

# 20 17

## ACTIVITY REPORT

### The Light for Sight Foundation

Zürich, Switzerland

[www.lightforsight.org](http://www.lightforsight.org)



# Letter from the Chairman

June 1, 2018

Dear Colleagues and Friends,

A heartfelt thanks and gratitude are given to all clinical partners, researchers, industrial partners, and donors who have supported the foundation and its mission this past year. The foundation has grown in terms of clinical partners since it was founded in November 2015. The growth is a sheer testament to the value and significance that its programs and mission have on the field.

This annual activity report provides a comprehensive overview of the activities categorized in the four main pillars of the foundation. Since the programs are primarily volunteer-based, a strategic plan is to identify individuals who would be able to work for the foundation to bring the programs and awareness of the foundation to the next level. The four main pillars include: outreach & awareness, access to treatment, education & training and research. Of these pillars, I am proud to highlight the following activities:

- In clinical partnership with the ELZA Institute and with Swiss ophthalmic device distributor Von Hoff AG (Schlieren), the Light for Sight Foundation provided free keratoconus screening at the popular Expat Expo in Cham (Zug) and Dietikon (Zurich) in the spring and fall of 2017.
- In countries where crosslinking is not covered by health insurance, the Light for Sight Foundation has developed a practice model on how to provide care for patients who are unable to afford the treatment.
- Also, along the lines of access to treatment, a clinical model is being developed, with the help and support from behavioral specialists, to increase compliance of low to non-compliant patients during diagnostic and routine eye examinations.
- Continuing educational courses about keratoconus were again provided to local optometrists in partnership with the ELZA Institute AG.
- Due to the significant finding from the Riyadh prevalence study that commenced in 2015/2016, the largest global prevalence study on keratoconus in children and adolescents was initiated (K-MAP study).

Last but certainly not least, the annual CXL Experts' Meeting was held for the second year under the leadership of the Light for Sight Foundation in Zurich, Switzerland. This meeting continues to grow in size and is the program highlight of the year. The meeting also provides the largest exposure to the key opinion and thought leaders in the field. So, I am pleased that the 2017 meeting was a success and that it will continue in 2018.

Again, I sincerely thank you for making the Light for Sight Foundation your charity of choice!

With gratitude,



**Farhad Hafezi, MD PhD**

Chairman, Light for Sight Foundation



Professor of Ophthalmology University of Geneva, Switzerland

Professor of Ophthalmology Roski Eye Institute, University of Southern California, Los Angeles, USA

Visiting Professor Dept. of Ophthalmology Wenzhou Medical University, China

Medical Director ELZA Institute AG, Zurich, Switzerland

# 01

## Mission Statement

### OUTREACH

To increase public awareness about keratoconus

### TRAINING / EDUCATION

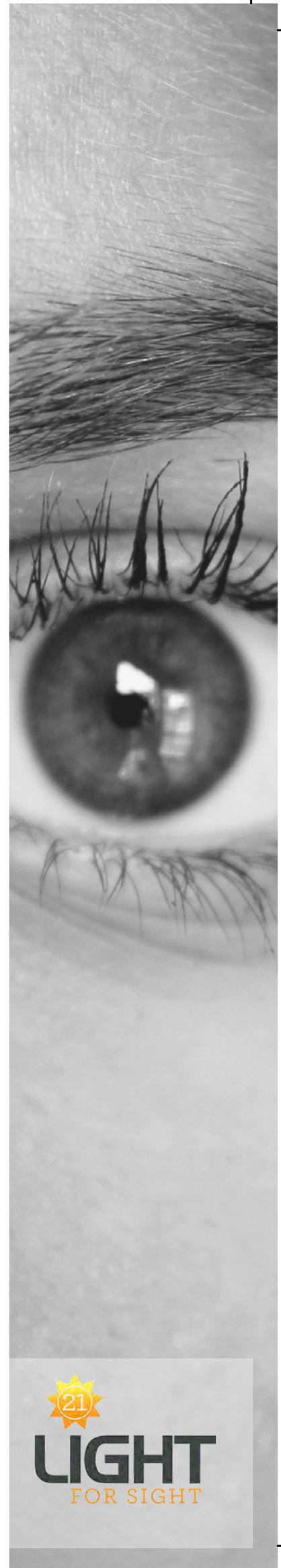
To improve knowledge about how to detect, treat and best manage keratoconus patients

### ACCESS TO TREATMENT

Regardless of financial barriers, to provide treatment options

### CONDUCTING RESEARCH

To improve on detection and treatment methods, and to ultimately find a cure



# Programs

Between January – December 2017, the following projects have commenced, activities have started/finished, and milestones achieved:

## OUTREACH

The term outreach in this context implies a means to increase awareness about the disease to promote screening in high-risk patient groups, possible referrals or treatment options. So, outreach should be focused on medical professionals who can provide treatment, to high-risk patients to encourage them to have regular eye screenings, or to community decision makers to implement change in the public-school system to allow for free in-school screenings. All three of these activities are forms of outreach and can make a significant impact in reducing severe visual impairment due to keratoconus.

