarks by VBF Founder & President Linda Rozell-Shannon as well as presentations from world-renowned birthmark experts and friends of VBF. Danielle Vlahos, VBF Board Treasurer, gave a short speech about her son Cole who was helped through VBF and Team Marathon. The participants in this marathon ran to raise money and awareness for VBF. Paige Salvador, VBF, Executive Director, spoke about her son who was helped by VBF 11 years ago and encouraged attendees to support VBF by participating in VBF’s 2007 International Awareness Day. Donna and Evan Ducker, authors of *Buddy Booby’s Birthmark*, shared their story of the positive reaction their book is receiving. The conclusion of opening remarks ended with a personal and touching letter read to Dr. Milton Waner by his patient Allison Wicker. Allison candidly recounted her experiences of living with her birthmark and how Dr. Waner had changed her life for the better.

Friday evening’s presentations also included a keynote speech from Dr. Martin Mihm, Jr. Dr. Thuy Phung and Dr. Patricia Burrows also gave presentations. Dr. Aaron Fay was awarded physician of the year for his outstanding work on treatment of vascular lesions of the eyelid, face and orbit and other treatment related to vascular birthmarks.

Following these presentations, attendees had the rare chance to see a mini-production of *Wanda’s World*. The tween musical, written by Eric H. Weinberger and Beth Falcone, is about a middle school girl with a large birthmark on her face. For more information, visit the website at [www.wandasworld.tv/](http://www.wandasworld.tv/).

After the show, attendees gathered into smaller group sessions with families and physicians in an informal setting to ask questions, share experiences and lend support and advice. Each breakout session had a group leader and physician specializing in a specific area of birthmarks.

On Saturday, attendees were together again for breakfast. Daycare was provided, and included a reading of *Buddy Booby’s Birthmark* by Evan and Donna Ducker and lots of fun, games, toys and snacks. Donna and Evan were also on hand to sign books. Christine Shannon sold VBF Care Bears and Glen Ethington sold VBF *Kids Who Care Bracelets*. Michael Politzer, VBF’s Teen KT Ambassador, customized VBF We Care Bears for children with birthmarks.

Also available were Family Support Sessions. These group sessions allowed interested parties to share their feelings about the psychological and social aspects of living with facial and physical differences under the guidance of a specialist. Others attended make-up sessions with trained aestheticians using Smart Cover Cosmetics.

One special guest at the conference was renowned photographer Nathan Caulford. Nathan has a facial birthmark and is working to compile a photo-essay. Nathan had the opportunity to photograph some of the attendees. You can learn more about Nathan at [www.caulford.net/glasseye](http://www.caulford.net/glasseye).

Four multi-disciplinary teams of doctors conducted clinic appointments. These four teams saw sixty-eight patients in all. Many of the patients were seeing a specialist for the first time and left feeling very hopeful that they could finally receive the treatment they need.

~VBF Board Members and Staff~

**Linda Rozell-Shannon**, President and Founder  
**Missy Scott**, VBF Web mistress, Non-Board Member

**Barbara Rothaupt**, VBF Volunteer Counsel, Non-Board Member

**Paige Salvador**, Executive Director

**Corinne Barinaga**, Administrative Director, Family Services, Physician Liaison

**Glenda Ethington**, Sturge-Weber Syndrome Community, Director VBF International Chapters, Co-Director Public Relations

**Greg Antonelle**, Vice President

**Liz Sorenesen**, Marketing/Co-Director Public Relations

**Danielle Vlahos**, Treasurer

**Tiffany Ethington**, Secretary

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**Lianne Chase**, Parent Representative

**Elissa Rifkin**, Parent Representative

**Elysa Baron, DC**, Parent Representative

**Dinah Gonzalez, MD**, Parent Representative

**Marvin Kalafer, MD**, Parent Representative

**Rachel Marer**, Adult Representative

**Saige Cavayero**, Student Representative

**JOON| From Page 1**

We had adopted Lili just 5 months earlier! Lili would be 2 years old that December and now we were looking at adding a little boy just 10 months her junior. Surely we were crazy. We prayed often about this little boy and in early October we requested his medical file.

What a puzzle! Joon Hyuk had several diagnoses in his thick file. We quickly learned that Joon was in Seoul, Korea and had a large hemangioma that wrapped around the back of his head and extended to his neck and around his right ear. He also had a large vascular mass in his throat. This mass had been blocking his airway and Joon spent most of his first year hooked up to breathing and feeding tubes in a hospital in Seoul. He seemed to be doing better at the time we found him and breathing and eating on his own, but was taking a powerful drug called Interferon to shrink the mass.

