



**LATE  
TESTIMONY**

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## IMMUNE DEFICIENCY FOUNDATION

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*The National Organization Dedicated to Research, Education and Advocacy for Primary Immune Deficiency Diseases*

April 13, 2011

The Honorable Josh Green, M.D.  
Hawaii State Capitol - Room 222  
415 South Beretania Street  
Honolulu, HI 96813

**RE: SCR 93 – STRONGLY SUPPORT**

Dear Senator Green,

The Immune Deficiency Foundation (IDF) thanks you for introducing SCR 93, which helps ensure that every Hawaii resident has access to reasonable prescription drug benefits and resolves that the practice of creating and using specialty tiers for prescription drugs in health plans is discouraged and should be avoided and eliminated wherever possible. IDF, founded in 1980, is the national patient organization dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases (PIDD) through advocacy, education and research.

SCR 93 is very important for the hundreds of Hawaiians who suffer from a primary immunodeficiency disease. Patients with PIDD are born with a malfunctioning or non-existent immune system and are thus vulnerable to multiple and numerous infections, viruses and fungi. To allow patients with PIDD to have a normal, healthy and productive life, they need to have Immunoglobulin (IgG) replacement infusion therapy (a blood plasma product) for the rest of their lives.

There is a disturbing trend among health insurers to discriminate against patients with rare and chronic diseases such as PIDD by switching their treatment to a higher or specialty tier of reimbursement for their treatments. By doing so, most patients cannot afford their life saving IgG therapy, thus condemning them to become sicker and sicker and constantly having to utilize the health care system for ER visits, ICU stays, multiple and constant antibiotic therapies as well as developing serious life threatening long-term and chronic disabilities in addition to their PIDD diagnosis.

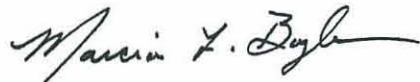
High cost specialty drugs such as IgG, are in danger of being classified in Tier 4, the highest and most expensive tier. As a result of the 4 tier drug formulary, patients with serious diseases, such as certain PIDD, neuropathies, MS, epilepsy and others that require specialty medications, are being asked to pay hundreds and even thousands of dollars for drug therapies to treat their diseases. Insurers are abandoning the traditional arrangement of charging patients a fixed amount, like a \$10, \$20 or \$30 co-pay for a prescription. Rather, they are instead charging patients a **percentage** of the cost of certain high-priced drugs, usually 20 to 33 percent for Tier 4. These costs can amount to thousands of dollars a month and limit access to vital, life-saving therapies because of the inability to pay. It amounts to a hollow benefit.

Insurance is supposed to spread health risk across a pool of payers. Specialty tiers do just the opposite. They narrow the pool and thus place the burden on those most in need of life saving therapies. This

practice is appalling and negates the very reason they had been paying for insurance in the first place — to be protected from financial hardship should they become ill.

Should you have any questions please contact Larry LaMotte, Director of Public Policy for IDF at 410-632-2552 or at [llamotte@primaryimmune.org](mailto:llamotte@primaryimmune.org) .

Regards,

A handwritten signature in black ink that reads "Marcia L. Boyle". The signature is fluid and cursive, with a long horizontal flourish extending to the right.

Marcia Boyle  
President & Founder

cc: Senate Commerce and Consumer Protection Committee

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**green2 - Kealaonalehua**

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**From:** mailinglist@capitol.hawaii.gov  
**Sent:** Wednesday, April 13, 2011 2:11 AM  
**To:** HTHTestimony  
**Cc:** Dmessiii@aol.com  
**Subject:** Testimony for SCR93 on 4/13/2011 9:00:00 AM

Testimony for HTH/CPN 4/13/2011 9:00:00 AM SCR93

Conference room: 229  
Testifier position: support  
Testifier will be present: No  
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Submitted on: 4/13/2011

Comments: