**NEIL ABERCROMBIE** GOVERNOR OF HAWAII



LINDA ROSEN, M.D., M.P.H. DIRECTOR OF HEALTH



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

In reply, please refer to: File:

### House Committee of Health

### HCR 99 ENCOURAGING THE DEPARTMENT OF HEALTH TO ESTABLISH A FETAL ALCOHOL SPECTRUM DISORDER INTERAGENCY COORDINATING COUNCIL TO COORDINATE AND DEVELOP FETAL ALCOHOL SPECTRUM DISORDER INFORMATION, EDUCATION, POLICIES, AND SUPPORT SERVICES

### Testimony of Linda Rosen, M.D., M.P.H. Director of Health

### March 21, 2014

1 **Department's Position:** The Department of Health supports the intent of this concurrent resolution

2 to establish an interagency coordinating council to coordinate and develop Fetal Alcohol Spectrum

3 Disorder (FASD) information, education, policies, and support services; however, staffing and funding

4 will be needed to support the requirements of this measure.

5 **Fiscal Implications:** Funding will be needed for the Department of Health to support the requirements

6 of this measure. The Department did not have adequate funding to fill the FASD Coordinator position

7 when it became vacant in 2013. Thus, there is currently inadequate infrastructure to support full

8 implementation.

9 **Purpose and Justification:** Fetal Alcohol Syndrome Disorder is the umbrella term used to describe a

10 range of disorders caused by prenatal alcohol exposure. These disorders include fetal alcohol syndrome,

11 alcohol-related neuron-developmental disorder, and fetal alcohol effects or alcohol-related birth defects

- 12 disorder. Alcohol exposure during pregnancy produces, by far, the most serious neurobehavioral effects
- in the fetus (Institute of Medicine Report to Congress, 1995). There is no known safe amount of alcohol

or safe time to drink alcohol during pregnancy. Because FASD affects all aspects of a child's life 1 2 throughout his/her lifetime (cognitive, social/emotional, physical/mental health, school/work activities, independent living, justice system, etc.) and requires support in all areas, the costs can be staggering. 3 According to the Substance Abuse and Mental Health Services Administration (SAMHSA), it costs the 4 nation nearly \$60 billion a year to cover FASD care. The care for one FASD child over his/her lifetime 5 can rise to as much as \$2 million. These costs of care are only in dollar amounts and do not consider 6 other personal and emotional challenges parents face when raising a child with an FASD. Yet, FASD is 7 completely preventable. Prevention starts with awareness that links drinking alcohol during pregnancy 8 with increasing risks of having a child with life-long disabilities. 9

10 In 2013, the FASD Coordinator retired leaving the position vacant. Without adequate funding, the Department is not able to fill the FASD Coordinator position. Because of the importance of this 11 public health issue, the Department continues to provide logistical support for the State FASD Task 12 Force bi-monthly meetings and a FASD Clinical Committee which meets monthly. To make 13 meaningful progress and impact for individuals and families affected by FASD requires building a 14 system of prevention and treatment services in partnership with interagency level representatives. 15 Building a statewide system of care can only be accomplished through a dedicated fulltime position to 16 convene and coordinate an interagency group to increase awareness about FASD, expand the capacity of 17 the state to identify and intervene with at-risk women, improve the statewide service delivery, facilitate 18 the development and implementation of a comprehensive system of care and a statewide strategic plan 19 addressing FASD. 20

21 Thank you for the opportunity to testify on this resolution.

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# HAWAII DISABILITY RIGHTS CENTER

1132 Bishop Street, Suite 2102, Honolulu, Hawaii 96813 Phone/TTY: (808) 949-2922 Toll Free: 1-800-882-1057 Fax: (808) 949-2928 E-mail: info@hawaiidisabilityrights.org Website: www.hawaiidisabilityrights.org