Phil and I spoke to many doctors by phone that month until we finally found the wonderful folks at the Vascular Birthmark Foundation in NY. Dr. Linda Rozell-Shannon was our link to some answers. She and Dr. Milton Waner reviewed Joon's file and were soon able to determine that the growth in Joon's throat was indeed a hemangioma and would not be life threatening! And moreover, Dr. Waner has committed to Joon's care if we could just bring him home.

It wasn't long before the Korean adoption agency called us back and apologized saying that we would not be able to adopt Joon. We were "too old". I felt as though I had been hit by a truck as the social worker there explained that Korea has an age limit for their adopting parents and that Phil was "way beyond" it.

The agency finally agreed to take our plea for an age waiver to the officials in Korea. Our case manager told us more than once that the chances of Korea granting our request were almost non-existent.

We prepared a letter to the officials in Korea. Also, Dr. Shannon and Dr. Waner wrote a very lovely and heartfelt letter for us to include.

The morning of February 16, 2006 we were told we had been granted our waiver and given permission to adopt Joon!



Joon with sisters Sofia and Lilianna

Fast-forward this story to today -

Joon (aka Tucker Joon) has now been home with us for over two months. He celebrated his 2nd birthday on the coast of Maine with his new family. He is quickly adapting to his new culture, with a profound love of Thomas the Tank Engine and fancying himself a train conductor most days. He is a happy little boy, and we are entirely blessed to be his parents.

## **BUDDY| From Page 1**

The book, which features a foreword by CBS television anchor Hannah Storm, was released in May of this year to excellent reviews.

Evan and his mom decided to donate a portion of the book's profits to the VBF, "...because I liked their website," Evan said. "It showed kids with birthmarks on the front page. All the other sites had pictures of doctors and adults--but not kids."

The VBF soon posted a blurb on their web site, announcing the pending release of *Buddy Booby's Birthmark*. Almost immediately, emails and pre-orders started trickling in from all over the world (including Chile, Germany, Australia, England, Ireland, Canada and the U.S).

Then, in October, the VBF named the book's main character, *Buddy* the red-footed booby bird, as their International Mascot for Birthmark Awareness. It turns out; the species' red feet are caused by a vascular condition--making them the perfect animal representatives for human birthmarks.

A previously taped segment for the CBS Early Show is to be televised nationally within weeks, and CNN has scheduled a feature on Evan and the book for a mid-December taping, (including an interview with Dr. Milton Waner of the Vascular Birthmarks Institute).

As part of the 2006 DOA, the Duckers received an email from a teacher who read their book to her classroom AND provided each child with a copy.

The letter was posted to the website, and before long, other teachers and parents--from Canada to California--began expressing interest in doing the same! In an effort to thank the schools for their involvement, the Ducker's mailed out special certificates of participation.

The "Read-Along" was born! Donna recently added an on-line registration form to her website ([www.buddyboobysbirthmark.com](http://www.buddyboobysbirthmark.com)), where schools and groups from around the world can enroll for the 2007 event. The site includes a free, downloadable press release for participants, and

a link to the VBF's site for fund-raising suggestions.

*Buddy Booby's Birthmark* and the International Read-Along campaign stand to make a significant contribution towards worldwide birthmark awareness and tolerance (of all differences) in schools. For further information, or to post comments or suggestions, email the authors: [info@buddyboobysbirthmark.com](mailto:info@buddyboobysbirthmark.com)

## **Glen's Gang VBF Kids Who Care**

Glen Ethington was born with facial pws, and shortly after, was diagnosed with Sturge-Weber syndrome (SWS). Like so many other people who look different, Glen has had to deal with social obstacles. People often stare at him or make comments, because his birthmark covers most of the left side of his face. He also has seizures due to SWS. He found ways to cope and to overcome these obstacles, but it is a lifetime process for those with SWS and other types of birthmarks. His condition is rare and he felt that sometimes it would be nice to talk to someone else with a birthmark – someone he didn't need to explain things to.

In April of this year, Glen started a newsletter and pen pal group for kids with birthmarks and their siblings, called Glen's Gang. Partnered with the VBF Kids Who Care Program, children are able to correspond with each other, knowing that the kids they are writing know exactly how they feel. They can share their likes, achievements, and discuss things that affect them. Kids can also contribute to the Glen's Gang Newsletter, and many of them have already sent pictures and stories that are featured in the monthly publication. There are many brothers and sisters of kids with birthmarks who take part in the group, as they are also affected by the social impact of living with a birthmark. The group has grown fast and already has over 40 members, including kids in Canada, and the United Kingdom. Parents, if your child would like to join the gang, write to Glen's Gang C/O SWSC, P.O. Box 24890, Lexington, KY, 40524-4890, phone 859-272-3857, visit the VBF/SWSC websites, or email [swsc@swscommunity.org](mailto:swsc@swscommunity.org).

