

The Vascular Birthmarks Foundation

www.birthmark.org

How to Appeal an Insurance Denial or Request Out-of-Network Treatment

*A Helpful Guide for Families Denied Treatment of a
Hemangioma, Port Wine Stain, Lymphatic Malformation,
Venous Malformation, Arteriovenous Malformation or other
Vascular Birthmark, Tumor, or Syndrome*



Prepared by:

Barbara Joyce, VBF Insurance Appeal Representative
Lesley Jordan, VBF Insurance Appeal Representative
Mary Montelongo, VBF Insurance Appeal Representative
Linda Rozell-Shannon, VBF President and Founder

EMAIL: HVBF@AOL.COM

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If you need this brochure it is because your insurance company has denied you or a loved one treatment of a vascular lesion. Typically, a denial is based on the fact that the insurance company determines that treatment would be cosmetic or elective. In other words, they do not believe that treatment is a medical necessity.

According to Rozell-Shannon, Marshall, and Waner (1997) “You have health insurance and you expect your benefits to cover the cost of treatment for a vascular lesion. Your insurance company or HMO denies coverage. It’s not an unusual situation. Many insurance companies still classify the treatment of vascular lesions as cosmetic surgery” (p. 139).

Because the subject of vascular birthmarks and tumors is scarcely covered in medical school, the information that insurance companies maintain on the diagnosis and treatment of these lesions is outdated. However, there is current information that indicates that most hemangiomas will not resolve to an acceptable appearance and therefore they will need some form of medical intervention. According to Waner and Suen (1999): “An issue often inadequately dealt with, but an extremely important one nonetheless, concerns the true meaning of the term involution. Unfortunately, a large proportion of parents have been led to believe that the hemangioma will disappear completely and leave no trace. Perhaps the current dogma concerning non-intervention, coupled with the lack of substantial experience on the part of physicians, is partly to blame” (p. 26).

Waner and Suen (1999) further stated, “Only 40% of hemangiomas involute with an acceptable result. Therefore, 60% of all patients with hemangiomas will require some form of corrective surgery” (p. 27). Williams, et al. (2003) also noted that “If these often disfiguring vascular lesions do not involute early, they may have profound psychosocial effects on the child and family” (p. 229).

Tanner, Dechert, and Frieden (1998) noted that most hemangiomas develop during the first few weeks of life, often starting as a tiny red dot, grow for up to one year, and then they begin a long and slow involution cycle (p. 446). The authors explain that it is uncommon for involution to be completed by 2 or 3 years of age. More likely, only 50% of hemangiomas have completely involuted by 5 years of age, 75% by 7 years of age, and 90% by 9 years of age (p. 446). It is because of this misunderstood perception that hemangiomas will involute or resolve on their own that many physicians are reluctant to treat and it is also the reason that many insurance companies do not approve treatment. From the outdated information that has been provided to the insurance companies, they operate under the false premise that all hemangiomas regress or involute on their own.

Many insurance companies still classify the treatment of vascular birthmarks as cosmetic or elective surgery. This is due to the fact that for decades the philosophy has been to “leave them alone, they will go away”. Unfortunately, insurance companies refer to medical textbooks, which contain this outdated philosophy, when making decisions about coverage for treatment for vascular birthmarks. It will take a great deal of time to change this way of thinking, but you still have hope for obtaining insurance coverage through an appeals process.

This brochure will provide you with some helpful tips for filing appeals, filing complaints against insurance companies, and for requesting “out of network” referrals for the treatment of you or your loved ones’ vascular lesion. While most of the appeals concern hemangiomas, this process is applicable to all vascular lesions.

Requesting an “Out-of-Network” Referral

1. You may need to seek a specialist who is not a member of your health plan. This physician is called an “out-of-network” provider. If you are seeking out-of-network care, it is imperative that your primary care doctor supports your position that the treatment is necessary.

Write a letter to your primary care doctor, which explains, in detail, why it is necessary for you to see the out-of-network specialist. You must document that the type of care you need is not available from providers within your health plan. Therefore, it is important to provide him or her with information about the specific expertise of the out-of-network specialist. Obtain a copy of the specialist's resume or CV and include it with your letter as it will detail the specialist's experience and will likely include information about scholarly articles, publications, and studies which the specialist has authored or participated in relative to vascular lesions.

Your primary care doctor may not be aware of all of the new, effective treatment options available so you may need to educate him or her with more current information from peer-reviewed medical publications, newspaper articles, pamphlets, Internet research, and even a copy of the Birthmarks book (www.birthmark.org). Many doctors are extremely busy and may not have time to adequately review all the literature you provide them. As such, it is suggested that your letter also summarize the information which you provide. Your primary care doctor will need this information to convince your insurance company to approve the out-of-network referral.

2. Seek additional medical opinions which support the need to seek "out-of-network" treatment. Find a doctor who will agree to do a phone consultation. Include an extensive description of the lesion and treatments done to date. Send him photos and reports of diagnostic tests such as an MRI, etc. Request that the doctor provide you with a report of his findings. Include a copy of the report with your request for out-of-network treatment.
3. Providing an abundance of information at this stage may help you to avoid an appeal later. Remember to always keep copies of everything you send.
4. Refer to the "Appeals" section of this document for additional suggestions in obtaining out-of-network treatment.

Denials

1. If you are denied coverage, either verbally or in writing, request a written explanation so that your appeal will address each reason cited by the denial letter.
2. Review the current Evidence of Coverage of your insurance plan to determine the time frame within which the appeal must be filed.
3. Call the insurance company to verify the specific address where the appeal must be sent and whether it must be sent to a specific individual and/or department.
4. Make sure that your appeal is received by the insurance company before the appeal deadline. You should mail the documents by way of Certified mail with a receipt. If possible, send the documents by way of overnight delivery. (It is easier to track this way.)
5. Always keep hard copies of the documents you mail. Also, keep copies of all email correspondence.
6. Whenever you speak with anyone about your claim/appeal get their first and last name and their phone number with an extension. Document this information along with the time and date of your call. Keep a logbook. This will help you if one representative gives you information which is contrary to information given to you by a different representative. It also makes it difficult for them to argue with the facts if you have every detail about the conversation, including whom you spoke with.

