

**morikawa2 - Shaun**

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**From:** mailinglist@capitol.hawaii.gov  
**Sent:** Wednesday, April 17, 2013 12:07 PM  
**To:** HLTtestimony  
**Cc:** hspoehr@papaolalokahi.org  
**Subject:** Submitted testimony for SCR62 on Apr 19, 2013 08:30AM

**SCR62**

Submitted on: 4/17/2013

Testimony for HLT on Apr 19, 2013 08:30AM in Conference Room 229

<b>Submitted By</b>	<b>Organization</b>	<b>Testifier Position</b>	<b>Present at Hearing</b>
Hardy Spoehr	Papa Ola Lokahi	Support	No

Comments: Papa Ola LOkahi supports this measure

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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**morikawa2 - Shaun**

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**From:** mailinglist@capitol.hawaii.gov  
**Sent:** Wednesday, April 17, 2013 6:09 PM  
**To:** HLTtestimony  
**Cc:** kenny.fink@juno.com  
**Subject:** Submitted testimony for SCR62 on Apr 19, 2013 08:30AM

**SCR62**

Submitted on: 4/17/2013

Testimony for HLT on Apr 19, 2013 08:30AM in Conference Room 229

<b>Submitted By</b>	<b>Organization</b>	<b>Testifier Position</b>	<b>Present at Hearing</b>
kenny fink	Individual	Support	No

Comments: Chair Belatti: Thank you very much for hearing this measure. Unfortunately I am on the mainland in my official capacity as the State Medicaid Director for a federal review of Hawaii's health insurance exchange, so I am unable to testify in-person. I am submitting this testimony in my individual and personal capacity as a parent of a child with neurofibromatosis (NF). I STRONGLY SUPPORT this measure and very much hope that your committee will pass it unamended. NF is the most prevalent genetic disorder, and the complications begin in childhood. NF can cause a wide range of congenital problems, but mostly it causes tumors on nerve cells. These tumors can occur on nerves in the skin causing deformity, the eye causing blindness, the ear causing deafness, and around the spinal cord causing severe pain. The course of NF is greatly variable and unpredictable; there is no cure. The Congressional Directed Medical Research Program (CDMRP) for NF is the largest source of federal funding for NF research. Continued research is necessary to reduce the suffering by children and eventually to find a cure. Thank you again for your hearing this resolution, for the opportunity to testify, and hopefully for your support.

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