**VBF Annual  
Mini-Fundraiser Highlights  
Summer Event**

**“ A Sizzling Night of Salsa”**

This summer VBF “turned it up a notch” by infusing Live Latin Music by Sensemaya and dance instruction by The Saratoga Savoy at its Annual Summer Event Fundraiser on August 17, at Saratoga Golf Club in Saratoga Springs, New York. The event was entitled “ A Sizzling Night of Salsa” and was hugely successful thanks to our co-chairs Elysa Baron and Cherie Williams.

VBF’s long-time friend, NY State Assemblyman James Tedisco, served as the Honorary Spokesperson and gave a personal and inspirational speech, as well as a presentation of a proclamation. Linda Rozell-Shannon gave welcoming remarks about the history and success of VBF, recalling how its eleven years has been a result of the hard work and dedication of its board members, physicians, friends and families. Dr. Edwin Williams, one of VBF’s founding physicians and his wife Cherie also beautifully narrated their long-term relationship with VBF and expressed their continued commitment to help children with facial differences.

Assisting with the evening’s events were our VBF junior volunteers. This group included Saige Cavayero, VBF’s newest Student Representative, and Jessica Summers, cousin of VBF Executive Director Paige Salvador.

A silent auction was featured again this year. A new addition was our diamond necklace raffle, organized by Cherie Williams. The lucky winner brought home a “circle of life” pendant on an 18 inch gold chain. This year’s sponsors included The Williams Center for Excellence of Latham, NY and Saratoga Springs, and Rapid Freight Systems of New Jersey. The event raised \$12,000. Thank you to all who made this possible. On behalf of VBF, I look forward to seeing old friends and new faces next year.

Please visit the VBF website to learn more about donating, sponsorship and attending or contact Paige Salvador at [BASPASTS@cs.com](mailto:BASPASTS@cs.com) and 518-209-6915.

**Join Us for VBF’s 2007  
International Awareness Day**

Please join us for VBF’s Fourth Annual International Awareness Day. This grassroots campaign serves to educate the public about vascular birthmarks and their related syndromes and raise funds to support the work of the VBF. This day officially takes place annually on May 15 and is celebrated by hundreds of friends from around the world; however, many events are conducted throughout the year.

One of the most wonderful things about being part of Day of Awareness is all the fun you can have while you work to help those affected by birthmarks. Some past events include a lemonade sale, a garage sale, dress down day at the office, a birthday party fundraiser, awareness bracelets and VBF care bears sales, a bake sale, a marathon, a book reading, a penny drive, a wine tasting party, a bowl-a-thon, an email campaign, a McDonalds Night fundraiser, an e-bay auction, a car wash, media stories, a real live Texas Hold’em Poker Tournament and the list goes on. There is something for everyone, especially you! So please make your plans to participate in this event. There will be more information on our website beginning January 1. Once you have registered your event, VBF will provide you with supportive materials and offer any assistance we can to make this campaign enjoyable and successful.

VBF is grateful to all those who have supported this, *our biggest annual fundraiser*, in the past and hope more of you will join us this year. We also encourage those of you participating this year to share your story of hope by allowing us to publish your story in our newsletter. Stories of inspiration help to send the message that we will continue to work together until every child and adult receives the best treatment options available and that VBF is working to support the research that in the future will provide answers and solutions.

If you are interested in participating, write to Paige Salvador at [BASPASTS@cs.com](mailto:BASPASTS@cs.com) or call 856-234-2126.

## Research Update

It has been a very exciting year for VBF regarding research. We have one major hemangioma project at the Nevada Cancer Institute and headed up by Dr. Lou Fink, Dr. Milton Waner and Dr. Ypo Ma. The research team has been working on implanting hemangiomas in mice and has been developing cell lines from the hemangiomas. The findings will be announced at the 2007 VBF Conference in Irvine, California. We are very excited about the preliminary results. Stay tuned for a major breakthrough in hemangioma research.

Additionally, VBF joined with our sister organization SWSC and funded a research project out of the Johns Hopkins University School of Medicine. This project is focusing on using the modified Atkins diet for controlling seizures associated with Sturge-Weber Syndrome. This is the SWSC first funded research project for SWS and we are eagerly awaiting the findings. We hope to be reporting the results in 2007.