7. If the insurance claim representative does not return your call within 48 hours, call and leave another message. Your call is one of hundreds they receive weekly, so they will only respond to people who persist. It is also a good idea to email them as this will provide you with proof that you tried to contact them. Also, many claim representatives check and respond to their email more often than phone calls.
8. If your request to see an out-of-network specialist is denied on the basis that comparable services are available within your plan, you may appeal the denial and/or pay the consultation fee yourself. You probably stand a better chance of getting treatment coverage by this specialist if you first get the consultation approved. However, you can pay the consultation fee out-of-pocket and continue to appeal for approval and/or reimbursement of the consultation fee. In this appeal, you must prove that there is no in-network doctor with the expertise needed (see “Appeals” section for details).
9. Your appeal may be denied because your insurance company is stating that this treatment/surgery is not medically necessary and/or is considered cosmetic. You may appeal this decision (See “Appeals” section for details). In addition, you may go forward with treatment by paying out-of-pocket while continuing to appeal and hope you will later be reimbursed. However, it may be easier to win your appeal prior to obtaining treatment versus requesting reimbursement afterwards. Your argument may lose a little “punch” after the fact. Obtaining reimbursement is difficult, but not impossible. Ultimately, your decision will depend on how long you can or want to wait for treatment. Consider filing a complaint with your State’s Department of Insurance and/or your State’s Department of Managed Care. You can find this information via an Internet search. Once a complaint is filed, the Department of Insurance will investigate your complaint and notify you of the appeals process. These Departments exist solely to ensure that insurance companies comply with state insurance regulations.
10. Notify your employer’s Benefits Department of the denial. The insurance company may not be following the specific guidelines for your plan.

Appeals

Each insurance company has a different appeals process usually consisting of several levels, which may include, but not necessarily limited to internal appeals, hearings and external appeals. Your benefit plan coverage document must clearly include the appeals process.

Internal Appeals

Your appeal is reviewed by a committee comprised of employees of the insurance company that are usually medical professionals (i.e. nurses, doctors).

Hearings

You may have the option to appear before a review board in person to state your case. Find out who the members of the review board are. The board may be comprised solely of medical professionals or of a combination of medical professionals and non-medical professionals. More important, find out if the review board is internal (employed by your insurance company) or external (review members have no affiliation with your insurance company). **Know your audience so that you can address them appropriately!** In addition, ask if you can bring a representative with you to support your position, especially if you are appealing before an internal review board. If you are fighting for your child, you may want to consider bringing your child with you. This may hit close to home for some members of the board and may work to your benefit.

External Appeal

Your appeal is reviewed by an independent review agent, which in some states is certified by the Commissioner of the Health Department and assigned by the Insurance Department. This review board has no affiliation with your insurance company and therefore has no financial interest in the outcome. **Depending on your insurance company's policy, the results of the external appeal are sometimes binding. Verify this before you proceed and be prepared that you may not have any recourse beyond this point.**

Tips For Filing Appeals:

1. File a complaint with your state's Department of Insurance as soon as you have been notified that your appeal has been denied. You can find this information via an Internet search. Copy the Insurance Department on your appeal letter and refer to the assigned complaint number.
2. **STICK TO THE TIME FRAME YOUR INSURANCE COMPANY PROVIDES.** You do not want to lose your appeal based on a technicality! Determine the exact date a decision must be made by the insurance company. The Evidence of Coverage will let you know how many days they have to decide your appeal. Mark that date on your calendar and call them two weeks before the deadline to make sure they have all of the information they need to make their decision. Document this conversation with an email. If you do not have their answer by their deadline, call and email them. Let the claim representative know it is the decision date and you need an answer in writing. If they do not respond, speak with/email their supervisor. Keep calling. Persistence pays.
3. Make sure you understand your insurance company's appeal process. If you have any questions, call your insurance company's Medical Case Management Department for clarification.
4. **NEVER** agree to a verbal appeal. Your insurance company's customer service representative will ad-lib your words and the effect will be lost. It is advisable to file a written appeal after collecting all of the necessary information. This may include photos, a letter from the specialist indicating why the treatment is *medically necessary*, medical literature and other supporting documentation. As long as you stick to the timeframe your insurance company provides, this is the best route.

Note: Families must deal with the lack of consistent information and an uncertainty over whether they will find an adequately trained physician. They struggle to get accurate information, and once they find the right physician, then they face the task of proving to their insurance company that treatment is a medical necessity.

According to Glassman, Model, Kahan, Jacobson, and Peabody (1997): "Policymakers, insurers, and health care organizations invoke "medical necessity" to define which services should be offered to patients. However, this term has many meanings and many uses, ranging from general definitions used in health insurance contracts, to specific definitions used to identify which services are "crucial" for individual patients or patient populations. Consequently, "necessity" has an ambiguous meaning; not surprisingly, the manner in which the concept of necessity is applied varies significantly within and across providers, insurers, and states" (p. 152).

5. Keep a detailed journal of the lesion(s) from birth to present, using specific dates. Document when the lesion bleeds, ulcerates, causes pain, problems, swelling, interferes with eating, sleeping, breathing, seeing, nursing, crawling, speaking, crying, or any other normal function, as well as emergency room visits or doctors visits.
6. Take close-up photos showing progression of the lesion, including bleeding and ulceration episodes. Include these photos as enclosures in your appeal letter even if the insurance company tells you it is

not necessary to do so. Send 8 x 10 photos. They are not as easily lost and they have greater impact. Use a binder, if necessary. In addition, email them to the insurance representative as many insurance companies are paperless and there is a chance your photos may not otherwise be seen.

7. If you are appealing after treatment has already been performed, send in “before” and “after” photos of your child. This can be very effective. Use pet names or cute terms to refer to your baby so that the reader will be touched by the personalization of your appeal on behalf of your precious angel.
8. Personalize your appeal. Mention your child by first name repeatedly. You want the claim representative to think about their decision affecting “Amy”, not “the child.”
9. Discuss how your life and your child’s life have been adversely affected by the lesion. If the lesion is near the eyes, ears or mouth you can indicate that it WILL LIKELY cause a problem with seeing, hearing, eating or speaking.
10. If the lesion affects the throat, cite the life-threatening potential of airway obstruction without treatment.
11. If the lesion affects the genital area, point out the potential for rectal or urinary tract obstruction without treatment.
12. **NEVER** use the word “cosmetic,” not even to say that treatment IS NOT COSMETIC. This word is “flagged” and when it appears in an appeal, the appeal is usually denied. For arguments against this being a cosmetic procedure, use the definition of a cosmetic procedure from the **American Board of Cosmetic Surgery** (www.americanboardcosmeticsurgery.org) versus the definition of plastic surgery from the **American Board of Plastic Surgery** (www.plasticsurgery.com). Also, the AMA and the Health Insurance Association of America has defined reconstructive surgery as surgery performed on abnormal structures of the body caused by congenital defects. Such surgery may be performed to improve function, but also to approximate a normal appearance.

