Dear honorable senators of the Senate Committee on Health,
In the year 2007, my daughter became ill. She was in her senior year of high school. She had been accepted to college and planned on leaving that fall. She had to postpone her dreams...then drop them altogether as her symptoms worsened and became overwhelming. I took her to over 15 doctors the following two years. I remember almost all of them had the same question when we first walked in "Has she had a Lyme test". My standard answer was "no" and the subject was never brought up again. I did not pursue this question cause I myself had heard of Lyme but did not know it was so debilitating. In 2009, I received a call from a friend whose son-in-law in Texas
had much of the same symptoms as my daughter. I was told about Lyme Disease, Igenex and Lyme Literate doctors. It would be her life line. But I still had the problem of how to get the Igenex test done.

I had a wonderful MD that I myself had used on occasion for over 8 years. I respected and trusted him. He was somewhat reluctant to do the Igenex test but agreed to do the test if I ordered it and brought it in AFTER he did the standard Elisa test. After, this test came back negative, which I suspected since she had been sick for over 2 years and would not show the antibodies in the first tier of the test, he canceled her appointments and said he is not doing the Igenex test. We showed up in his office for her appointment anyways, test materials in hand and would not leave till he signed the agreed papers for the Igenex Lyme test. We sat in his office for over an hour before he finally signed the orders and we got the test done. I was told to make sure I got a copy of the test results by my friend. I did...they were CDC positive, Igenex positive. When Dr. John Lebow of 1755 Coburg Road Suite 6 of Eugene, Oregon 97401 read me the results over the phone, he said "I'm reading this as negative and your daughter will have to find someone else to treat her." I find this so unethical, so surreal...yet, here it is. See attached..
Sincerely,
Patricia Cokel
Springfield, Oregon
(541)513-6471 Written on behalf of Lyme patient Autumn Cokel

PALO ALTO, CA 94303
(800)832-3200

PATIENT: COKEL, AUTUMN
DOB: 11/12/88 AGE: SEX: F

SAMPLE ID: 275761

JOHN LEBOW, DO

1755 COBURG #3
EUGENE, OR
97401

DRWN: 08/03/09
RCVD: 08/06/09
PRNT: 08/19/09

DIRECTOR: JYOTSNA SHAH, PhD

Tests performed at 795 San Antonio,P Alto,CA 94303, except portion of process of PCR & RWB which is performed at 797 San Antonio, P Alto, CA 94303

TEST NAME	RESULT	UNITS
LYME IgM WESTERN BLOT	.....	

REVISED 07/27/09

IGeneX Interpretation is based on internal validation studies. By IGeneX criteria, IgM WB is considered positive if two or more of the double starred bands below are present. The IgM WB is considered negative if less than 2 starred bands are present. A positive suggests exposure to B burgdorferi. By CDC/NYS criteria, IgM WB is reported positive if 2 of the following bands are present:23-25,39,41kDa. The IgM WB is negative if less than 2 bands are present.

LIMITATION: Positive result for 31 and/or 34kDa may be present after Lyme vaccination in uninfected persons. Infection with HSV,EBV,HCV and/or syphillis (RPR+) may give false (+) results. In a sample set of 165 well characterized specimens with 36% positivity rate, the assay specificity and sensitivity was 96% and 73% by IGeneX criteria; and 99% and 58% by CDC/NYS criteria respectively.

****PRESENCE OF ONLY ONE DOUBLE STARRED BAND OR INDETERMINATE DOUBLE STARRED BANDS IN A NEGATIVE REPORT MAY INDICATE CLINICAL SIGNIFICANCE.****
THEREFORE, WE RECOMMEND TESTING WITH ANOTHER METHOD AND/OR RETEST IN 4-6 WEEKS.

BAND INTENSITY: Negative (-): No visible band present. Indeterminate (IND): Band present with intensity < Weak (1+) Positive Control. Positive (1+ to 4+): Band present at an intensity >/= Weak (1+) Positive Control.

IGENEX IGM RESULT	POSITIVE
CDC/NYS RESULT	POSITIVE
18 kDa.	-
22 kDa.	-
**23-25 kDa.	-
28 kDa.	-
30 kDa.	-
**31 kDa.	++
**34 kDa.	-
**39 kDa.	+
**41 kDa.	++
45 kDa.	+
58 kDa.	+
66 kDa.	+
73 kDa.	-
**83-93 kDa.	+

Diagnosis should not be based on laboratory tests alone. Results should be interpreted in conjunction with clinical symptoms and patient history.

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