VBF has several pending research projects that we hope to receive funding to support. If you are interested in donating to support research please indicate that with your donation. We are a long way from discovering the cause and cure for hemangiomas and other vascular lesions such as port wine stains but we are a lot closer than we were even five years ago. All progress happens from research and we are excited that we are now actively involved in research. Dr. Martin Mihm, our VBF Director of Research also continues to focus a lot of effort studying various treatments for hemangiomas and port wine stains. We are hoping for a great presentation from Dr. Mihm and Dr. Nelson at the VBF 2007 Conference in Irvine, California.

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### VBF Chapters *“In Their Own Words”*

In January of 2004 the Sturge-Weber Syndrome Community became the first Chapter of the VBF. By 2006, the VBF has established International Chapters on every continent. VBF is grateful to

the parents and patients who volunteer their time and efforts on behalf of individuals with birthmarks and related syndromes. Our volunteers make a difference in their own communities, as well as advocating for vascular birthmarks. Here are some of the VBF Chapter Representatives, *“In Their Own Words”*...

#### VBF Australia - Clara



My name is Clara Sofu, and I was born on the 6<sup>th</sup> of August 1982, Melbourne, Australia, which happens to be the same day as my mother's birthday.

I am the third child, out of four, with two older sisters and one younger brother.

I was born with a small-medium, round, pinkish-red port wine stain on the upper right hand side of my lip.

My mother and father had never seen anything like this before, and the family had commented to my mother that she had done something wrong while she was pregnant with me (which is untrue). When my parents took me to the physician, he had told them that my birthmark will fade as I get older, which was not the case.

In December 2003, I started having laser treatments. So far, I have had five laser treatments and it has gotten much lighter. Although my port wine stain is small, I still know how it feels to be born with one on your face. I have recently graduated with a Degree in Science, and love helping people, as I believe that everyone in this world are special, especially children.

#### VBF Australia - Eloisa



My name is Eloisa Evangelista. I am a 20-year-old university student living in Melbourne, Australia. However, unlike most 20 year olds I was born with a port wine stain covering the left side of my face, which also expands across the rest of my

body in scattered areas. Apart from that, I was also born with congenital glaucoma and experience no vision in that eye.



I became involved with VBF, because it wasn't until recently that I discovered that I wasn't the only one experiencing living with a vascular disorder. I discovered that there were other people not only in Australia, but also across the whole world who shared the same similar story. Not only could I benefit from hearing the advice and gaining the support of those like-minded, but I also hoped in turn, that my story could help the confidence and self-esteem of other teenagers living with a birthmark. In future, as a representative of VBF Australia, I hope to increase the awareness of vascular disorders within our society and create a support group amongst those dealing and living with any type of birthmark. Next year, I hope to graduate as a qualified Orthoptist with my primary concern to enhance research regarding the connection between Port Wine Stains and glaucoma.

#### **VBF India - Santo**



I am Santo Banerjee. One and half years ago, when my son Sumangal was born, was the first time we heard about the disease Sturge-Weber

syndrome (SWS). My son was born with redness over two-thirds of his face. The first four months he did not have any problems, though he was under watch. The first time he had seizures he was four months old (at that time he was suffering from diarrhea and he was hospitalized). After recovery we were sent to a pediatric neurologist who told us about the website that we have come to know as the VBF and SWS foundation. The website contains all the necessary information regarding any vascular birthmarks, from where we first learned that we must go for his eye examination at least once a year.

The second time he was hospitalized he was nine months old. After that he had weakness of his right hand and right leg. He got his sitting balance at the age of ten months. He is getting anticonvulsant medicines twice daily, but his convulsions are not totally controlled.

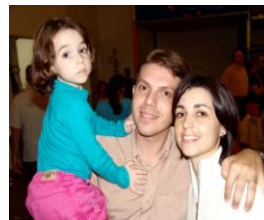
Doctors told us that this is a rare and special type of case, and so we wanted to know more about the disease. Over email we got close to Glenda Ethington, she is a very nice person and for the

first time after getting a reply from her we realized there is no need to panic about the disease.

In our country we don't have sufficient facilities for these types of patients. My son is now one and half years old. He can sit but does not stand without any support. There is a website corresponding to our country, but the site does not contain sufficient information or a list of neurologists. We wanted to join VBF India to help the patients having SWS or any related problems in our country (like my son).

We want to make rich our website. We are searching for some neurologists and good institutes in our country. We are also looking for patients having any kind of birthmarks. We want to put their names, address and phone numbers into a database, so we can help others learn about the disease.