Plastic, cosmetic, and reconstructive surgery defined:

“These three types of surgery share some common techniques and approaches, but they have somewhat different emphases. Plastic surgery is usually performed to treat birth defects and to remove skin blemishes such as warts, acne scars, or birthmarks. Cosmetic surgery procedures are performed to make the patient look younger or enhance his or her appearance in other ways. Reconstructive surgery is used to reattach body parts severed in combat or accidents, to perform skin grafts after severe burns, or to reconstruct parts of the patient's body that were missing at birth or removed by surgery. Reconstructive surgery is the oldest form of plastic surgery, having developed out of the need to treat wounded soldiers in wartime.” (www.answers.com). Sometimes “plastic” and “reconstructive” surgery are used interchangeably to mean to restore to a normal appearance, such as in the removal of a large vascular tumor such as a hemangioma.

According to the American Board of Cosmetic Surgery, “Cosmetic Surgery is a subspecialty of medicine and surgery that uniquely restricts itself to the enhancement of appearance through surgical and medical techniques” Retrieved from Americanboardcosmeticsurgery.org. The treatments that are performed on patients with vascular lesions are considered plastic or reconstructive in that they are used to restore the patient’s appearance to normal. The surgical treatment and removal of a hemangioma or other vascular tumor or lesion, according to the American Board of Plastic Surgery (www.plasticsurgery.com) “deals with the repair, reconstruction, or replacement of physical defects of form or function involving the skin, musculoskeletal system, cranio-maxillofacial structures, hand, extremities, breast and trunk, and external genitalia” (www.plasticsurgery.com).

ASPS Applauds Introduction of Legislation to Increase Access to Reconstructive Surgery for Children

For Immediate Release: March 23, 2007

ARLINGTON HEIGHTS, Ill.—The American Society of Plastic Surgeons (ASPS) today announced its support of the Children's Access to Reconstructive Evaluation and Surgery Act—or CARES Act. This bi-partisan legislation was introduced today in the House of Representatives by Reps. Carolyn McCarthy (D-NY) and Patrick Tiberi (R-OH).

In response to an increasing number of insurance companies denying coverage for reconstructive procedures to correct deformities in children, the CARES Act would require insurance companies to provide coverage for the treatment of a child's congenital or developmental deformity or disorder due to trauma, infection, tumor, or disease. Seven years ago, President George W. Bush signed comparable legislation into law while Governor of Texas.

"The ASPS and Coalition for Coverage of Children's Deformities believe that a statutory requirement for insurance coverage of children's deformities is vital to correct the growing problem of insurance companies denying care on the grounds that the care provided is cosmetic in nature," said Roxanne Guy, MD, ASPS president. "The American Medical Association defines reconstructive surgery as being performed on abnormal structures of the body caused by congenital defects, developmental abnormalities, trauma, infection, tumors or disease. Reconstructive surgery is generally performed to improve function and approximate a normal appearance. The CARES Act identifies the distinction between cosmetic and reconstructive surgery."

Lauren Mandel, now a teenager, was denied such coverage when she was a little girl. Insurance covered the life threatening procedures for her arterial venous malformation (tumors made of blood vessels) but denied surgery to fix her jaw and teeth, stating it was considered a cosmetic procedure. Lauren finally had the surgery, which was paid for by her parents. "My daughter deserves that chance as does every child in this country," said Bernadette LaPoppa, Lauren's mother. "No family should have to face the obstacles we have faced or experience financial hardship to receive necessary care from the appropriate medical specialist."

According to the March of Dimes, 3 percent of babies born annually (120,000) suffer from birth defects. A birth defect is an abnormality of structure, function, or body metabolism present at birth that results in physical or mental disabilities or is fatal. Of the 120,000 children born annually with birth defects, approximately 40,000 require reconstructive surgery. Examples of these deformities include cleft lip, cleft palate, skin lesions, vascular anomalies, malformations of the ear, hand, or foot, and other more profound craniofacial deformities. Although surgeons are able to correct many of these problems, an increasing number of insurance companies are denying access to care by labeling the procedures "cosmetic" or "non-functional" in nature. A survey of ASPS members revealed that nearly 54 percent of respondents indicated they had pediatric patients who have been totally denied insurance coverage, or had experienced significant and deleterious obstacles in obtaining approval for coverage of surgical procedures.

"The CARES Act is common sense legislation that will improve the current delivery system and restore patients' and families' trust and confidence in their health plans. Too many American families are being denied access to health care that would prevent long term physical and psychological injuries. The procedures used to treat these children are, by definition, reconstructive, and should be covered by insurance," said Dr. Guy. "Speaking on behalf of the ASPS membership, we thank the sponsors of this proposed legislation and appreciate their support. As plastic surgeons, we recognize this disparity on a personal level with our young reconstructive patients and their families."

For referrals to ASPS Member Surgeons certified by the American Board of Plastic Surgery, call 888-4-PLASTIC (475-2784) or visit www.plasticsurgery.org where you can also learn more about cosmetic and reconstructive plastic surgery.

The American Society of Plastic Surgeons (ASPS) is the largest organization of board-certified plastic surgeons in the world. With more than 6,000 members, the Society is recognized as a leading authority and information source on cosmetic and reconstructive plastic surgery. ASPS comprises more than 90 percent of all board-certified plastic surgeons in the United States. Founded in 1931, the Society represents physicians certified by The American Board of Plastic Surgery or The Royal College of Physicians and Surgeons of Canada.

