

# OCULAR SURGERY NEWS<sup>®</sup>

## COVER STORY



OSN round table, part 2:  
How to become a better  
femtosecond laser cataract  
surgeon

## Point/Counter

Is femtosecond laser  
more efficiently used  
inside or outside the  
OR?

## COMMENTARY



Femtosecond lasers  
represent a paradigm  
shift in modern  
cataract surgery



Extrusion cannula  
used for levitation of  
dropped IOL

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ESCRS Winter Meeting



Light for Sight 21  
raises awareness,  
promotes detection  
and treatment of  
keratoconus in children  
with Down syndrome

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preponderant use of  
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### The Young Ophthalmologist

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## GLOBAL NOTEBOOK

## Light for Sight 21 raises awareness, promotes detection and treatment of keratoconus in children with Down syndrome

Reference centers in 25 countries worldwide provide cross-linking treatment following a specific protocol.

Within the framework of the Light for Sight 21 initiative, a large nonprofit cooperation of specialized centers worldwide is actively engaged in the effort to eliminate severe visual impairment in children with Down syndrome who have progressive keratoconus.

Light for Sight 21 ([lightforsight.org](http://lightforsight.org)) is a nonprofit organization founded in 2011 by **Nikki Hafezi, MAS IP ETHZ**, and her husband **Farhad Hafezi, MD, PhD**, an OSN Europe Edition Board Member.

“I was going through the literature on Down syndrome and found that in this population group, keratoconus had a much higher incidence rate than the general population (1:1,500) due to this group’s disposition of having connective tissue disorders compared to the general population,” Nikki Hafezi said. “With this information, I asked Farhad how many Down syndrome patients he had treated. He said that he had treated two children in 8 years, which didn’t quite fit the higher incident rate. From then I knew that something needed to be done.”

Light for Sight 21 has brought together volunteers from 25 countries. More than 40 clinics have been approved as reference sites for



Nikki Hafezi

screening and treating keratoconus children and adolescents with Down syndrome with cross-linking. The treating ophthalmologist, called an L4S Ambassador, is obliged to waive his or her honorarium if the ambassador deems that the family cannot afford the treatment.

“We want our ambassadors to be able to take care of these patients, but the first crucial step is get the word out about recognizing possible symptoms and where to seek help when they occur,” Nikki Hafezi said. “We need to work with our media friends and partners to help disseminate information not just amongst ophthalmologists, but general practitioners, pediatricians and patient organizations.”



Farhad Hafezi

Farhad Hafezi said that keratoconus is still a relatively unknown disease among medical professionals caring for children with Down syndrome.

“In spite of the well-documented association between trisomy 21 and keratoconus, very few, even among general ophthalmologists, are aware of it. What happens most of the time is that these kids are tested by an optician or an eye doctor, show high astigmatism and visual acuity of 20/40 or less, and go away with just a pair of glasses,” he said.

### **Specific protocol and eligibility criteria**

Farhad Hafezi created in Geneva a three-level protocol for cross-linking in Down syndrome patients. If the patient is fully cooperative, standard epithelium-off corneal cross-linking is performed. In case of reduced cooperation, the same procedure is done without epithelium removal under local anesthesia.

“The efficacy is not equally high using the epi-on procedure, but we know that there is a major risk of infection if these patients rub their eyes and are not fully cooperative with eye drop administration. Carina Koppen, MD, reported a high rate of infection in a small

case series of Down syndrome patients who underwent cross-linking, related to reduced compliance with postoperative medications,” he said.

If the patient has zero compliance, epi-on cross-linking is performed under general anesthesia.

“In the zero compliance instances, we first talk to the parents for consent to administer general anesthesia, examine the eye with a portable Placido topography device, and if we see keratoconus, we immediately do an epi-on procedure,” he said.

Compliance with the Geneva protocol, and therefore the license to perform general anesthesia, is a condition to become a Light for Sight reference center. Other eligibility criteria are a minimum of 100 treatments or 3 years of previous experience with cross-linking. Centers or individual doctors who do not qualify can still be involved by referring patients to their local or national reference sites.

### **Fast-growing initiative**

When the project was first presented at the European Society of Cataract and Refractive Surgeons meeting in 2012, many leading corneal surgeons immediately joined in and are actively contributing in different ways.

In Istanbul, Efehan Coskunseven, MD, personally contacted patient organizations and offered to organize information sessions. He opened his practice for a couple of weekends a month and invited families with Down syndrome children to come for a free screening. If keratoconus was detected, treatments were performed.

In Antwerp, Belgium, Marie-Jose Tassignon, MD, PhD, and Koppen offered the example of a best practice model with an interdisciplinary Down syndrome team of pediatric ophthalmologists, pediatricians and internists working together with patients and liaising with patient organizations.

Easy accessibility, a familiar environment and contained costs are

important for patients and their families.

“Many of the parents told us time and time again, ‘Please do not make us travel a long distance for these treatments,’ because it inflicts fear and expenses and uncertainty for everyone,” Nikki Hafezi said.

### Platform for research

Genetic alterations of collagen structure and function are responsible for several conditions affecting Down syndrome patients. These include connective tissue, musculoskeletal, pulmonary and cardiac problems, and most likely keratoconus.

The effects and efficacy of cross-linking in the abnormal collagen of these corneas are still largely unknown, and the Light for Sight 21 project offers a good platform for research.

“Besides our practical involvement in the humanitarian action, we are researchers, so we created an online database where reference sites can directly enter their data in view of a large prospective study. Up to now, we have data on about 50 eyes where we performed ORA, Corvis, aberrometry, Pentacam and keratography measurements to learn more about the cornea of a Down syndrome person. We are still in the preliminary stages, but our database is growing as more and more centers participate,” Farhad Hafezi said. – by Michela Cimberle 

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**Disclosures:** Farhad and Nikki Hafezi report no relevant financial disclosures.