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February 25, 2015

Dear Medical Director:

The American Academy of Pediatrics (AAP) is a professional medical society of over 62,000 pediatricians, pediatric medical sub-specialists and pediatric surgical specialists dedicated to the health, safety, and well-being of infants, children, adolescents and young adults. I am writing to you to advocate for appropriate benefits coverage and payment for children with vascular anomalies, including infantile hemangiomas and vascular malformations.

Vascular anomalies affect 5-6 % of newborns [1,2]. Most of these children have infantile hemangiomas (IHs), which are vascular *tumors*, and are the most common tumors of childhood. These lesions typically proliferate early, with most growth occurring between one and two months of age [3], and 80% of growth reached by 3 months [4]. Unlike other tumors, IHs have the unique ability to involute after proliferation. Unfortunately, a subset of IHs develops complications during the rapid growth phase that cause pain, functional impairment, or permanent disfigurement. Not infrequently, by the time specialist evaluation is requested and insurance approval is obtained for treatment, IHs have already caused these complications. Early intervention, including topical, intralesional, or systemic medical therapy, laser treatment, and surgery, can result in a dramatic reduction in growth and, in some cases, eradication of the lesion.

Vascular *malformations* are classified based on the predominant vessel type: capillary (“port wine stains”), venous, lymphatic, arterial, or mixed. They are congenital lesions, but some may become clinically apparent later in life, expanding as the patient grows. Vascular malformations do not involute, and their growth may be accelerated by trauma, infection, and hormonal changes. As with infantile hemangiomas, vascular malformations may result in pain, functional impairment, and disfigurement. The risk of complications depends on the type of malformation and location. For example, venous, lymphatic, and arteriovenous malformations may become bulky, resulting in deformity of the soft tissue and/or bony structures, and impairment of function such as vision, eating, swallowing, speech, and ambulation. Pain may result from thrombosis or inflammation. Bleeding may be present when lesions involve the skin, gastrointestinal tract and/or other organ systems. Large or widespread vascular malformations often cannot be completely removed, and there are no reliable systemic treatment options. Insurers should be aware of the high likelihood of complications and recurrences throughout the patient’s life.

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The vascular malformation that is most poorly understood by insurers is the port wine stain. Intervention for these lesions is often denied on the premise that intervention is for “cosmetic” reasons only, and approval is reserved for those patients with nodules or bleeding. Evidence suggests that, in fact, laser treatment of port wine stains in early childhood may result in better control of these lesions [5], and may reduce the likelihood of nodule formation in the future. Furthermore, advanced lesions are known to produce growth factors that cause local overgrowth of bone and soft tissue.

In considering insurance approval for patients with vascular anomalies, it is critical that medical directors distinguish “*cosmetic*” or *aesthetic* interventions from those that are *restorative* or *reconstructive*. While cosmetic procedures are intended to **improve the appearance of normal body features** and are not essential to physical health, reconstructive procedures **restore physical function and minimize disfigurement** from accidents, disease, or birth defects. For example, a facelift for a *normal* 70 year-old patient to look like a 60 year-old person is a cosmetic procedure- the individual is attempting to achieve “supra-normal”. In contrast, a procedure to improve the appearance of a patient with a birth defect of the face (e.g., a vascular anomaly) is a reconstructive procedure (*not* cosmetic)- the intervention is attempting to return that patient to *normal* (it is not normal to be born with a vascular anomaly). Interventions for other deforming congenital anomalies that cause psychosocial morbidity (e.g., cleft lip, frontonasal dysplasia, and craniofacial deformities) are universally approved by virtually all insurance companies, and treatment for vascular anomalies should be considered similarly.

Coordinated, collaborative multispecialty care is often optimal for appropriate treatment of vascular anomalies including specialists such as dermatologists, otolaryngologists, plastic surgeons, pediatric surgeons, and interventional radiologists, as well as pediatricians. It is critical that insurers facilitate the multidisciplinary care required by these patients. Timely evaluation and treatment lead to minimizing or eliminating long-term sequelae.

Early treatment of vascular anomalies should be considered medically necessary for benefit plan coverage and payment due to the high risk of serious medical and psychological issues. Therefore, we call upon public and private payers, including health plans, to provide comprehensive benefits coverage and appropriate payment for evaluation and treatment of vascular anomalies. In the long run, it will be more cost effective for carriers to cover early intervention and treatment of these disorders. Children who are not treated properly at the earliest possible stage may not only require more reconstructive procedures down the road, but often require psychological counseling to address living with these debilitating and disfiguring lesions.

I look forward to your response regarding your health plan’s benefits coverage for vascular anomalies. The AAP is actively engaged in identifying and developing resources for the early treatment of infants with vascular anomalies, and is poised to work with health plans and payers for appropriate benefits coverage for these lesions that achieve the goals of improving quality of

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care and managing costs in a model of care that ensures children and families have access to appropriate care.

Should you require additional information regarding vascular anomalies, please contact Lynn Colegrove, AAP staff manager to the AAP Section on Dermatology at lcolegrove@aap.org.

Sincerely,



Sandra G. Hassink, MD, FAAP
President

SGH/lc

References

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