The Modified Sinskey Anterior Extirpation Procedure for Nystagmus
Robert W. Lingua, MD
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The following information is being provided to assist potential candidates for Nystagmus Surgery. Thank you for your inquiry, and please do email us with any further questions.

History:

Prevailing procedures for nystagmus often have sub-optimal results. They are designed to relocate the null point or dampen the magnitude of the nystagmus movements. All traditional surgeries reposition the eye muscle but keep the muscles attached to the eye. Since the impulses for the nystagmus movement come from the brain, and are not affected by surgery on the eye muscle, reattaching the muscle allows the nystagmus to continue.

In 2002 a novel surgery was proposed for patients with nystagmus. Dr. Robert Sinskey proposed that control of the nystagmus would be optimal if we removed the front portion of the muscle so the twitching muscle could not reattach to the eye. In 2012, I saw the video of one of Dr. Sinskey’s patients operated in 2002, followed for 10 years, and I was so impressed with the control of the nystagmus that we began offering this novel surgery to patients in January, 2013.

In the initial Sinskey report in 2002, 4 patients experienced a marked improvement in the nystagmus but two developed strabismus (eye misalignment) and one developed a hematoma (large blood clot). Over the last 2 1/2 years, I have modified this procedure to reduce the appearance of the nystagmus, and also, to reduce the risk of these complications. See “Risk” discussion below.

To assist candidates in their decision the following Q&A, based on our data to the present date, is presented below:

“How much can the shaking be reduced?”

After 39 patients, all recorded with “infrared nystagmography”, average reduction in nystagmus waveforms was approximately 65%. Some patients experienced only a mild change, 22%, while others, a great change, 100%. We cannot predict ahead of time to what degree the nystagmus will be reduced for each patient. Patients with other eye disease that
reduce vision are less likely to be reduced and others with fairly normal eye exams (infantile nystagmus syndrome) may be helped the most. This procedure has not been investigated for VERTICAL nystagmus. The nystagmus will typically reappear to a lesser degree, in the first week or two following surgery and not demonstrate its optimal reduction for 6-12 weeks. Please be patient! You may have eyeglasses prescribed as early as three weeks after the surgery.

“Will the vision be improved?”

Different estimates are given based on age. The following percentages represent what we recorded in our first 39 patients. “Lines” of vision refers to the eye chart and an increase of one line means the patient could read the next line smaller on the eye chart after the surgery, compared to before the operation. Optimal acuity may not be realized for 3 months since it takes that long for the nystagmus to be optimally reduced.

Summary chart of our findings:

<table>
<thead>
<tr>
<th>Vision at..........</th>
<th>Distance</th>
<th>Near</th>
</tr>
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<tbody>
<tr>
<td>AGE:</td>
<td>Under 10/Over 10</td>
<td>Under 10/Over 10</td>
</tr>
<tr>
<td>Increase at least 1 line</td>
<td>58%/50%</td>
<td>66%/60%</td>
</tr>
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</table>

So at least 50% of all patients will experience an increase of 1 line of vision, at distance and/or near.

Increase 2 or more lines | 33%/25% | 50%/20% |

About 25% of patients will experience an increase of 2 lines or greater at distance and/or near.

There is a 50% chance that the vision will not be improved by the surgery in patients over 10, and a 30% chance that the vision will not be improved in patients 10 or less. Therefore younger patients have a better prognosis for vision improvement.

“What is the chance a second operation will be required soon to correct a misalignment of the 2 eyes, or double vision?”

The risk for reoperation varies by age.

10 years or less | 32% |
| Over 10 | 13% |

Older patients have less risk for reoperation for strabismus.
What you can do now:

1) Please take a short digital video of your eye movements, and send it to us electronically, along with...

2) A scanned copy of your last eye exam, including distance and near vision, and, vision in your “null point”, if you have one.

3) We must know that your eye doctor will continue to see you on return and we will send them a letter of introduction. Please see the attached letter and hand carry it to them. They must sign that they agree to see you by the 6th week after surgery for a vision check. Remind them the nystagmus may still be present until the 12th week! We need the vision checked at 6 and 12 weeks to record your results!! Once you have their cooperation we can schedule your procedure.

4) Please include any results of special tests you have received, for example, ERG or OCT. Operative reports of any prior surgery is also necessary. Your doctor can communicate with us directly, if you prefer. Send all correspondence to rlingua@uci.edu or sbohanna@uci.edu.

5) Please print this document and initial each page. Bring it to the consultation.

6) A decision on surgery will not be made without having reviewed all the required documentation.

General information about the surgical experience:

There are 6 muscles to each eye that control eye movement and position. We will be operating on 2 to 5 of them, in each eye. The procedure takes about 2.5-3 hours and is done under general anesthesia. Patients may leave the surgical area after recovering for approximately 1 hour. The eyes will be sore and you may have a headache requiring ibuprofen or other mild analgesic. The most important thing to do heal comfortably is to apply ice packs 20 minutes on and 20 minutes off, the first day. Some children may keep their eyes closed for a day after the procedure. Some patients require more analgesia and if the swelling is significant, and we may prescribe oral steroids for 5-6 days. The eyes are not patched, and I will prescribe eye drops 4 times per day for 10 days. I will see you the next day, the third day, and thereafter in 1-2 weeks, then 1-2 months, then in 6 months, if you live locally.

If you are coming from outside the area, it is necessary that we establish a working relationship with your current eye doctor to determine if they would be willing to see you in the pre- and postoperative period, so that you can return home as soon as possible. Please feel free to share this information with them, and invite them to contact us. Plan to stay here for at least 10 days.

