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"Every Child Deserves A Smile."

January 31, 2007

Good Morning Sen. Handley, Rep. Sayers and Members of the Public Health Committee:

My name is Erin McCall-Goldie and I am the President and Founder of F.A.C.E. (Families Advancing Craniofacial Excellence). F.A.C.E. is a non-profit organization dedicated to improving the quality of life and providing a voice for children with craniofacial differences. I am also a mother of a 5 year old child born with a craniofacial difference known as a cleft lip and cleft palate.

A cleft lip is a separation of the two sides of the lip. The separation often includes the bones of the upper jaw and/or upper gum. A cleft palate is an opening in the roof of the mouth in which the two sides of the palate did not fuse, or join together, while the unborn baby was developing in the first 4 to 6 weeks of gestation. A child born with a cleft frequently requires several different types of services, e.g., surgery, dental/orthodontic care, and speech therapy, all of which need to be provided in a coordinated manner over a period of years. The latest statistics from the Department of Health and Human Services Centers for Disease Control and Preventions states that Orofacial Cleft is the 3rd highest birth defect in the United States.

I am here today to bridge any misconception regarding health care for craniofacial children and why Universal Health Care is imperative for the comprehensive care for craniofacial children. As you know, not all insurance plans are created equally, while current insurance coverage is becoming less obtainable due to high premium rates, many families have to choose between keeping a roof over their heads and food on the table versus paying for ones medical insurance coverage.

For craniofacial families the cost is higher, not only financially but emotionally. When a mother gives birth to a child with a craniofacial difference, no one could prepare that mother for the long process of medical procedures that child will need to endure just to be able to eat, speak, and develop. Most children will need multiple surgeries starting at 3 months of age and continue into their adult life. Unfortunately the assumption of insurance companies providing coverage for medical and orthodontic surgeries for our children is very false and misleading. As you are aware, self funded insurance plans do not have to follow any state mandates (please refer to SB1 2003 for orthodontic coverage for craniofacial children). Self funded insurance plans also dictate when a craniofacial child can have surgery, they may send you to a craniofacial doctor in their network plan, however that doctor does not perform craniofacial surgeries on a weekly basis so that particular doctor will refer that craniofacial family to a comprehensive craniofacial team, but the team is not in that network and the self funded insurance company will not add the team to its network therefore any procedures and surgeries for that craniofacial child will not be covered and necessary medical procedure can be delayed.

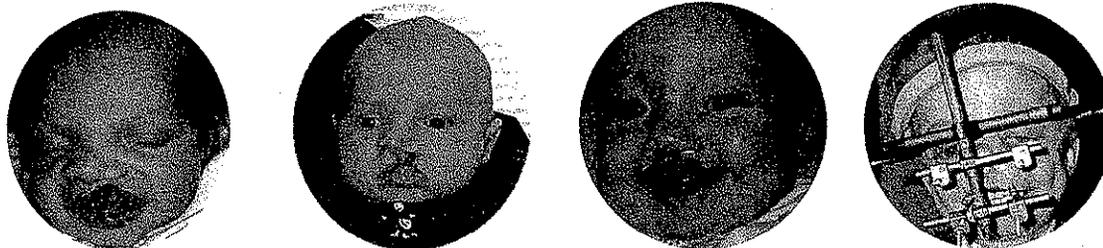
The major concern that our organization receives from craniofacial families is of problems with their insurance coverage, how do I pay for this, my insurance company denied my son's bone graft surgery because they don't provide coverage for orthodontics and they claim it's a cosmetic procedure. Many families take drastic measures, just to pay for their child's comprehensive care such as re-financing or selling their home to pay for medical bills, going into bankruptcy, occurring hundred and thousand of dollars of medical bills, and even divorcing a spouse because the financial stress is unbearable.

When a mother of a child with Crouzon syndrome calls her insurance company to tell them that their 2 year old son needs a metal halo device to be screwed into his skull to pull the bones in his forehead out forward so his eyes don't fall out of his socket, her insurance company said I'm sorry but we don't feel that is a necessary medical device, we will not cover it, your out of pocket expense is \$30,000.

The birth of a child should be a joyous occasion, for craniofacial families it's a time of concern and confusion for the well being of their child. Craniofacial families should not need to be insurance experts and make sacrifices to be able to provide the best comprehensive medical care for their child. Families need affordable, sustainable and high quality health care. I encourage you to support Universal Health Care; Universal Health Care is the answer.

Thank you for allowing me the opportunity to address this committee,

Erin McCall-Goldie, President
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