

Department of Ophthalmology

Cryotherapy (freezing treatment) to reduce the risk of Retinal Detachment in Stickler Syndrome

Stickler syndrome (<u>www.stickler.org.uk</u>) is a group of genetic (inherited) disorders associated with short-sight (myopia), retinal detachment, cleft palate, deafness and arthritis. There are at least five different types of Stickler syndrome, but the majority of sufferers have either type 1 or type 2 Stickler syndrome. In Stickler syndrome the risk of visual loss or blindness through retinal detachment is very high.

Retinal detachment is a condition where the light sensitive 'film' at the back of the eye becomes separated as a result of a retinal tear or tears. For further information about retinal detachment, visit the Vitreo Retinal Service website (www.vitreoretinalservice.org) or ask your consultant or specialist nurse for further information.

Patients with Stickler syndrome are at particularly high risk of an unusual form of retinal detachment due to **giant retinal** tear (GRT). This is a particularly serious and complex situation where the retina tears part or all the way around its circumference (figure 1). In addition, because of the inherited nature of the problem, both eyes of an affected patient are at equally high risk.

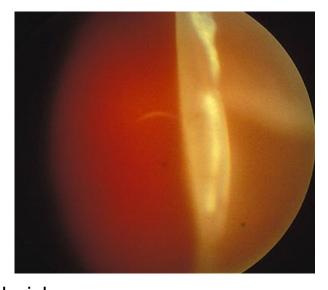


Figure 1 Giant retinal

Patient Information



Studies in both the UK and the USA have shown that without preventative treatment the majority of patients with Stickler syndrome will suffer a retinal detachment in one or both eyes.

Prevention of retinal detachment is especially important in children as they are often unaware of changes in their vision. They also quickly compensate for sight loss and therefore often present late, by which time it may be more difficult or impossible to salvage useful vision.

In contrast to some other forms of retinal detachment, the tendency for giant retinal tear in Stickler syndrome means that it is possible to carry out preventative treatment to reduce the likelihood of detachment or blindness in affected patients.

Cryotherapy (freezing treatment) is performed under a general anaesthetic and takes about 40 minutes, after which you will normally stay in hospital overnight. There will be a review by your surgeon the following morning, before you go. As with any medical therapy, no treatment has a one hundred percent success rate, but the surgery is aimed at substantially reducing the risk of retinal detachment. Our current research suggests that it reduces the risk by approximately ten-fold in patients followed up for an average of 15 years.

For the first 48 hours after surgery it is normal for the eyes to be mildly uncomfortable, puffy, red and watery. This may be more pronounced on the second day than the first. However, these symptoms gradually subside over a week to ten days.

In general, children tend to 'bounce back' and recover more rapidly than adults, but you should still expect them to feel rather miserable for about 24 hours. The eyes will remain swollen for about 48 hours and red for about a week with near vision returning to normal within three to four weeks.

Regular paracetamol (if required) for the first few days should help with any pain.

Patient Information



The cryotherapy 'glue' normally takes several weeks to mature to full strength and the surgeon will therefore review progress after approximately four to six weeks. If you or your child have **any** concerns about the vision of either eye at any time, you should get in touch with our Vitreoretinal Service (contact details below). The service is available for **any** concerns following surgery – or at any time there is concern about vision.

Are there any risks with cryotherapy

The surface of the eye and the eyelids will be swollen and puffy for a week or so. This can be particularly troublesome in adults who are nearing the age for needing reading glasses and can last for six to eight weeks.

What are the alternatives to having cryotherapy for prevention of retinal detachment?

Some people may choose not to have cryotherapy. In all patients it is very important to look out for symptoms of retinal detachment/ retinal tears (new floaters, spots in the vision and shadow advancing from the edge of the field of vision) and seek prompt specialist treatment.

The Addenbrooke's hostel

Addenbrooke's are now pleased to offer ophthalmology patients who live outside of the catchment area free overnight accommodation in a hostel which is on the hospital site. This will allow patients who have a lengthy journey to come to Cambridge to stay the night before surgery or the night after surgery.

Glossary

Vitreous: jelly-like substance filling the back of the eye

Retina: light sensitive layer of the eye

RD: retinal detachment GRT: giant retinal tear

PVD: posterior vitreous detachment

Patient Information



Prophylaxis: preventative treatment **Cryotherapy**: localised freezing therapy

Useful contacts

Vitreoretinal Service

Box 41

Addenbrooke's Hospital

Cambridge University Hospitals NHS Foundation Trust

Hills Road Cambridge CB2 0QQ

Website: www.vitreoretinalservice.org

Telephone: 01223 348842

Fax: 01223 217054

Emergency Telephone: 01223 217778 (Monday to Friday 09:00

until 17:00)

Emergency Telephone: 01223 216916 (evenings and weekends)

Annie McNinch, Stickler Specialist Nurse: 01223 348843 for all

enquires.

Am789@cam.ac.uk

Stickler Syndrome Support Group P.O. Box 371 Walton on Thames KT12 2YS

Telephone: 01932 267635

www.stickler.org.uk info@stickler.org.uk



We are a smoke-free site: smoking will not be allowed anywhere on the hospital site.

For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:

If you would like this information in another language or audio, please contact Interpreting services on

telephone: 01223 256998, or email:

<u>interpreting@addenbrookes.nhs.uk</u> For Large Print information please contact the patient information team:

patient.information@addenbrookes.nhs.uk

Document history

Authors Consultant Ophthalmic Surgeon

Pharmacist N/A

Department Cambridge University Hospitals NHS

Foundation Trust, Hills Road, Cambridge, CB2

0QQ www.cuh.org.uk

Contact number 01223 274600

Publish/Review date September 2017 / September 2020 (minor

amendment made March 2018)

File name Cryotherapy_in_stickler_syndrome_V4.doc

Version number/Ref 5/PIN1821/Document ID 12280