#### **VBF Latin America - Andrea**



My name is Andrea Domingues. In 2001, when our daughter was born, we had no idea what hemangioma or lymphangioma meant and we did not have enough

answers from the doctors, so we faced a difficult situation alone. After some months we discovered a specialized team of doctors, and for the first time, we met other families in our situation. We decided to work to spread information and to help people in the same situation. We created a biannual newsletter and a virtual community to exchange experiences with other families.

In 2004, we discovered the VBF website where we found a lot of important information and realized that it was not only a Brazilian problem. There are many families around the world suffering because of the lack of information and society's reaction. In 2005, we participated in the Day of Awareness creating a Brazilian event that will be held again. Now we are a Brazilian association with the mission to inform people about research and treatments for hemangiomas/lymphangiomas with the hope to help the improvement of the treatments in Brazil.

Our daughter Gabriela was born with hemangioma, lymphangioma and gigantism in her feet and left hand. After two days of her birth without answers, a doctor told us about Klippel-Trenaunay and Proteus syndromes. So we started to go to a lot of doctors for finding some treatment and it was terrible to see them with a look of doubt on their faces. It has been a hard time for us, because we didn't understand if she would live and what we did wrong. Besides, we did not know anyone in the same situation. No one could understand what we were feeling.

Gabriela had 3 surgeries for correcting her feet and for using OK 432 in lymphangioma areas. She also had laser treatment on superficial lesions.

We do everything we can to make her life as normal as it could be. Since Gabriela was born our life changed a lot: for better! We thank God for this gift. She is a big fighter - she never gives up. She is a winner. She is an example.

#### **VBF - New Zealand – Gabrielle**



My name is Gabrielle Martell-Turner. My daughter, Clemency, now 5 years old, had a large hemangioma on her chin, which was removed in November 2005.

*Plans for immediate future* - to send a nationwide press release out including all major papers, parenting, woman's magazines, National radio stations and T.V network (NZ only has a population of nearly 4 million so not as daunting as it sounds).

*Long-term goal* - fundraise to enable us to hold a family open day(s) for families and children to mix and share information and to hopefully have doctors there for informal advice. I attended similar days when living in England run by the Birthmark Support Group and they were fabulous.

I am the Co-president of Whangaparaoa Playcentre - north of Auckland – our largest city, and also PR Convenor for the North Shore

Playcentre Association. Being a full time Mum is my passion and my favorite job in the world. My children both attend Playcentre as their sole early childhood education facility and this enables me to be a full time Mum in the best way I can think of. Playcentre is unique to New Zealand. There are 22 Playcentres in my region alone and they all operate as licensed Early Learning Centres. The difference between Playcentre and all other ELC's such as Kindergarten is that parents are the teachers. When you enroll at Playcentre you embark on a training program that you can take as far as you wish but, collectively, all the points gained by parents at different training levels enables the Playcentres to operate. Playcentre believes that parents are the best first educators and we cater for children from birth to school.

I am JUST as passionate about setting up a viable network in NZ for children and the parents of children with birthmarks. I found it very difficult to find any support here when we moved back to NZ. The level of education regarding birthmarks is low and this needs addressing.

#### **VBF/SWSC-Canada - Tom**



Hi everyone, I'm the tall one with sunglasses on the front-page picture of our new Canadian website. I'm 38 years old and I was diagnosed 4 years ago with SWS. I do have a mild PWS on top of my eyelid and I have more on my scalp.

My goal with this Canadian website is to be able to help anyone out there in Canada - that you are not alone when you find out you are diagnosed with SWS, PWS, or VB. There are many of us out there that think we are the only ones, but we are not. We just don't know where to turn too. Hopefully this is where the SWSCC will come in handy for all Canadians and Quebecers out there.

(Read Tom's Journal chronicling his recent brain surgery on the VBF/SWSC-Canada website <http://swscommunitycanada.org/journal.php>)

## ~VBF Chapters~

VBF Africa

<http://vbfafrika.org>

VBF Asia

<http://vbfasia.org>

VBF Australia

<http://vbfaustralia.org>

VBF Europe

<http://vbfeurope.org>

VBF India

<http://vbfindia.org>

VBF Israel

<http://birthmark.org.il>

VBF Latin America

<http://vbflatinamerica.org>

VBF New Zealand

<http://vbfnewzealand.org>

VBF/SWSC-Canada

<http://swscommunitycanada.org>

Sturge-Weber Syndrome Community

<http://swscommunity.org>

The VBF would also like to acknowledge Anomalie Vasculaire, the first and only all-French language website for vascular anomalies.

The group and website was founded by Lise Daoust of Canada, who has an AVM of the lip.

