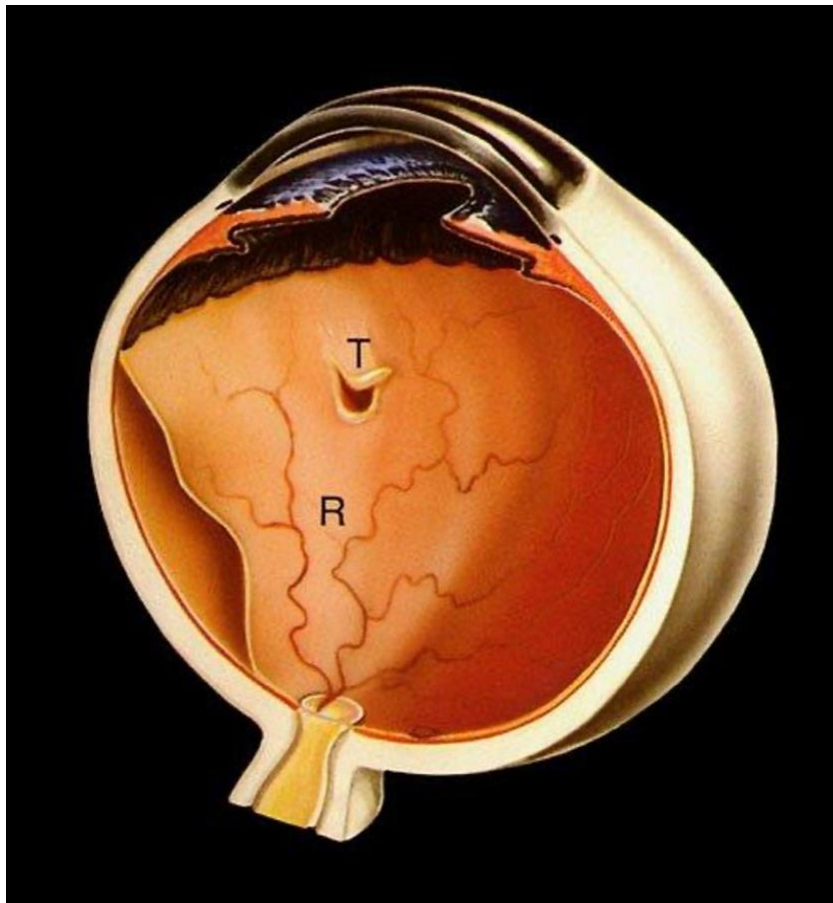


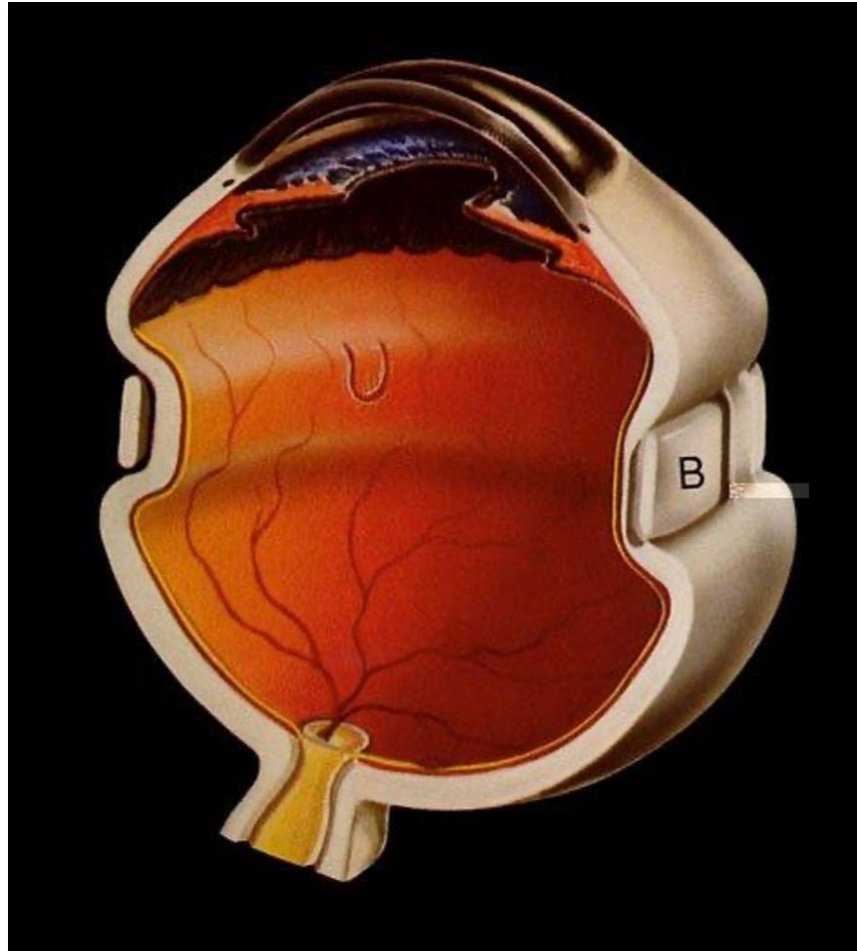
# A NEW TREATMENT TO PREVENT RETINAL DETACHMENT IN STICKLER SYNDROME

Stickler syndrome (SS) is the highest risk inherited condition predisposing affected individuals to retinal detachment (RD, Figure 1) and consequent loss of sight. It is dominantly inherited with approximately a 65% lifetime risk of RD occurring in at least one eye.<sup>1,2</sup>



*Figure 1. Illustration of a retinal tear and a retinal detachment. Artist Stephen Gordon ©1983.*

Half of Stickler detachments occur before age 20, even during infancy. The second eye suffers detachment in 80% of affected individuals, usually within five years.