13. Mention in your letter that The World Health Organization has classified hemangiomas as rare tumors. Most medical plans cover treatment for tumors.
14. For arguing medical necessity in your appeal letter:
 - The skin overlying the hemangioma is much thinner than normal. The result is that it can be easily scratched or dry out and crack, which has happened to (name of your child). This can lead to ulceration (breakdown) of the hemangioma. Spontaneous ulceration can happen in any superficial hemangioma such as (name of your child). Even a fingernail scratch can damage the tissue of the hemangiomas significantly enough to ultimately cause ulceration. (Name of your child) is constantly grabbing her hemangioma and could very easily cause trauma to this delicate tissue layer. An ulcerated hemangioma is painful causing infants to be irritable and eat and sleep poorly. Ulceration increases the risk of infection and scarring. Ulcerated hemangiomas heal slowly. The vascular nature of this tumor also puts (name of your child) at risk of **severe bleeding**. This is a problematic hemangioma, which is also located in a spot that makes it vulnerable to physical trauma. (Name of your child) is at the stage in her development when she is crawling and beginning to try to pull herself up on our furniture in an attempt to stand up. A fall could cause this tumor to bleed **profusely**.
 - Talk to your specialist and ask him to write a medical necessity letter to your insurance company and include this copy in all of your appeals.
15. State the importance of having a skilled doctor with training in the field to treat the lesion. You don't want a doctor who has had limited training and experience on the general use of a laser or someone who "thinks" he can do the procedure.
16. Describe the expertise of the specialist. For example: **Dr. Waner is the Co-Director of the Vascular and Birthmark Institute of New York in Manhattan. He is the leading vascular tumor specialist in the country and is a world-renowned expert with many years of experience in this area. His practice is dedicated exclusively to the treatment of vascular tumors such as hemangiomas and vascular malformations. Dr. Waner has successfully treated thousands of hemangiomas like my child's. Dr. Waner has developed an expertise in the management of these tumors and is able to remove them with little or no bleeding. This accounts for his success. Due to this unique expertise Dr. Waner developed, he receives referrals from all over the world to treat patients similar to my child.**
17. Indicate that a specialist can do a complicated procedure in fewer treatments than an inexperienced one. Emphasize the cost-effectiveness of such an action. For example: **Most surgeons who do not perform these surgeries on a routine basis use a cautious "serial" approach". In other words, they will do three surgeries where Dr. Waner can successfully remove this hemangioma as one outpatient surgery. In the long run this is more cost-effective than any other options.**
18. If your child's lesion is disfiguring, indicate that prompt treatment by a specialist will save potential psychotherapy treatments down the road if the child remains untreated.
19. **ASK YOUR PRIMARY CARE PROVIDER TO REQUEST YOUR APPEAL BE EXPEDITED.** A request to your insurance company for an expedited appeal may need to come from your primary care provider. Check your Evidence of Coverage for this information.
20. **KEEP THE MOMENTUM GOING.** Do not stall in between appeal levels. It is best to keep going while you have everything fresh in your mind!

21. During the middle of your appeal letter you may want to “insert” a picture of your baby so that the birthmark is looking back at the reader of the letter. Be mindful of the picture you choose to insert. The picture should say “I need your help to get rid of this vascular lesion.”

Lastly, if you have followed all appeal procedures and still have difficulty with your appeal, contact VBF’s Insurance Appeal Representative at: hvbf@aol.com. Type “Insurance Guide” in the subject line of your email.

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CASE STUDIES AND CORRESPONDING SAMPLE APPEAL AND REFERRAL LETTERS

Sample A

Case Study “A”: Left Arm and left hand superficial hemangioma

Gina’s hemangioma initially appeared on her left forearm and hand the day after she was born and resembled a purple bruise of about one-half inch by one-half inch in size. The hospital’s pediatrician who examined her the day after she was born advised us that she might have developed a bruise from the birthing process, or that she might have a “Mongolian spot.”

Within one week, the lesion had more than doubled in size and turned bright red. At Gina’s one-week check-up, a different pediatrician advised us that she had a hemangioma. He indicated it would eventually go away and advised we not seek treatment.

We decided to select a new pediatrician, Dr. Frances Green. Dr. Green advised us that she did not have ample experience with hemangiomas to properly diagnose the lesion and recommend treatment. As such, she referred us to Pediatric Dermatologist, Dr. Jane Smith.

We first saw Dr. Smith when Gina was three months old. By that time, her hemangioma covered most of her left hand and forearm and was cobbled. Dr. Smith diagnosed it as a flat, superficial hemangioma and advised us that it would likely continue to grow until Gina was at least one year old. She indicated that it would respond well to PDL laser treatment and that it would likely require between four and six treatments.

Our medical group denied the request for treatment based on the contention that it was cosmetic and would not be effective. We appealed the decision through our health care insurance company. We included language from the Evidence of Coverage for our plan which pointed out that tumor removal was covered by the plan and

not considered cosmetic. We also included a study refuting the one cited by them which detailed the effectiveness of laser treatment on hemangiomas like Gina's. In addition, we included a letter from Dr. Smith explaining why the treatment was necessary.

After thirty days of reviewing our appeal, the insurance company reversed the medical group's decision and ordered them to authorize the laser treatment. The medical group authorized the treatment the same day.

Gina was eight months old at the time of her first laser treatment. The outpatient surgery was done under general anesthesia with no complications. A second surgery was done at ten months of age, a third one at one year, and one at fourteen months. At this point, the lesion is more than fifty percent gone and much of the skin is now smooth.

Approximately six laser treatments are planned.

Sample "A" Appeal Letter

ABC
Appeals and Grievances Department
Post Office Box 1234
Any City, Any State 10000

Date: 01/01/2000

Re: Patient Name
DOB: 01/01/2000
ID # or Case#:

To Whom It May Concern:

Please consider this correspondence a formal grievance which is being filed to appeal ABC HealthCare's denial of laser treatment and further Dermatological office consultation by Dr. Jane Smith for our daughter's hemangioma. A copy of the denial letter from ABC HealthCare (hereinafter "ABC") dated September 1, 2006 is enclosed.

Gina's hemangioma initially appeared the day after she was born and resembled a purple bruise of about one-half inch by one-half inch in size. Within one week, it had more than doubled in size and turned bright red. In the past five months, Gina's hemangioma has rapidly proliferated into a bright red tumor which covers most of her left hand and forearm. (Photos are enclosed.) It continues to grow at a rapid and alarming rate.

