

108TH CONGRESS
2D SESSION

H. R. 4872

To direct the Secretary of Health and Human Services to establish a
retinoblastoma public awareness and prevention program.

IN THE HOUSE OF REPRESENTATIVES

JULY 20, 2004

Mr. MEEKS of New York introduced the following bill; which was referred to
the Committee on Energy and Commerce

A BILL

To direct the Secretary of Health and Human Services to
establish a retinoblastoma public awareness and preven-
tion program.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Retinoblastoma Aware-
5 ness and Prevention Act of 2004”.

6 **SEC. 2. FINDINGS.**

7 Congress finds the following:

8 (1) Retinoblastoma is the most prevalent form
9 of eye cancer among young children and is the third
10 most common cancer affecting children.

1 (2) Although the disease is curable, it is almost
2 always fatal when left untreated. As such, early de-
3 tection of retinoblastoma is essential to avoid dan-
4 gerous and lengthy procedures such as enucleation
5 of either one or both eyes and potential spread of
6 the cancer throughout the rest of the body.

7 (3) Of all children who are diagnosed with
8 retinoblastoma, 90 percent are the first ones in their
9 family to develop the disease. As such, many parents
10 are slow to react to the symptoms because they are
11 unfamiliar with the disease.

12 (4) The cancer originates as a tumor within the
13 retina, the light sensitive layer of the eye.

14 (5) Although the exact cause of retinoblastoma
15 is unclear, there is a connection between the disease
16 and an abnormality in chromosome 13 in which a
17 piece of the chromosome is nonfunctional or missing.
18 Furthermore, there is a connection between children
19 who are conceived through in vitro fertilization and
20 a heightened incidence of retinoblastoma. This new
21 realization raises the issue of whether there are
22 more unknown abnormalities and other potential
23 dangers associated with in vitro fertilization treat-
24 ment.

1 (6) Because many children do not suffer from
2 any symptoms, retinoblastoma can be a secret killer.
3 However, common symptoms of retinoblastoma are
4 crossed eyes, poor vision, painful red eyes, inflamma-
5 tion of the tissue surrounding the eye, protrusion of
6 the eyeball, and vitreous hemorrhaging or bleeding
7 around the eye. The majority of children who suffer
8 from retinoblastoma have a white pupil reflex,
9 known as the cat's eye reflex, rather than a black
10 pupil or red reflex.

11 (7) Once a patient has been diagnosed with
12 retinoblastoma, the physician must determine the ex-
13 tent of the disease in the eye and whether the dis-
14 ease has spread outside the eye in a process called
15 staging. There are three primary forms of
16 retinoblastoma. In its intraocular form, the cancer
17 occurs in either one or both eyes but it has not
18 spread to surrounding tissues and organs in the rest
19 of the body. In its extraocular form, the cancer has
20 spread to tissues around the eye or to other parts
21 of the body. If the retinoblastoma is recurrent, the
22 cancer has come back to the eye or continues to
23 grow after it has been treated.

1 **SEC. 3. RETINOBLASTOMA AWARENESS AND PREVENTION**
2 **PROGRAM.**

3 Part P of title III of the Public Health Service Act
4 (42 U.S.C. 280g et seq.) is amended by adding at the end
5 the following new section:

6 **“SEC. 3990. RETINOBLASTOMA AWARENESS AND PREVEN-**
7 **TION PROGRAM.**

8 “(a) AWARENESS AND PREVENTION PROGRAM.—The
9 Secretary shall establish a retinoblastoma awareness and
10 prevention program that shall include—

11 “(1) public and community awareness programs
12 concerning the prevention and identification of
13 retinoblastoma and the provision of services for chil-
14 dren, adolescents, and adults with retinoblastoma;

15 “(2) the development and placement of public
16 service announcements to educate the public about
17 retinoblastoma; and

18 “(3) the development of strategies to educate
19 parents about retinoblastoma, early warning signs,
20 and risk factors based on the best available medical
21 information and to encourage parents to discuss
22 retinoblastoma with their child’s physician.

23 “(b) GRANTS AND TECHNICAL ASSISTANCE.—The
24 Secretary may award grants, enter into cooperative agree-
25 ments and contracts, and provide technical assistance to

- 1 private and public entities for the purpose of carrying out
- 2 subsection (a).”.

