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Crosslinking for Patients with Down Syndrome

One group that especially benefits from corneal cross-linking (CXL) is the Down syndrome community. The incidence of keratoconus (KC) in Down syndrome patients is more than 20 times that of the general population. Down Syndrome is caused by trisomy of chromosome 21 (three copies instead of the normal 2 copies of the chromosome), which is where several collagen-encoding genes are located. Down syndrome patients show an increased rate of collagen-related disorders, among them KC. Keratoconus in Down Syndrome patients represents a major challenge to the eye specialist, because options are limited: in most of these patients, grafting a cornea in advanced KC is not an option, because patients would rub their eyes after surgery, putting the transplant and the entire eye at risk.

Nikki Hafezi has been working in ophthalmology for more than 10 years. Working in Switzerland as an intellectual property specialist, she helps academic researchers protect their ideas, supporting them in creating patents, founding spin-off companies, and developing new medical products and pharmaceuticals.

When Nikki learned in 2011 that leading Cross-Linking experts had treated only a handful of Down syndrome patients so far, she recognized an imminent need: patients with Down Syndrome are almost never diagnosed with KC and treated by CXL, because of a lack of information and screening on multiple levels.

Nikki had a partner for this enterprise in her husband, Farhad Hafezi, MD, PhD, one of the world's leading ophthalmologists. Trained in Switzerland, he is a member of the team that had developed the first CXL device and had brought CXL technology into ophthalmology in 2003.



The result was the Zurich-based charity, Light for Sight 21. The mission of Light for Sight 21 is to increase awareness about KC among Down syndrome families and to educate health professionals and primary care

eye doctors who manage these patients about the importance of screening for KC and treating the disease.

International ophthalmologists have been eager to join the Hafezis to help Light for Sight 21 succeed. In more than 25 countries, education and advocacy take place. Only eye surgeons who have extensive experience with cross-

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linking are invited to participate as Light for Sight Ambassadors. These ophthalmologists perform CXL on Down syndrome patients according to a set protocol (Light for Sight protocol) that takes into account how cooperative the patient will be during the procedure and post-op period. Also, these eye surgeons contribute patient follow-up information to an international research database that will yield useful information about CXL outcomes in the Down syndrome community.

Now that CXL has been approved by the FDA, the charity hopes to identify ophthalmologists and eye centers in the U.S. to join in their important work. NKCF wholeheartedly supports their efforts! To read more about this very inspirational charity, visit their [website](#).

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