



STATE OF HAWAII
DEPARTMENT OF HEALTH
P.O. Box 3378
HONOLULU, HAWAII 96801-3378

In reply, please refer to:
File:

House Committee on Health

H.C.R. 90, REQUESTING THE ESTABLISHMENT OF A CLEFT LIP AND CLEFT PALATE CENTER OF EXCELLENCE

Testimony of Loretta J. Fuddy, A.C.S.W., M.P.H.
Director of Health

April 1, 2011, 9:00 a.m.

1 **Department's Position:** The Department of Health (DOH) does not support this resolution since the
2 work to establish a cleft lip/cleft palate (CLCP) center of excellence has already been completed.
3 Hawai'i has a Cleft and Craniofacial Center at Kapiolani Medical Center for Women and Children
4 (KMCWC), with the DOH Children with Special Health Needs Program (CSHNP) assisting in
5 providing information, support, and service coordination for families.

6 **Fiscal Implications:** The DOH does not have funding to support another CLCP center in Hawai'i.

7 **Purpose and Justification:** This resolution requests the DOH, in partnership with local experts, to
8 create a CLCP center of excellence, and that this center should promote awareness of cleft lip/palate
9 birth defects and provide resources/information to families. The DOH is to report on strategies to
10 establish and promote the CLCP center.

11 The Kapiolani Cleft and Craniofacial Center (KCCC) at KMCWC currently serves over 300
12 children and youth up to age 18 years. This center has met the 17 standards for a Cleft Palate Team
13 established by the American Cleft Palate-Craniofacial Association and Cleft Palate Foundation. The
14 team includes craniofacial surgeon, neonatologist/pediatrician, geneticist, audiologist, speech therapist,
15 pediatric dentist, oral surgeon, orthodontist, and other specialists.

1 The DOH CSHNP collaborates with the KCCC by providing information and support to
2 families. A Nurse and Social Worker provide service coordination, assist families in identifying needs
3 and resources, and assist families with referrals to community programs. As a safety net, CSHNP
4 provides financial assistance for eligible underinsured children/families whose insurance does not cover
5 orthodontic services or travel from Neighbor Islands to Oahu for medical specialty services. The DOH
6 does not provide funding to KCCC.

7 We are concerned that creating another CLCP center would split the already limited health care
8 resources for CLCP services.

9 Thank you for the opportunity to testify.

Friday – April 01, 2011 – 9:00am
Conference Room 329

The House Committee on Health

To: Representative Ryan I. Yamane, Chair
Representative Dee Morikawa, Vice Chair

From: Lynn Iwamoto, M.D.
Director
Kapi'olani Medical Center for Women & Children Craniofacial Center

Re: **HCR 90/HR 82 REQUESTING THE ESTABLISHMENT OF A CLEFT LIP AND
CLEFT PALATE CENTER OF EXCELLENCE**

TESTIMONY IN OPPOSITION

My name is Dr Lynn Iwamoto, Medical Director for the Kapi'olani Cleft and Craniofacial Center.

We are writing in opposition to HCR 90/HR 82 requesting the establishment of a cleft lip and cleft palate center of excellence as this resolution would create duplicative services already in existence in our community and would negatively impact the effectiveness of existing programs.

In 2007, Kapi'olani Medical Center for Women and Children (Kapi'olani) physicians identified a need for services for children and their families affected with oral-facial birth defects including cleft lip and palate. A complete review of available services within the state and analysis of what would be required for a comprehensive, coordinated approach for this population of children led to the formation of the Kapi'olani Cleft and Craniofacial Center.

Based on the review, the Kapi'olani team met with the State Department of Health, which provided data on congenital anomalies in Hawai'i and the incidence of cleft. It was felt that a team-based, comprehensive multidisciplinary approach is the best way to recognize and treat the full spectrum of problems associated with the craniofacial conditions, including dental issues and those related to speech and language skills. The team was developed following the national standards set by the American Craniofacial and Cleft Palate Association. Kapi'olani's Cleft and Craniofacial team was approved by ACPA (American Cleft Palate and Craniofacial Association) as meeting their standard for team composition and services provided in 2009 and again renewed for 2010 based on their revised and more stringent approval process.