We consulted with Gina's Pediatrician, Dr. Frances Green. Dr. Green referred us to Pediatric Dermatologist, Dr. Jane Smith, at ABC Medical Center because of Dr. Smith's expertise with hemangiomas like Gina's. A copy of Dr. Smith's curriculum vitae is enclosed. As noted, Dr. Smith is the Chief of the Division of Pediatric Dermatology and an assistant Professor of Dermatology at ABC Medical Center.

IN THE EXPERT OPINION OF DR. SMITH, LASER TREATMENT IN GINA'S CASE IS MEDICALLY NECESSARY

Dr. Smith evaluated Gina on August 2, 2006. She advised us of the fact that Gina's hemangioma is a **tumor**. She indicated the hemangioma was a flat, superficial hemangioma. Dr. Smith further indicated it is growing rapidly and will continue to grow for at least another seven months. The texture of Gina's skin on her hand and arm has been affected by the hemangioma. The skin is thickened. The longer the hemangioma is allowed to grow, the greater the area of skin on her hand and arm will be affected by thickened skin. As such, Dr. Smith

indicated laser treatment was necessary as soon as possible to stop the growth of the hemangioma and to lessen the amount of affected skin. **She indicated laser treatment would be extremely effective in Gina's case because her hemangioma is flat and superficial.** In addition, Dr. Smith recommended further follow-up with her four weeks from the date of her evaluation on August 2, 2006. Dr. Smith's office requested authorization for laser treatment and further office consultation. As indicated above, ABC denied these requests.

Enclosed please find correspondence from Dr. Smith regarding the medical necessity of the laser treatment for Gina's hemangioma. Of particular significance is the fact Dr. Smith indicated the trial ABC relied upon for its denial is irrelevant in this case.

REMOVAL OF TUMORS IS COVERED BY THE PLAN

ABC'S Evidence of Coverage for our plan indicates "when reconstructive surgery is performed to correct or repair **abnormal** structures of the body caused by congenital defects, developmental abnormalities and ...**tumors**...and such **surgery creates a normal appearance to the extent possible, then surgery to remove or change the appearance of any part of the body is covered.**"

Here, Dr. Smith advised us of the fact Gina's hemangioma is a tumor. This is an uncontroversial medical fact. Gina's vascular malformation is not "normal". It is disfiguring, as evidenced by the attached photographs. Therefore, laser treatment is reconstructive surgery, in Gina's case. It will create a normal appearance for her, and greatly improve her appearance.

REMOVAL OF THE HEMANGIOMA WILL PREVENT FURTHER MEDICAL COMPLICATIONS AND MENTAL HEALTH ISSUES

It is well known that even mild trauma to a hemangioma like Gina's can result in profound pain, ulceration, swelling and bruising. Ulceration frequently results in scarring which requires surgical treatment. Given the location of Gina's hemangioma, these complications are likely, especially when she begins to crawl and her body weight is on her hands and arms. Beyond this, physical trauma to her hand and arm is extremely likely given that children have a proclivity toward injury, especially those learning to crawl and walk.

The size, bright red color and location of Gina's hemangioma make it impossible to ignore. This is well documented by the attached photographs. All children who meet Gina point to her hemangioma, and those that can speak ask what is "wrong" with her. Some children react with fear upon seeing it. Adults who come into contact with Gina are not above staring at her and asking what "happened" to her.

The psychosocial distress of conspicuous hemangiomas like Gina's is well-documented, as is the self-awareness of children as early as the age of two years, which is even more prominent in girls than boys. Therefore, a prominent hemangioma like Gina's has great potential to jeopardize her mental health and social development. Dr. Smith's correspondence confirms "significant psychosocial impairment" is likely in Gina's case.

Dr. Smith believes laser treatment for Gina's hemangioma is medically necessary. It is a reconstructive procedure to rectify a deforming and potentially painful childhood vascular abnormality. The term 'medical necessity' is conveniently subjective, but not included in the pending "Treatment of Children's Deformities Act," supported by fifteen American medical associations¹ which mandates insurance coverage for the treatment of hemangiomas to restore normal appearance to children who have them.

¹ The American Academy of Child and Adolescent Psychiatry, The American Academy of Dermatology, The American Academy of Otolaryngology-Head and Neck Surgeons, The American Academy of Pediatrics, The American Association of Neurological Surgeons & The Congress of Neurological Surgeons, The American Association of Pediatric Plastic Surgeons, The American

Further, it should be noted the request for authorization for the laser treatment was reviewed and denied by an *Internist* for ABC. Clearly, ABC's reviewing physician lacks the extensive knowledge, specialty training and clinical experience with Dr. Smith possesses as a Pediatric Dermatologist.

Finally, enclosed please find a copy of an article published in Journal Watch Dermatology which documents the effectiveness of laser in the treatment of superficial hemangiomas like Gina's. This is one of many articles which addresses the benefit of laser treatment in cases like ours.

Based on the foregoing, we request ABC re-evaluate its decision to deny coverage for treatment of our daughter's condition. Please note we are prepared to pursue this matter to a successful resolution.

We look forward to your prompt response. Thank you.

Very Truly Yours,

John and Mary Smith

cc: Dr. Jones

See footnote (1) below.

Sample "A" Photos

Before laser treatments



After 3 laser treatments



Sample B

Case Study “B”: **Midline Forehead Hemangioma**

Susie was born with no obvious sign of a hemangioma. At approximately 2-3 weeks of age, a light, pale pink, flat “blotch” appeared in the upper center of Susie’s forehead. This spot was roughly the size of the diameter of a pencil eraser. Susie’s pediatrician immediately identified it as a hemangioma.

Susie’s hemangioma continued to grow rapidly in diameter and also became raised and dark red. By age 3 months it was the size of a quarter and raised at least 2 stacked quarters in height. Susie’s pediatrician referred her to Dr. John Brown, a plastic surgeon who is a participating provider (“in-network”) in her health insurance plan. Dr. Brown performed pulse-dye laser therapy in conjunction with intralesional steroid injections. No improvement was noted and, in fact, Susie’s hemangioma continued to grow.

