

## **Statement of the American Society of Plastic Surgeons**

### **Before the House of Representatives Education and Labor Committee Subcommittee on Health, Employment, Labor, and Pensions Subcommittee on Workforce Protections**

#### **"Expecting More: Addressing America's Maternal and Infant Health Crisis"**

**January 28, 2020**

Chairwoman Wilson, Chairwoman Adams, Ranking Member Walberg, Ranking Member Byrne, and members of the Subcommittees, the American Society of Plastic Surgeons thanks you for holding today's hearing to focus on health issues impacting women and children. As the committee considers these important issues, we would like to highlight legislation to address congenital anomalies, the *Ensuring Lasting Smiles Act* (ELSA), H.R. 1379.

The American Society of Plastic Surgeons (ASPS) is the largest association of plastic surgeons in the world, representing more than 7,000 members and 93 percent of all board-certified plastic surgeons in the United States. Our mission is to advance quality care for plastic surgery patients and promote public policy that protects patient safety and ensures appropriate access.

For more than two decades, the ASPS has championed federal legislation advocating for access to care for individuals with congenital anomalies. Our members work with children and families to ensure appropriate insurance coverage and see first-hand the challenges and long-term impact of denials or delays in coverage. ASPS first worked on the *Treatment of Children's Deformities Act* introduced in 1998 during the 105<sup>th</sup> Congress. The legislation has enjoyed broad, bipartisan support and in fact was included in the House of Representatives *Patient Protection and Affordable Care Act* during the 111<sup>th</sup> Congress. The legislation, then titled *Children's Access to Reconstructive Evaluations and Surgery (CARES) Act*, was part of a bipartisan package of non-controversial amendments considered and accepted during the ACA markup in the House Energy and Commerce Committee. Although the House version of the ACA did not become law, the bipartisan work in this area helped to realize a uniform definition for reconstructive surgery which importantly clarifies that "follow up treatment needed to correct or improve a part of the body because of birth defects, accidents, injuries or medical conditions" is included.

Although many states have acted to clarify coverage in areas such as cleft lip and cleft palate, federal legislation is necessary to ensure that ERISA plans ensure access. Congenital anomalies often require multi-stage procedures to approximate a normal appearance and timely intervention is important to a child's development.

The Centers for Disease Control and Prevention (CDC) classifies birth defects as "common, costly, and critical" and reports that one in 33 newborns in the United States suffers from a congenital anomaly. Of the 120,000 children born annually with a congenital anomaly, approximately 40,000 require reconstructive surgery. Craniofacial anomalies can restrict a child's ability to breathe, eat, and speak in a normal manner. Therefore, surgery to repair an anomaly – which is highly individualized – is intended to help a child obtain the ability to function and grow normally. Early intervention by a team of specialists, including plastic surgeons, is necessary to assess and oversee the patient's treatment and development, sometimes over the course of several years.

Examples of these anomalies include cleft lip; cleft palate; skin lesions; vascular anomalies; malformations of the ear, hand, or foot; and other more profound craniofacial conditions. On average, children with congenital or developmental anomalies can expect anywhere from three to five surgical procedures before normalcy and function are achieved. Although surgeons can correct many of these problems, some insurance companies deny access to care by labeling the procedures "cosmetic" or "non-functional" in nature. However, the American Medical Association defines surgery performed on abnormal structures of the body caused by congenital defects or developmental abnormalities as reconstructive – not cosmetic. Denial or delay of these procedures – which by definition are reconstructive – could lead to long-term physical and psychological injuries. Furthermore, insurers frequently overlook the dental and orthodontic needs of these patients – which are essential to their achieving normal form and function – and mislead affected patients and the public when deeming these procedures cosmetic. When private insurance denies a child's reconstructive surgery, families many times end up turning to Medicaid, Children's Health Insurance Program (CHIP), or other state-sponsored programs.

To a layperson, repair of a craniofacial anomaly may seem cosmetic in nature. However, reconstructive surgery is performed to treat structures of the body affected aesthetically or functionally by congenital anomalies or birth defects. It is generally done to improve function and ability but may also be performed to achieve a more

typical appearance of the affected structure. The *Ensuring Lasting Smiles Act* excludes coverage for cosmetic procedures.

We'd like to share how access to these procedures impacts the lives of our patients. For example, Peter is an electric guitar player and motivational speaker. Born with Goldenhar Syndrome, he has undergone 30 surgeries in 18 years. All of Peter's surgeries have been to improve his ability to breathe, eat, hear, and see. His largest reconstructive surgery involved placing a custom TMJ implant on his left side, grafting bone from his skull on the right side, and moving both mandibles forward to enlarge his upper airway. The reconstruction also necessitated a second round of orthodontia treatment. Even with private insurance, Peter's out of pocket expenses exceed \$100,000 due to high deductibles and copays, no dental coverage, and non-covered needs such as glasses, hearing aids, and prosthetics. Peter is missing his left ear and cannot wear contacts due to cysts in his eyes. An ear prosthesis, therefore, is needed to retain his glasses. Peter would like to have genioplasty (or chin augmentation) to complete his jaw reconstruction, but the surgery is considered cosmetic and not covered. For patients born with congenital craniofacial birth defects, this surgery is most certainly not cosmetic.

Another example is Lauren. Lauren was born with a bilateral cleft lip and palate, which means she had splits on both sides of her upper lip leading up to the base of her nose and was lacking a roof in her mouth. By the time she was seven years old, she had seven surgeries. Her insurance company told her family these surgeries were cosmetic and would only cover some, if any, of the costs. At age 17, Lauren had another major surgery, which consisted of surgically repositioning her upper and lower jaws and chin to correct a severe underbite and adding support in the upper parts of her face, including her cheek area, which she congenitally lacked. Her health insurer initially deemed the surgery unnecessary and notified her that she would have to pay for it herself. Her surgeon pushed back against this denial, explaining that if Lauren did not receive this care, her speech would be significantly impacted – something she had worked so hard to correct following her previous surgeries. Lauren's surgeon also told the insurance company that her face would slowly concave in, growing in a "c" shape, and that her underbite would get progressively worse making it harder for her to eat. The insurer ultimately agreed to cover the cost of surgery; however, they subsequently denied coverage for a dental-related procedure associated with her condition. Her family has spent \$20,000 to cover the cost of her treatment since birth.

The *Ensuring Lasting Smiles Act* is supported by the American Society of Plastic Surgeons as well as more than 35 patient and provider organizations

including the American Academy of Pediatrics, American Association of Oral and Maxillofacial Surgeons, American College of Surgeons, American Dental Association, March of Dimes, National Foundation for Ectodermal Dysplasias, National Organization for Rare Disorders, and children's hospitals including the Ann & Robert H. Lurie Children's Hospital of Chicago and the Children's Hospital of Wisconsin.

This bipartisan legislation will have a direct impact on patients with congenital anomalies by providing coverage for medically necessary services that repair or restore a patient's anomaly – ensuring patients with birth defects have access to lifesaving treatments. We look forward to working with you to advance this important legislation.