Lise also helped translate the VBF/SWSC-Canada website into French. -

<http://www.anomalievasculaire.org>



## VBF 3rd Annual International Awareness Day 2006 Families Establish Tradition of Awareness and Fundraising

VBF established the tradition of Awareness Day for vascular birthmarks on May 15, 2004. Since that day, VBF families have established their own tradition of raising awareness and funds for VBF. There are many families who celebrated Awareness Day in 2004 and 2005 and have continued that tradition this year. Families new to the community of vascular birthmarks have also joined in VBF in raising awareness, and perhaps they too will carry on the tradition.

Each and every project is important to VBF and to those we serve. The generosity of the Awareness Day participants is amazing and we thank all of you for giving your time and support.

Here are some of the highlights of the VBF 3rd Annual International Awareness Day 2006 - including an article by Robin Houwman on her inspiration for establishing a fundraising tradition with help from support group friends.

**Repeat Event – South Dakota – Event began November 2004 and is ongoing - MSN Vascular Birthmark Support Group Pendant Sale - Earrings are now available – Visit the website at**

**<http://www.vascularbirthmarksupport.com/>  
Robin Houwman and Annette Stoner organizers – Article by Robin Houwman**

I was introduced to the world of birthmarks after the birth of my second daughter, Chloe. Her hemangioma was located on the back of her neck. It quickly grew and then ulcerated.

Our pediatrician was not concerned and suggested that we just wait and see what happened. The ulceration was very painful for Chloe so I insisted on another option.

He referred us to a dermatologist. It was soon evident that the location and size of Chloe's hemangioma were causing developmental issues - the hemangioma was getting so big and painful that she was no longer able to turn her head.

About that same time, I learned about the VBF and the MSN Support Group. I literally felt like my prayers had been answered. The warmth, support and assistance of those groups lead us to the right treatment and fantastic support along the way.

When I finally received a phone call from Dr. Waner, I knew that our nightmare would soon be over. Because of the developmental issues and the ulceration, he recommended surgery right away. Our surgery date was just three weeks later. The surgery lasted about an hour and Chloe has had a textbook recovery. Her scarring is minimal and she was able to return to normal functioning with her neck within days of the surgery.

Throughout our journey, I had the wonderful and incredible support of people whom I met through the VBF and the MSN Support Group.

The idea of the fundraiser came from Kim, "Emiliasmommy" as she is known on the group. She had noticed a fundraiser at a hospital for a certain type of condition and wondered if the MSN Support Group could do something similar. I had a friend who designed and made jewelry. She designed a few samples for us to choose from. The pendants were quickly chosen and we decided to include an informational card about birthmarks with each pendant. We held a poetry contest where members submitted poems about birthmarks and then held a weeklong vote. We selected a poem written by Christine, known as "powerfulgazelle". Contributors to the card were Corinne Barinaga, Jules Kendall, and Elissa Rifkin. We also sold zipper-pulls during the first year of the fundraiser.

Last fall we added a selection of bracelets and a key chain to our offering. Annette Stoner, one of the MSN Moms, makes the bracelets and key chains. She has plans to add earrings in the future.

Two years into the fundraiser I see no end in sight. The orders still come in on a weekly basis and people are still moved to tears when they receive their pendants or bracelets along with the unexpected card and poem. This has been an incredibly fulfilling experience for me and I hope to be involved in the fundraiser for many years to come. To date, our donations to the VBF and another birthmark group have totaled \$12,100.

**Repeat Event - New Jersey - VBF 2nd Annual Celebrity Spring Cleaning – Online EBay® Auction** – For the second year in a row, Greg and Elyssa Antonelle hosted this auction in honor of their son Nicholas, who has a lymphatic malformation. Some of the celebrities donating items were Rachel Ray, Martha Stewart, Maya Angelou, Michael McDonald Phil Collins, and NBA "Superstar" Vince Carter. Greg is the Vice President for VBF. Auction Website: [www.CelebritySpringCleaning.com](http://www.CelebritySpringCleaning.com)

**Repeat Event – Texas - 3rd Annual North Texas Vascular Birthmarks Foundation Benefit** – Natalie Bolinger hosted "We're Going All In for the Kids" with dinner, silent auction and Texas No Limit Hold 'Em Poker on August 4th, at the newly opened Meritt Bois D' Ranch in Denton. This is the second year for the poker event. For the first Awareness Day, Natalie conducted a mailing campaign with a brochure about her daughter Nicole, who had surgery to remove a hemangioma on her right cheek. Natalie also sold VBF bracelets.