In general, surgical cases for patients travelling from long distances to Irvine, are performed on the second or fourth Tuesday of the month, and, coordinated as follows, in the Irvine, Gavin Herbert Eye Institute.
<table>
<thead>
<tr>
<th>Monday PM</th>
<th>Tuesday</th>
<th>Wednesday PM</th>
<th>Thursday</th>
<th>Friday AM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultation, Q&amp;A, Consent document</td>
<td>Sugery</td>
<td>First postoperative visit.</td>
<td>Rest</td>
<td>Postoperative exam #2: Care Q&amp;A</td>
</tr>
<tr>
<td>Testing: Nystagmography Photography, Dilated retinal exam</td>
<td>Medications</td>
<td>If necessary, you may have the muscles adjusted for alignment, perhaps requiring a second general anesthetic</td>
<td></td>
<td>Nystagmography Photograph</td>
</tr>
</tbody>
</table>

**The usual patient experience:**

On the day of consultation, we will meet and discuss your candidacy and expectations, risks and benefits, and proceed to signing a consent document, after all your questions have been answered. An electronic recording of your eye movements and clinical videos and pictures, will be performed. Expect that entire process to last about 2 hours. That evening you may be contacted by the anesthesia department.

There is an ongoing IRB approved prospective evaluation of muscle removal and function postoperatively. **You will be asked to participate in a study to take muscle measurements during the surgery that may help us understand how to avoid or limit the risks for future patients. There is a separate, additional informed consent for this study.**

The next morning you will return to GHEI, for the surgery.

**Following surgery,** you will want to keep the eyes closed and rest. No patches are required. Ice packs are recommended.

**The second day,** the eyes can open easier and there will be tearing and light sensitivity. I will see you in the office where we first met. If there is an unacceptable misalignment of the eyes, we will want to correct that as soon as possible. This may require a return to the operating room and a second anesthetic.

**In the first week** the eyes will be sore trying to move side to side, so school work or driving is not advised.

**After one week,** progress your activity as you feel fit. No swimming for 2 weeks - shower and bath OK, after 24 hours.
The nystagmus will be reduced right away, but may still be seen to a small degree, decreasing in the coming months. In our cases, the nystagmus is reduced 60-100% from the 1st to the fourth month. We have observed peak recovery of the nystagmus in the 3-6 months following the procedure.

Eye movement side to side improves in the first week, and, the nystagmus progressively quiets, over the entire first 6 months.

Before surgery, surgical candidates have poor eye control in every position of looking. Often side gaze has worse nystagmus than the straight ahead position. Because we operate on the muscles that govern side gaze, side gaze may be mildly limited by this procedure. At this time we cannot predict to what degree. On average it is reduced approximately 25%.

For patients to have proper expectations, your goal for the surgery should be to quiet the nystagmus looking straight ahead, and optimize your vision, even though side gaze may be reduced, and there is a risk of secondary surgery for strabismus, that is currently 20%.

Risks:

The surgery is done on the eye muscles outside the eye and no surgery is done inside the eye. None the less we cannot guarantee that something unexpected could occur to reduce vision or cause a complete loss of vision. This loss has not yet occurred.

The primary risk is postoperative strabismus (eyes are mis-aligned) that could require secondary surgery for repair. According to present data, this complication will occur in approximately 20% of patients. If secondary surgery is required for strabismus, or double vision, I will want to correct that right away. In cooperative adults adjusting the muscle position can sometimes be done in the office under eyedrop anesthesia. I may ask you to consent to a second general anesthetic for optimal re-alignment.

Adults who have the procedure may also experience double vision, if they develop strabismus.

These risks are similar to any other eye muscle surgery performed on adults and children. When they occur there may be need for secondary eye muscle surgery, or eyeglasses with prisms.

In our early series, secondary surgery improved the alignment to a satisfactory degree in most patients. One child maintains an outward position, and is still pending final correction as of this printing. Another young adult has persistent vertical nystagmus after the horizontal component was treated.

Cost:
The following codes are provided for you to ask your insurer if the procedure is covered, in which case you would be responsible only for any uncovered fees and insurance deductibles.

Diagnosis: Nystagmus ICD-9 Diagnosis code 379.50

Procedure Codes: CPT codes- For the nystagmus procedure.............................67312-50, 67316-50, 67318-50, 67320-50.

If reoperation is required for strabismus, then 67311-67332-adjustable suture may be required.

If your insurance will not cover the procedure, the University will generate a cash price to include the cost of the operating room, surgeon fees and clinic charges, on an individual basis.

Sincerely,

Robert W. Lingua, MD rlingua@uci.edu

Please visit the web site: www.eye.uci.edu

CONTACT FOR COORDINATION/APPOINTMENTS

NOTE: Please be sure to alert SUSAN (949-824-4122), at GHEI, of your plans to visit!

We are not aware of routine eye appointments made through the hospital call center (949-824-2020) and they will not have this information to assist you.

Susan Bohannan

sbohanna@uci.edu Phone 949-824-4122 Fax 949-824-4015

Gavin Herbert Eye Institute, Department of Ophthalmology
University of California, Irvine, 850 Health Sciences Road, Irvine, Ca 92697-4375
http://www.eye.uci.edu/nystagmus.html
https://www.youtube.com/watch?v=VCP0C3F2zi4&feature=youtu.be
http://mediacenter.ascrs.org/media/ascrs-innovator-session