In the months to follow, Susie’s hemangioma became irritated and bled from trauma caused by wearing a winter hat. By age 6 months of age, Susie’s hemangioma grew significantly larger in both diameter and height and became ulcerated. Dr. Brown performed another pulse-dye laser treatment in conjunction with intralesional steroid injections. The ulcer healed within a few days following this treatment, however, the hemangioma still continued to grow at an alarming rate.

By 8 months of age Susie’s hemangioma was pedunculated, meaning it was mushroom-like and had a stalk. Dr. Brown determined that another treatment was necessary due to the hemangioma’s rapid growth. Soon after this treatment was scheduled, Dr. Brown’s office informed Susie’s parents that their insurance company had denied both previous claims for laser and steroid treatment and were not pre-approving the third treatment. Susie’s parents filed a verbal appeal with the customer service representative from her health plan, which was denied immediately based on the insurance company’s claim that there was no evidence that treatment was necessary.

Susie’s parents then discovered Linda Rozell-Shannon, the President and Founder of the Vascular Birthmark Foundation, who educated them on hemangiomas and appropriate treatment for Susie’s now raised and pedunculated hemangioma. Susie’s parents decided to obtain a second opinion from Dr. Milton Waner. Susie’s insurance company would not approve an out-of-network second opinion. Appeals were filed by both Susie’s parents and her pediatrician and were denied. Susie’s parents proceeded with the second opinion without approval from their insurance plan.

Dr. Waner informed Susie’s parents that Susie’s hemangioma would never go away and needed to be surgically removed. Despite many phone calls and letters from Susie’s pediatrician to her insurance company, and a phone call between Dr. Waner and the insurance company, a request to the insurance company for surgical removal of this hemangioma was denied based on the insurance company’s claim that there was no evidence of medical necessity and that this procedure was cosmetic in nature.

Susie’s parents made the decision to pay out of pocket for Susie’s surgery. At age 10 months, Susie’s hemangioma was successfully removed by Dr. Waner in one 75 minute out-patient procedure. Susie’s parents unsuccessfully went through several internal appeal processes before deciding to file an external appeal for which the results were binding. Results are pending.

Sample “B” Appeal Letter

External Appeals Committee
PO Box 1234
City, MA, 56789

Dear External Appeals Committee:

We have been through a long ordeal with ABC Health Plan regarding denials. We are hopeful that you can assist us in obtaining financial coverage for necessary surgery for our 10 month-old baby daughter, Susie Smith. Anna's pediatrician, Dr. Peter Wolf, recently submitted a request to ABC Health Plan for out of network surgery by Dr. Milton Waner. Photos speak a thousand words, so please refer to the enclosed pictures of our baby, which show progression of the condition for which we are seeking surgery, before reading the remainder of this letter.

Susie has a large, complicated, and pedunculated hemangioma on her forehead. Hemangiomas are vascular tumors made up of proliferating blood vessels. Susie's hemangioma has been proliferating for over seven months and has shown no signs of regression. This hemangioma has ulcerated and we believe that it causes her discomfort due to pressure caused by the skin around the tumor being pulled extremely tight because it can not accommodate the tumor's rapid growth. It has also bled on several occasions. To date this hemangioma continues to be problematic and has negatively affected the quality of life of our entire family.

Dr. John Brown had been following the progression of this tumor from September, 2006 to March, 2007. Dr. Brown has performed two laser treatments and direct injection of steroids but Susie's tumor continues to grow, ulcerate and bleed. It still continues to damage what was once normal skin tissue. Laser treatment can be effective for certain types of hemangiomas. We since learned that laser treatments have little or no effect on hemangiomas such as Susie's, which are raised and pedunculated.

As Susie's parents, it is our responsibility to clarify the diagnosis and suggested course of treatment. We also need to be aware of all treatment options available to our baby so that we can make an informed decision and be confident that the option we choose is the best one. It is also ABC Health Plan's responsibility to evaluate the medical necessity of Susie's course of treatment based on her individual condition and not on outdated, classic, pediatric textbook jargon. Therefore, we requested that Susie be seen by Dr. Milton Waner. Dr. Waner is the Co-Director of the Vascular and Birthmark Institute of New York in Manhattan. He is the **leading vascular tumor specialist in the country and is a world-renowned expert** with many years of experience in this area. His practice is dedicated **exclusively** to the treatment of vascular tumors such as hemangiomas and vascular malformations. Dr. Waner has successfully treated thousands of hemangiomas like Susie's. However, despite Dr. Waner's credentials and expertise, this request was denied. We obtained a second opinion from Dr. Waner at our own expense and Dr. Waner feels that Susie's hemangioma should be removed because it is aggressive, pedunculated, and problematic. He also stated that Susie's hemangioma will not "go away" as is commonly assumed of all hemangiomas. Dr. Waner routinely operates on children Susie's age and younger.

We feel so fortunate to have found Dr. Waner, the country's leading expert in vascular tumors, **who can remove this tumor in just one, short, out-patient surgical procedure, in a hospital with pediatric anesthesiologists**. The threat of this tumor ulcerating again and bleeding profusely can be behind us forever and further medical expenses can be avoided.

Dr. Herman, The Medical Director at ABC Health Plan stated that Susie's hemangioma will "go away". **The theory that hemangiomas should be left alone and they will "go away" is outdated. In reality, only 40% of hemangiomas will completely involute. The remaining 60% require surgery or laser treatment. This is why hemangiomas must be evaluated on an individual basis.**

Dr. Michael Gibson is a reputable physician who treats hemangiomas. Dr. Gibson is a Plastic Surgeon at ABC Medical Center and has impressive credentials (enclosed). We sought Dr. Gibson's opinion of Susie's

hemangioma via email by submitting a picture. Dr. Gibson's enclosed email response stating that Susie's hemangioma will **never go away and requires surgery** also supports our position.