**Repeat Event – New York - 3rd year - Birthday Party for VBF – Diversity Poster/Article** - Lianne Chase has hosted her birthday party to raise awareness since the inception of Awareness Day. This year, the company she works for included her sons in their diversity poster, as well as in the company newsletter. Her sons Cody and Casey have a vascular birthmark. Lianne is a VBF Parent Representative.

**Sticky Prints – Donates 50% of sales on Awareness Day to VBF** – Sticky Prints the online store for magnetic photo frames, donated 50% of their sales for VBF. [www.stickyprints.com](http://www.stickyprints.com)

**Repeat Event– Brazil – 2nd ABRAPHEL Meeting of people with Hemangioma and Lymphangioma** – The Brazilian Group, ABRAPHEL, hosted their second meeting on May 7, 2006, to honor VBF Awareness Day. Several doctors were in attendance, as well as patients and families. Organizer of the meeting, Andrea Domingues, serves as the VBF Latin America Representative. Her daughter Gabriela was born with hemangioma, lymphangioma, and gigantism in her feet and left hand.

**Repeat Event – South Carolina - 3rd year - Children’s Auction** – For the third year in a row Jackie Burke hosted a children’s auction. Children from Lakeside Outreach Church donated items for the auction. Jackie’s 10 year-old daughter, Abigail, had surgery in July for AVM of the lip.

**Repeat – 3rd Event – Buddy Booby’s Birthmark Read –Along, We Care Bear and Kids Who Care Bracelet Sale** - Glen Ethington, VBF Kids Who Care member, participated in the Buddy Booby Read-Along and sold bears and bracelets. Glen read the book to the Kindergarten class at his school, and donated the book to the school’s library, which was signed by the authors Evan and Donna Ducker. He also started a newsletter and pen pal group called Glen’s Gang, and was featured in a local newspaper article.

**Repeat Event – Wisconsin - 2nd Annual VBF Rummage Sale, Brat Fry and Bake Sale** – For the second year, Sandra and Todd Peters held a rummage/bake sale and brat fry. Their daughter, Elizabeth Peter, had hemangioma of the neck. Last year Elizabeth also sold VBF stickers to be placed on “Elizabeth’s Wall of Fame” with the name of the family donating to VBF.

**Repeat – 2nd Event - Pennsylvania - Buddy Booby’s Birthmark Read-Along and VBF Bracelet Sale** - Traci Lebofsky hosted her second event for VBF Awareness Day with the Buddy Booby Read-Along to the 3rd grade class at Leadership Learning Partner Charter School. She also sold VBF Kids Who Care bracelets. Last year Traci hosted “Breakfast and Bowling for Vascular birthmarks”. Her daughter Gioia has a hemangioma.

**North Carolina - Newspaper Article and VBF Fact Pamphlets** - Keith and Sherry Ludlum distributed VBF pamphlets to local doctors offices, and their daughter Natalie was featured in a local newspaper article. Natalie had a hemangioma on her right eyelid and surgery at 7 months old to remove it.

**Repeat Event – Kansas – 2nd VBF Awareness Fundraiser Walk** – For the second year in a row, Kelly Barkmeier organized a walk to raise funds for VBF. The event was held at Shawnee Mission Park, with the assistance of friends and family. Her 2 year-old daughter, Lily, has hemangioma on the right cheek.

**Repeat Event – Illinois – 2nd Annual Bake Sale** - Amy Ledbetter hosted a bake sale for awareness at Citizens National Bank and Cross Country Mallin. Assisting Amy were Greg, Darren, Damon, and Danae Ledbetter, Delores Ferguson, and Carolyn Ledbetter. Her daughter, Danae, has a vascular malformation.

**Repeat – 2nd Event - Pennsylvania - Lily Mollencott** hosted a Pennies for a Purpose awareness event by mailing coin wrappers to companies. For the first VBF Awareness Day, Lily passed out VBF informational pamphlets.

**Virginia – Washington, DC – Oct. 29 Marine Corps Marathon** – Jason Stamper of Virginia ran in the Marine Corps Marathon on October 29th, along with four of his friends. ([www.marinemarathon.com](http://www.marinemarathon.com)) Jason and wife Carly have a daughter, Addison, with parotid hemangioma. The family is featured in an article on the homepage of the VBF website “It’s Never Too Late To Raise Awareness”.

**Ireland, Belfast – 25th Annual Belfast Marathon** – On the first of May, Delia Rooney and friends ran the relay in the Belfast Marathon. They were sponsored by colleagues at work, family and friends. Delia’s daughter, Abigail, had nasal hemangioma.

