

ASSEMBLY RESOLUTION No. 101

STATE OF NEW JERSEY 219th LEGISLATURE

INTRODUCED FEBRUARY 20, 2020

Sponsored by:

Assemblyman RONALD S. DANCER

District 12 (Burlington, Middlesex, Monmouth and Ocean)

SYNOPSIS

Promotes increased public awareness about Stargardt's Disease.

CURRENT VERSION OF TEXT

As introduced.



1 **AN ASSEMBLY RESOLUTION** promoting increased public awareness
2 about Stargardt’s Disease.
3
4 **WHEREAS**, Stargardt’s disease is the most common form of inherited
5 juvenile macular degeneration, and typically causes vision loss
6 during childhood or adolescence; and
7 **WHEREAS**, Stargardt’s disease, also known as fundus flavimaculatus
8 or Stargardt’s macular dystrophy, affects approximately one in
9 10,000 children in the United States, and is named after German
10 ophthalmologist Karl Stargardt, who discovered the disease in
11 1901; and
12 **WHEREAS**, The disease causes progressive damage or degeneration of
13 the macula, a small area in the center of the retina that is
14 responsible for sharp, straight-ahead vision; and
15 **WHEREAS**, Stargardt’s disease does not cause a loss of peripheral or
16 night vision, but children affected by the disease may have trouble
17 adjusting between dark and light environments. Color vision is also
18 affected in later stages of the disease; and
19 **WHEREAS**, Stargardt’s is passed along to children when both parents
20 carry mutations of a gene associated with processing Vitamin A in
21 the eye. These mutations allow clumps of lipofuscin, a fatty
22 substance, to accumulate in and around the macula, and as a result,
23 central vision becomes impaired; and
24 **WHEREAS**, Stargardt’s is often diagnosed by the presence of small,
25 yellowish spots of deteriorating tissue in the outer covering of the
26 retina, and symptoms include blurry or distorted vision, an inability
27 to see low lighting, and difficulty recognizing familiar faces; and
28 **WHEREAS**, The progression of symptoms of the disease is different for
29 each child, and those with an earlier onset of Stargardt’s tend to
30 experience more rapid vision loss. Vision loss may decrease slowly
31 at first, then worsen rapidly until it levels off, and most people
32 suffering from the disease end up with 20/200 vision or worse; and
33 **WHEREAS**, Although some research indicates that exposure to bright
34 light may play a role in triggering the retinal damage that occurs
35 with Stargardt’s disease, there is no known treatment for the
36 disease; and
37 **WHEREAS**, Over the past several decades, researchers at the National
38 Eye Institute, part of the National Institutes of Health, have
39 identified various genes that contribute to inherited eye diseases,
40 including Stargardt’s disease. This has led to better diagnostic tests
41 and a greater insight into possible treatments for the disease; and
42 **WHEREAS**, Gene replacement and stem cell based therapies are
43 showing promise for treating Stargardt’s disease, and several
44 human safety trials of these therapies are currently underway; and
45 **WHEREAS**, While research into Stargardt’s disease has led to better
46 diagnostic tests and possible treatment options, a number of
47 services and devices have been developed to help people with the
48 disease carry out daily activities and maintain their independence.

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1 These include: hand-held lenses; electronic reading machines;
2 closed circuit video magnification systems; and digital eyewear
3 headsets; and

4 **WHEREAS**, Because Stargardt's disease is an inherited disease, it is
5 important for people with Stargardt's or a history of the disease in
6 close family members to undergo genetic testing and counseling;
7 and

8 **WHEREAS**, It is also important to increase the public's awareness and
9 understanding of Stargardt's disease, the treatment options being
10 developed through research, and the services and devices that are
11 available to reduce the impact of Stargardt's and help those with the
12 disease carry out daily activities and maintain their independence;
13 now, therefore,

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15 **BE IT RESOLVED** by the General Assembly of the State of New
16 Jersey:

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18 1. The Governor is respectfully urged to promote the public's
19 increased awareness and understanding of Stargardt's disease, the
20 importance of genetic testing and counseling, the treatment options
21 being developed through research, and the services and devices that
22 are available to reduce the impact of Stargardt's and help those with
23 the disease carry out daily activities and maintain their
24 independence through the issuance of a proclamation calling upon
25 public officials and the citizens of this State to promote awareness
26 of Stargardt's disease with appropriate activities and programs.

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28 2. Copies of this resolution, as filed with the Secretary of State,
29 shall be transmitted by the Clerk of the General Assembly to the
30 Governor of the State of New Jersey.

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STATEMENT

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35 This resolution urges the Governor to promote increased public
36 awareness of Stargardt's disease, a degenerative vision condition
37 that primarily affects children. The public awareness information
38 will include information concerning the importance of genetic
39 testing and counseling, the treatment options being developed
40 through research, and the services and devices that are available to
41 reduce the impact of Stargardt's and help those with the disease
42 carry out daily activities and maintain their independence.