<sup>3</sup> Because Stickler detachments are difficult to repair (Figure 2), many patients become legally or totally blind.<sup>4</sup>



*Figure 2. Illustration of a scleral buckle repair of a retinal detachment. Artist Stephen Gordon © 1989.*

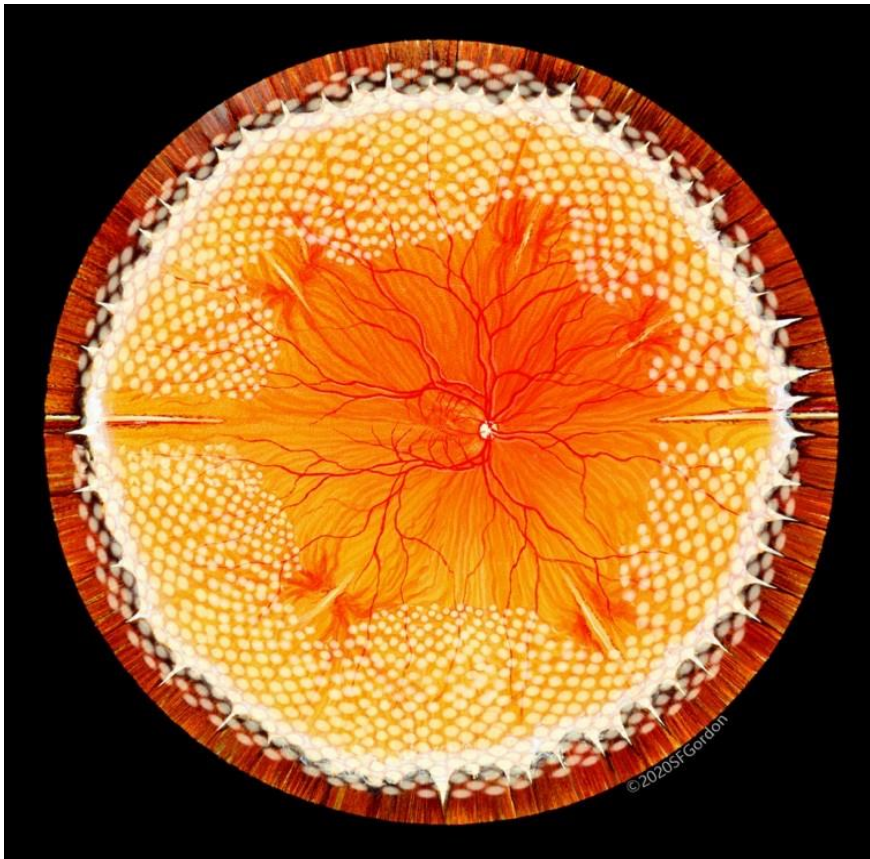
Research physicians associated with the Helen Keller Eye Research Foundation have been developing RD prevention treatments for over 25 years. They pioneered the concept of encircling laser treatment to strengthen the peripheral retina where most causative tears occur (Figure 3, [Video 1](#)).<sup>5-7</sup>