**England, South Yorkshire** – Kay Lewin hosted a Tea with South Yorkshire Mayor and a drop-in support session for families with vascular birthmarks. There was also a raffle, bake goods sale, and Bingo at the retirement home in Munsdale. She also sold VBF bracelets to raise funds for VBF. Kay was recently diagnosed with Sturge-Weber syndrome and is a Representative for VBF Europe.

**Daily Stroll – Donates 5% of gross advertising revenue to VBF** – The Daily Stroll a leading Internet source for shoppers, designers, and retailers, donated a portion of their advertising revenue for VBF Awareness Day. Liz Sorensen, Editor-in-chief of the online publication, is the VBF Co-Director of Public Relations. Visit the website at: [www.thedailystroll.com](http://www.thedailystroll.com)

**Buddy Booby’s Birthmark – Read-Along – Evan and Donna Ducker** – Authors of Bubby Booby’s Birthmark hosted an International Read-Along for VBF Awareness Day. This will be an annual Event and Buddy Booby is now the Official VBF Mascot. Visit the VBF or Buddy Booby websites to enroll in this groundbreaking campaign. 10% of proceeds from sale of the book go to VBF.

**Arizona - Email Letter Campaign** - Gordon McGuire of Handycapped.com and his mother Gloria Stakemiller emailed friends spreading the word about VBF awareness Day. Gordon also highlighted Awareness Day on his website [www.handycapped.com](http://www.handycapped.com).

**New York – Pancake Breakfast and Dollars for a Difference Collection** - Joanmarie DiMirco hosted a pancake breakfast and distributed collection boxes for VBF Awareness Day. Her daughter, Daniela, has extensive glomous malformation.

**Repeat – 2nd Event – New York - Teen Dance Party** – Saige Cavayero hosted a Teen Dance Party to celebrate awareness. Last year Saige designed the VBF Courage Confidence bracelets and sold them to raise funds for VBF. Her successful campaign inspired the VBF Kids Who Care Bracelets. Saige was born with facial hemangiomas.

**Repeat – 2nd Event - New Jersey – Wine Tasting Party - “An Evening of Wine”**  
On June 15, Paige and Blaine Salvador hosted a wine tasting fundraiser at their home to raise funds and awareness for the VBF. The evening featured a showcasing and tasting of eight bottles of various wine selections, conducted by a local sommelier. About sixty friends attended. Paige talked about her son Tyler who was born twelve years ago with a hemangioma. Linda Shannon networked Tyler into treatment when Tyler was just one year old. Paige and Blaine were told about a physician named Dr. Milton Waner and in turn decided to have him remove Tyler’s birthmark from his lip. Paige also gave a short speech about the importance of the continuation of work of VBF. The event raised \$2,300.00. Paige is the Executive Director of the VBF. Last year Paige hosted “Golf with the Girls”.

**Repeat - 2nd Event - Vermont - Pennies for a Purpose and VBF Collection Boxes** – Betsy Kenyon asked students at Enosburg Elementary School to collect pennies for VBF Awareness Day. Betsy also distributed collection boxes at various locations. Last year Betsy passed out informational pamphlets to raise awareness.

**Email Letter Writing Campaign** – Eric and Andrea Lamberg emailed a letter to over 100 friends and family members asking for support and donations for VBF. Their son Jack had surgery at 3 months old to remove a hemangioma over his eye.

**Repeat Event – Illinois – 2nd year - LaSalle Bank Chicago Marathon** – For the second year in a row, Jen Battistoni ran in the Chicago Marathon (October 22nd). Proceeds from the run exceeding \$500 will be donated to the VBF. Jen serves the VBF as a parent resource for her area.

## VBF Donor/Fundraiser Registration Form

I would like to host the following VBF Fundraiser (Check all that apply and fill in contact information below):

Kids Who Care \_\_\_\_\_  
Buddy Booby Read-Along \_\_\_\_\_  
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 International Chapter

Chapter Name: \_\_\_\_\_

\_\_\_\_ Sturge-Weber Syndrome Community

\_\_\_\_ VBF/SWSC – Canada

### 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

### \*Contact Information

Fill out form where applicable:

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.): \_\_\_\_\_
- Buddy Booby Read-Along** – Sign up at <http://www.buddyboobysbirthmark.com/>

(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 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](mailto: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](mailto:BASPASTS@cs.com)

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

\_\_\_\_ 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

## **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

International Conferences – PWS and All Birthmark Types

Family Education and Support/Physician and Public 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

Glen's Gang Newsletter and Pen Pal Group

Buddy Booby's Birthmark Read-Along

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### **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](http://www.birthmark.org)**



**Buddy – VBF's Official Mascot**

**Join the Buddy Booby Read-Along**