We have done our research and feel comfortable and confident with Dr. Waner. Our position is that we want this hemangioma to be **surgically removed** by Dr. Waner **now** based on the following information:

- Susie has undergone laser therapy and direct injection of steroids but her tumor continues to grow, has ulcerated and continues to damage what was once normal skin tissue. It is also at risk of repeat ulceration and profuse bleeding, especially due to its location (i.e.: bump on the head).
- The enclosed literature indicates that a large pedunculated tumor like Susie's which has bled and ulcerated and has not been successfully treated by direct steroid injection and laser treatment necessitates removal.
- Large, facial, pedunculated hemangiomas are more likely to leave significant scarring and are therefore aggressively treated early.
- Vital and important structures are frequently found within the substance of the hemangioma making this type of surgery very risky. The surgical removal of hemangiomas is hazardous since they are vascular and therefore bleed profusely during surgery. Further compounding this is the fact that any blood loss in a young child is much more significant than in an adult. For this reason, most surgeons will not operate on hemangiomas. **Dr. Waner has developed an expertise in the management of these tumors and is able to remove them with little or no bleeding. This accounts for his success. Due to the unique expertise Dr. Waner developed, he receives similar referrals from all over the world.**
- Dr. Waner can successfully remove this hemangioma as **one outpatient surgery**. In the long run this is more cost effective than any other options.
- We spoke with a Mom in Dr. Waner's waiting room whose baby has a facial hemangioma. This Mom informed us that Dr. Waner told her that her baby's hemangioma would eventually go away and therefore he was not going to treat it. This gave us additional confidence that Dr. Waner is not overly aggressive and does not remove hemangiomas that do not need to be removed.
- Susie is ten months old. Her hemangioma was **NOT** present at birth. It began to appear at age 2-4 weeks and was only a barely visible, light pink, flat blotchy area. Now, only nine months later, it is a large, dark red, raised mushroom-like tumor which continues to proliferate during the phase in which the uncomplicated hemangiomas are beginning to regress. Susie's tumor is showing no signs of involuting (progression photos enclosed).
- Susie has a second hemangioma on her shoulder that is currently **NOT** rapidly proliferating, **NOT** ulcerating, **and NOT** medically significant and **NOT** causing discomfort of any type. Therefore, she is not being treated for this hemangioma. This is the type of hemangioma that literature refers to when they suggest that taking no action is the best course. This is a perfect example that not all hemangiomas are the same and should be evaluated individually.
- At only ten months old, Susie is already aware of her hemangioma. She grabs it when she looks at herself in the mirror and often touches it then touches another person's forehead simultaneously. She is already aware that she is different.
- Psychosocial issues of living with a facial deformity have been documented and support the need for reconstructive surgery. Since Susie's tumor will not "go away", there is no point in waiting for it to be removed. Dr. Waner has stated that **now is an ideal time to remove this tumor versus waiting because children in my child's age group are much less likely to require scar revision surgery following the initial surgery. Operating now could spare Susie an additional surgery and therefore could be more cost effective.**
- This tumor has negatively affected the quality of life of our entire family. People have made rude and insensitive comments while in public. Susie is beginning to understand conversation, and is becoming aware of her surroundings and differences. This type of situation can be very traumatic to a child.

ABC Health Plan has denied our last appeal stating that this procedure is cosmetic and not medically necessary. **A cosmetic procedure, according to the American Board of Cosmetic Surgery (www.americanboardcosmeticsurgery.org), “is a subspecialty of medicine and surgery that uniquely restricts itself to the enhancement of appearance through surgical and medical techniques. It is specifically concerned with maintaining normal appearance, restoring it, or enhancing it beyond the average level toward some aesthetic ideal.”** What is done at the Vascular and Birthmark Institute is considered plastic surgery, which, according to the American Board of Plastic Surgery (www.plasticsurgery.com), **“deals with the repair, reconstruction, or replacement of physical defects of form or function involving the skin, musculoskeletal system, cranio-maxillofacial structures, hand, extremities, breast and trunk, and external genitalia.”** Today such surgeries are done on babies under 6 weeks old (cleft palates) and complicated hemangiomas like Susie’s are treated immediately and aggressively so as to prevent tissue destruction. The skin tissue on Susie’s hemangioma is no longer normal skin tissue evidenced by the fact that it does not contain any hair follicles. Due to this tumors destruction of Susie’s normal skin tissue Susie’s hair growth stops at the base of her hemangioma. This abnormal tissue is also delicate and subject to trauma much more easily than normal skin tissue.

The medical necessity arguments are many and are outlined in detail throughout this letter. The skin overlying the hemangioma is much thinner than normal. The result is that it can be easily scratched or dry out and crack, which has happened to Susie. This can lead to ulceration (breakdown) of the hemangioma. Spontaneous ulceration can happen in any superficial hemangioma such as Susie’s. Even a fingernail scratch can damage the tissue of the hemangiomas significantly enough to ultimately cause ulceration. Susie is constantly grabbing her hemangioma and could very easily cause trauma to this delicate tissue layer. An ulcerated hemangioma is painful causing infants to be irritable and eat and sleep poorly. Ulceration increases the risk of infection and scarring. Susie already has one scar on her hemangioma that resulted from a now healed ulcer. Ulcerated hemangiomas heal slowly. The vascular nature of this tumor also puts Susie at risk of **severe bleeding**. This is a problematic hemangioma which is also located in a spot that makes it vulnerable to physical trauma. Susie is at the stage in her development when she is crawling and beginning to try to pull herself up on our furniture in an attempt to stand up. Due to the fear that a bump on her forehead can cause the tumor to bleed **profusely** we are extremely cautious and have to stop her from much of this activity. Stopping her from this activity is **hindering her normal development**. In addition, the usually simple task of putting on a winter hat is a difficult one because it rubs on Susie’s hemangioma and has made it bleed. We have purchased larger hats but they do not adequately provide protection for her ears in the cold weather or completely cover her eyes. There is no solution to this other than putting on hats that fit correctly and run the risk of irritating this tumor. The ulcer Susie had followed a bleeding episode which resulted from wearing a winter hat. **No parent or child should have to live like this!**

We have enclosed pictures of Susie from birth to present for your review. We have also enclosed a letter from Drs. Waner and Levitin, medical literature and an email note from Dr. Michael Gibson which support our position, and all related correspondence from ABC Health Plan.

If you have any questions or need additional information, please feel free to contact us. Thank you so very much for your assistance in this matter.

