special report CCanetvvork



newsletter of the children's craniofacial association

Cher—honorary chairperson

september 2003

drive for fair insurance coverage launched in washington

he CCA drive to guarantee insurance coverage for patients with craniofacial conditions was launched recently in a room just off the floor of the United States Senate. Patients and families related stories of how insurance companies denied coverage. There were cases in which needed surgeries were labeled "cosmetic," medical coverage for craniofacial conditions ended when patients reached the age of 18, and coverage was denied for necessary ancillary treatments beyond surgery.

Congressman Mike Ross of Arkansas called such actions by insurance companies unethical and immoral. He called on CCA families to let



the public and elected officials know about coverage denial, saying that this type of behavior would not stand up to public scrutiny, but if patients and their families remain silent, unethical insurance companies will prevail.

Rep. Ross introduced the Reconstructive Surgery Act of 2003 (HR 1499) in Congress and, as of this writing, now has nine cosponsors for the legislation. The legislation establishes the requirement that insurance companies provide coverage for medically necessary reconstructive surgeries caused by congenital defects, developmental abnormalities, trauma, infection, tumors or disease. Ten states already have such a requirement, but there is a need to make it a national mandate.

Rep. Ross and Senator Blanche Lincoln of Arkansas hosted the CCA meeting at the Capitol. They explained that one of their constituents, a craniofacial patient named Wendelyn Osborne, brought this matter to their attention and has been a tireless advocate in support



of the legislation. They pointed out that she was effective because she continues to call, write and visit legislators making her case for fair treatment.

Also speaking at the event were representatives of the National Organization for Rare Disorders and Cleft Advocates, Inc. These organizations will be joining with CCA to support the legislation. CCA will be gathering additional allies in the drive for adequate coverage. Easter Seals, The March of Dimes, and the National Foundation for Facial Reconstruction also support the legislation.

CCA families are urged to immediately contact their elected Senators and Representatives in Congress and urge them to support the Reconstructive Surgery Act of 2003 (House Resolution 1499). The most effective communication is to ask for a meeting when the Senator or Representative is available in his or her home state. But if that is not

possible, a letter or email is also effective. Information about the cost of surgeries and treatment, problems with insurance companies regarding denial of coverage or concern that coverage will be denied in the future are important messages to bring to the elected officials.



To find the phone number, postal or email address of your Senators and Representatives, visit **congress.org** on the Internet. Enter your zip code and it will provide you with the contact information for your elected representatives.





















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