## THE HOUSE OF REPRESENTATIVES THE TWENTY-SEVENTH LEGISLATURE REGULAR SESSION OF 2014

## Committee on Health Testimony in of Support of HCR 99/HR73

Friday, March 21, 2014, 8:30 AM. Conference Room 329

Chair Belatti and Members of the Committee:

The Hawaii Disability Rights Center testifies in support of this Concurrent Resolution. In September 2013 we attended a Proclamation Ceremony at the Governor's Office to commemorate International Fetal Alcohol Spectrum Disorder Awareness day. The Governor spoke passionately about the need for this program and indicated it was a high priority for him. In light of that, we were rather surprised to see that the Department of Health was refused permission by the Administration to seek funding in the Budget for a position of a Coordinator for this program.

We see this as an important, emerging issue and a problem that has not been adequately addressed. Children born with FASD fall into a huge gap group. They very well may not qualify for services from CAMHD at the Department of Health because they may not have a requisite mental health diagnosis. They may not qualify for services from the Developmental Disabilities Division because they may have an IQ that is regarded as too high for eligibility. Yet they have a range of social and emotional and psychological and behavioral problems that can exist with them forever and prevent them from functioning at a level that will properly integrate them into the rest of society. They need help. They need services.

To date, the efforts to address the problem of fetal alcohol spectrum disorder have focused on the conduct of the mother in the context of seeking prevention. While we do not doubt that prevention is a crucial component, we also believe that focusing solely on the mother's behavior is not going to comprehensively address the problem. To some degree it is just not realistic to expect that no one is ever going to drink during their pregnancy. We must do more. We must address the service needs of the children who have already been born and will continue to be born with fetal alcohol syndrome.





This Resolution is a worthwhile step in the right direction. It acknowledges the need for the development of services for these children and for a plan to address their needs. We would suggest that in order to bolster the Coordinating Council's effort, the request to convene it should be directed at the Office of the Governor, rather than the Department of Health. The Department may lack the resources as well as the political stature to be the convener of a Council of this nature.

Thank you for the opportunity to testify in support of this measure.

From:	mailinglist@capitol.hawaii.gov
Sent:	Wednesday, March 19, 2014 9:14 PM
То:	HLTtestimony
Cc:	paulakomarajr@yahoo.com
Subject:	*Submitted testimony for HCR99 on Mar 21, 2014 09:00AM*

### HCR99

Submitted on: 3/19/2014 Testimony for HLT on Mar 21, 2014 09:00AM in Conference Room 329

Submitted By	Organization	<b>Testifier Position</b>	Present at Hearing
Paul A. komara, Jr.	Individual	Support	No

Comments:

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Cc:	ilikered3@rocketmail.com
Subject:	Submitted testimony for HCR99 on Mar 21, 2014 09:00AM



### **HCR99**

Submitted on: 3/21/2014 Testimony for HLT on Mar 21, 2014 09:00AM in Conference Room 329

Submitted By	Organization	<b>Testifier Position</b>	Present at Hearing
Linda Elento	Individual	Support	No

Comments: The Legislature's special attention to the educational implications of the health needs of the children referenced in this bill as a funding priority for the Department of Education. HCR238 addresses a similar need for funding and coordination between the DOE and the Department of Health as the DOE has effective communication obligations to students under Title II of the Americans with Disabilities Act. \* The Department of Education is currently not able to provide effective instruction for all IDEA and Sec. 504 eligible students in Hawaii. \* In my research and experience, the Department of Health has yielded to the Department of Education when a child is transferring from services from the Department of Health upon the child's 3rd birthday. Even though the IDEA allows for states to continue Part C early intervention services for children who turn three years old, in lieu of Part B preschool special education, our state has still chosen to cut off these children from the Department of Health. A Memorandum of Agreement between the DOE and the DOH would benefit our children, their families, and the departmental personnel who are not able to find, train or fund the contracted services or staff to provide for their developmental, educational , communication and language needs. \*. Thank you for the opportunity to present testimony this morning.

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

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