Sincerely,
Jane and Dick Smith

cc: Dr. Peter Wolf
Dr. Milton Waner
Ms. Linda Rozell-Shannon, VBF

Sample “B” Photos

2 hours before surgery



24 hours after surgery



Sample C

Case Study “C”: Anterior Fontanel Hemangioma

Baby boy, John was delivered via C-Section at 38 weeks gestation. At 1 week of age, a strawberry birthmark appeared over his fontanel. The hemangioma grew very quickly. At six weeks of age, the hemangioma was already larger than a half dollar and raised about $\frac{1}{4}$ inch. At 10 weeks of age, the hemangioma began to ulcerate. Several visits were made to the pediatrician who referred the parents to a dermatologist. The dermatologist confirmed that the hemangioma was ulcerated. He told the parents that it was rapidly growing and recommended seeking a physician to remove it. The dermatologist, as well as the pediatrician, prescribed bactroban ointment, which was applied three times a day to keep the ulcerated area moist. He also recommended that a CT scan be performed. The baby had the CT scan performed at age 3 months. The CT scan stated “no definite evidence of intracranial extension; however, multiplanar MR imaging of brain would be better suited for this purpose. No intracranial hemorrhage, hydrocephalus, or mass effect”.

In early July 2004, the parents were referred, by a family friend, to a pediatric neurosurgeon. The doctor confirmed that the hemangioma probably needed to be excised; however, recommended that the parents wait until he was a little older and bigger. The doctor saw the baby again 6 weeks later in August 2004. At that visit, the ulceration appeared to have mostly healed. The doctor felt that the hemangioma had begun to involute. Again, she wanted to wait another 6 months. She explained that the surgery would probably involve inserting tissue expanders and could potentially involve a good amount of blood loss.

When John was 11 months old, he was seen by the pediatric neurosurgeon a final time. At that visit, the hemangioma measured 6 cm x 6 cm x $2\frac{1}{4}$ cm. The area once ulcerated was now scarred throughout the entire middle portion of the hemangioma. The baby was developing normally and had no other medical issues. The

parent's main concern with their son's hemangioma was the social implications that he may encounter because of its location and size. They worried about the lack of hair growth in the middle of his head due to the scarring from the ulceration. In addition, they were concerned about the excision technique that the pediatric neurosurgeon had explained to them. The doctor had removed only 6 or 8 hemangiomas in her career. She was semi-retired and saw patients only once a week.

The parents contacted Dr. Milton Waner at the Vascular Birthmark Institute. After reviewing their son's case, Dr. Waner agreed to perform surgery to remove the hemangioma.

This family was insured through an HMO. On behalf of the pediatrician, the baby's mother wrote the referral letter requesting a referral to Dr. Waner. The referral letter included a case history of their son, the names of the doctors that had examined him, the techniques the two doctors (neurosurgeon and Dr. Waner) performed to remove the hemangioma, articles on Dr. Waner and surgeries that he had performed, and pictures of the growth of the hemangioma throughout the months. The HMO approved the out of network referral and the surgery.

When John was 13 months old, Dr. Waner successfully removed the hemangioma. The procedure took an hour and half and involved a 24 hour stay at the hospital. A drain was inserted; however it was removed prior to discharge the next day. At present, hair has grown over the incision line and John shows no side effects from the surgery.

Sample "C" Referral Letter

John Jones is a 10 month old male with a hemangioma located on the anterior fontanel. The lesion measures approximately 6 cm long; 6 cm wide and 2 ½ cm high. At about 10 weeks old, the hemangioma became ulcerated, bled, and was painful for the infant. Bactroban ointment was prescribed for infection control. After 3 months of intense use of the ointment, the ulcerated area healed, leaving a scar in the middle of the hemangioma.

After extensive research of physicians within the ABC Healthplan network, none could be found that specialized or had extensive experience in treating or removing hemangiomas, especially one so closely located to the brain.

At the recommendation of a friend of the family and with the approval of ABC Healthplan, the parents took the baby to a pediatric neurosurgeon, Dr. Mary Brown, at XYZ Medical Group in City, State. Dr. Brown is semi retired and holds office hours once a week, and is considered an out of plan physician but is associated with a plan facility. Dr. Brown saw the patient when he was 3 months old, six weeks later, and again at 10 months old. She felt that the hemangioma would need to be removed since the probability of it resolving on its own was slim; however, she felt that we should wait until the baby was much older (around 4). Dr. Brown has removed approximately 6 – 8 hemangiomas over her career. Her removal procedure involves the possibility of adding tissue expanders over several months, followed by the actual removal of the hemangioma.

The parents located Dr. Milton Waner at Temple Israel Medical Center in New York. Dr. Waner is an Otolaryngologist by training but specializes in endovascular surgery and the treatment of birthmarks and vascular malformations (He is considered a Pediatric Facial & Plastic Reconstructive surgeon). Dr. Waner has performed over 4,000 treatments/surgeries on vascular lesions such as hemangiomas. Morbidity and mortality do not appear to be factors of Dr. Waner's procedures. Dr. Waner has developed specialized surgical techniques and instruments to safely remove vascular lesions on young children. There is minimal blood loss and minimal scarring. The surgery does not require any tissue expanders procedure and most surgeries only involve an overnight hospital stay, depending upon the size of the hemangioma. Most surgeons who do not perform these

surgeries on a routine basis use a “serial” approach and perform multiple procedures over time. Dr. Waner is the only surgeon in the county who operates on vascular lesions full time

Due to the sensitivity of the area and the expertise of the physician we respectfully request a referral of John Jones to Dr. Milton Waner. While Dr. Brown is qualified, her experience in performing the excision, and her semi-retired status, is not extensive enough to provide confidence in the final outcome of treatment. The parents are also concerned with the psycho-social impact of waiting for the removal of the hemangioma until the child is older.

The success of the outcome and risk of complications are dictated by the number of times the surgeon has performed the procedure and the number of procedures that have to be performed. Dr. Waner’s treatment is a cost effective solution since the likelihood of multiple procedures or follow-up treatment is minimal.

Attached please find pictures of the infant at 10 weeks, at 4 months, and at 9 months of age. Also included are articles on Dr. Waner’s treatment and experience.

Sample “C” Photos

Before Surgery



After Surgery



Please email us to let us know if this guide has been helpful to you for preparing your appeal or request for out-of-network treatment. Also, let us know if you have any suggested changes.

EMAIL: HVBF@AOL.COM. Please put “Insurance Guide” in the subject line.



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