*Figure 3. Illustration of ora secunda cerclage (OSC) retinal detachment laser prophylaxis applied to the peripheral retina. Artist Stephen Gordon ©1999.*

But standard encircling laser treatment that has been successful in other high-risk eyes has proven inadequate to prevent Stickler detachments.<sup>6</sup> And cryopexy is limited to the prevention of giant tears that cause less than half of Stickler detachments.<sup>3,4,8-10</sup>

To maximally protect Stickler syndrome eyes, retinal physicians Robert Morris, Scott Parma, Mathew Sapp, Matthew Olmanns, Matthew West and Ferenc Kuhn have recently completed research to develop a new laser-based, non-invasive treatment (link to article: <https://www.dovepress.com/stickler-syndrome-ss-laser-prophylaxis-for-retinal-detachment-modified-peer-reviewed-article-OPHTH>). “Ora Secunda Cerclage/Stickler Syndrome” or “OSC/SS” strengthens the entire peripheral retina, and it has safely and effectively prevented RD in all five treated eyes of one family for a period averaging over eight years (Figure 4, [Video 2](#)). In contrast, 82% of affected individuals (5 of 6) in this family developed RD in eyes not treated with OSC/SS.<sup>11</sup>



*Figure 4. Illustration of more extensive OSC for Stickler syndrome (OSC/SS). Artist Stephen Gordon © 2020.*

A description of the OSC/SS treatment was recently published in the journal *Clinical Ophthalmology* in January 2021.<sup>11</sup> This was the first detailed report of a laser-based prevention for Stickler retinal detachments in the 55 years since Dr. Gunner Stickler described Stickler syndrome in 1965.<sup>12</sup>

OSC/SS has now become the basis for the first clinical trial of laser prophylaxis for retinal detachment (see [clinicaltrials.gov](https://clinicaltrials.gov)). It will be studied for many years by research physicians worldwide to further prove its safety and effectiveness. But it is available now to Stickler-involved persons who are seeking maximal protection from RD.<sup>13,14</sup>

The ability to safeguard the eyes of patients with Stickler syndrome against the threat of RD is a welcome, life-changing advance, finally allaying fears of blindness that have plagued Stickler-affected families for generations.

Certain Stickler patients who have been treated with OSC/SS laser prevention have offered to help counsel other Stickler patients. They may be contacted through the Foundation.

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The retina is a thin layer of neural tissue lining the back of the eye. It is the “film” of the eye. It changes light into electrical currents that are sent to the brain via the optic nerve and are interpreted as vision. The retina cannot be transplanted.

Spontaneous detachment of the retina from the back wall of the eye is the most common cause of sudden, severe loss of vision. With advancing age, the vitreous gel of the eye liquifies and becomes mobile. It pulls on the peripheral retina, causing tears that then allow fluid to pass beneath the retina and eventually extend into the area of central vision (Figure 1). As the retina floats off the eye wall, the affected patient sees a dark curtain of lost sight that soon becomes total, and permanently blinding, in the absence of effective surgical repair.

Stickler eyes have a mobile vitreous gel from birth, capable of tearing the retina even at a young age and leading to the highest known risk of RD.

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#### **FUNDING:**

Partial funding for this research was provided through grants from THE KENT COMPANIES, MIDLAND, TEXAS and the HANNA CHARITABLE TRUST, BIRMINGHAM, ALABAMA to the Helen Keller Eye Research Foundation. Extensive in-kind support was received from RETINA SPECIALISTS of ALABAMA, LLC, BIRMINGHAM, ALABAMA.

#### **ABOUT THE FOUNDATION:**

The Helen Keller Eye Research Foundation was founded by members of the Keller family to ally Helen’s famous legacy with modern biomedical research, helping to prevent blindness. Donations to this (IRS designated) non- profit foundation are welcomed.

#### **LINKS TO SUPPLEMENTAL REPORTS:**

[OSC/SS ARTICLE](#)

[SUPPLEMENTAL REPORT A. GENETIC ASPECTS](#)

[SUPPLEMENTAL REPORT B. A STICKLER AFFECTED FAMILY](#)

[SUPPLEMENTAL REPORT C. THE CAMBRIDGE REPORT](#)

[SUPPLEMENTAL REPORT D. THE FUNCTIONAL IMPACT](#)

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