The first clinic was held November, 2007 where 6 infants were evaluated and a treatment plan developed. Today, March 2011 the clinic sees more than 300 active patients in 5 clinics per month and does over 90 surgeries annually. These referrals come from all counties within the state. The clinic created a comprehensive referral system throughout the state which includes opportunities for prenatal counseling and newborn referral. The reported incidence of babies born with cleft lip and cleft palate in the state of Hawai'i is approximately 30-35 per year. The team referral rate of these infants is 80-90% annually.

The team is comprised of all required subspecialists which include neonatology, pediatrics, case management, geneticists, behavioral health, plastic, pediatric craniofacial and oral maxillofacial, and ENT surgery as well as general pediatric dentistry and orthodontic specialty. A full array of rehabilitation specialists participating in the treatment program include speech, language, feeding and hearing specialists as well as a registered dietician. From the onset the program partnered with the Department of Health to ensure that there is ongoing continuity of care and communication with schools and other community providers. The team has been well received throughout the state with recent physician and parent surveys demonstrating a 95% satisfaction score.

Kapi'olani also created a child and family support group which provides opportunities for socialization and emotional support with other families of children with similar conditions which help to let families know they are not alone. This support group also provides ongoing education and information about navigation of services throughout the continuum of care. The program recently was able to secure philanthropic funding to support families with unreimbursed dental and orthodontic services.

Due to Hawai'i's population, birth rate and geographic uniqueness we already face issues with the availability of subspecialists. Creating another center of excellence would strain already limited resources. The Kapi'olani team would welcome expanded collaboration with other health care practitioners interested in providing resources and excellent coordinated care to this special population of children.

We ask that you defer this resolution.

Testimony of
Thomas G. Crabtree, M.D.
Hawaii Permanente Medical Group

Before:
House Committee on Health
The Honorable Ryan I. Yamane, Chair
The Honorable Dee Morikawa, Vice Chair

April 1, 2011
9:00 am
Conference Room 329

**Re: HCR 90/HR 82 REQUESTING THE ESTABLISHMENT OF A CLEFT LIP AND
CLEFT PALATE CENTER OF EXCELLENCE**

Chair, Vice Chair, and committee members, thank you for this opportunity to provide testimony on HCR 90/HR 82 for purposes of establishing a cleft lip and cleft palate center of excellence.

Kaiser Permanente strongly supports this measure.

I am a plastic and reconstructive surgeon with the Hawaii Permanente Medical Group at Kaiser Permanente Hawaii specializing in post traumatic, oncologic and congenital defect reconstruction. In addition to my plastic surgery responsibilities, I also serve as the senior medical advisor to the Center for Excellence in Disaster Management and Humanitarian Assistance of the U.S. Pacific Command, and currently serve as the Chair of the Surgical Council for Operation Smile. Operation Smile's mission is to transform the lives of children who suffer from cleft lip, cleft palate and other facial deformities by offering free cleft care to children globally and teaching safe cleft surgery to our partners around the world.

According to the Centers for Disease Control and Prevention, more and more babies in the United States are being born with cleft lip and/or cleft palate. Cleft lips and palates are the nation's second most common birth defect. Roughly one child out of every 750 is born with a cleft. In Asian and Pacific Island cultures the number is even higher. In Hawaii approximately 40-60 kids a year are born with clefts.

It is well recognized that excellence in cleft care is rarely achieved without a dedicated team providing comprehensive treatment from infancy to adulthood. This collaborative multi-disciplinary team of specialists typically includes a pediatrician, geneticist, an ENT specialist, a speech therapist, a hearing specialist, a dentist, an orthodontist, an oral maxillofacial surgeon, child life specialist, social worker and a plastic surgeon. The collaborative team of specialists work together to ensure that treatment goals are customized for

each child, and health care providers can make the best choices for treatment by consulting with each other. Therefore, this same collaborative multi-disciplinary effort will be best served by establishing a Comprehensive Statewide Cleft Center in Hawaii to ensure that each child in our state is provided with the most effective care plan and treatment. Naturally, a population of our size would be best served by a single comprehensive center rather than several independent entities, i.e. Kaiser Permanente, Kapiolani Hospital and Tripler Medical Center. Hawaii has a unique opportunity to further its reputation as the Health State by supporting the creation of a statewide cleft care center to best serve all of Hawaii's children.

In supporting this measure, Kaiser Permanente would like to participate in the development of the Centers for Excellence by sharing its expertise to assist in developing protocols for delivering superior and effective cleft care.

Thank you for the opportunity to comment.