**LIGHT**  
FOR SIGHT



## Light for Sight Clinical Network

To continue with the work conducted in 2015-2016, the clinical partner network has now sub-divided the partners into categories to be able to attract more people to affiliate themselves with the foundation. These categories include:

### Clinical Partner:

- Individuals who satisfy the requirements of becoming a treating clinical partner

### Clinical Associate:

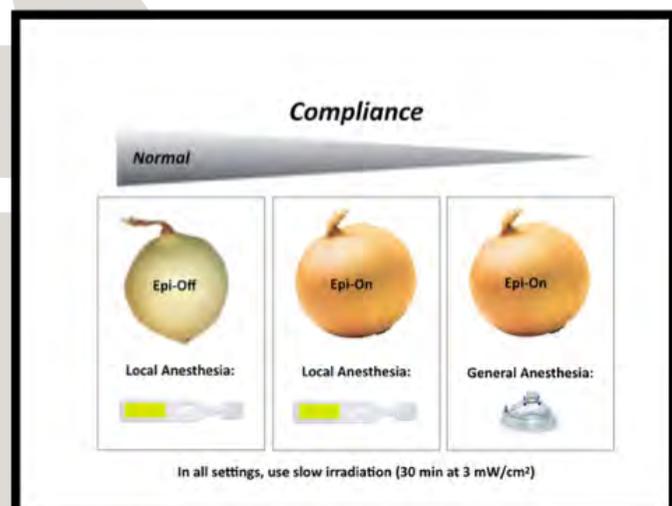
- Ophthalmologists who do not yet qualify but are able to refer patients to a qualified clinical partner
- Optometrists/optician who are unable to treat but can refer patients to clinical partners

To recruit clinical partners, the strategic goals were to keep the criteria simple in order to be inclusive but not at the expense of the quality or experience of the treating surgeon. The result equated to a total of four requirements:

- Have conducted at least 100 CXL (“Dresden Protocol”) procedures or have conducted CXL in his/her clinical practice for a minimum of three (3) years
- Will comply with the Light for Sight Protocol, which entails that the clinical partner has access to general anesthesia if the patient is deemed non-compliant\*

\* Compliance refers to the patients' cooperation level.

- Will accept to at least screen all pediatric patients, including individuals who are low to non-compliant (e.g. Down Syndrome individuals)
- Will waive at least his/her honorarium if he/she deems that the patient is unable to afford the treatment



## Light for Sight Clinical Network

At the end of 2017, the Light for Sight Foundation collected a total of 31 qualified clinical partners representing 22 countries. All 31 partners agree to comply with the “Light for Sight Protocol”.

There are many more clinical partners who have expressed interest, but these partners are not included in the total partner count until their signed partnership agreement is signed and returned. A goal in 2018 is to identify the partners with an expressed an interest and a focus on obtaining a signed agreement.



## Light for Sight Global Information Platform

In a digital world, access to information and international exposure is highly dependent on the presence the foundation has on the Internet. Therefore, the board of directors dedicated a relatively large amount of resources to the design and upkeep of the website. From content to usability, the website was one of the first projects that was deemed necessary and a high priority.

The initial design and content were selected to target patients who were recently diagnosed keratoconus in mind. The thought process was that the foundation would respond to their needs and search trends. Based on the statistics acquired from website analytics tools like Google Analytics, the website was adapted. The website evolved to provide an easy and intuitive flow and display of information. This flow involved understanding what the causes the disease, possible symptoms, treatment method options and where to (safely) seek treatment.

An interesting finding was that the main traffic was driven by keywords found in search engines. While the website was provided both in German and English, the main traffic was based on English-speaking visitors seeking information about treatment. And, these visitors were primarily from Switzerland and the United States.

The website is continually being improved and updated. More information can be found at:

<https://www.lightforsight.org>

## TRAINING AND EDUCATION

There are three different types of educational activities that the Light for Sight Foundation supports. These three programs include:

- Train the Trainer: Ophthalmologist (and/or corneal specialist)
- Build the Referral Base: (Referring) healthcare professionals
- Empower the Patient: Patient/Family



### CXL EXPERTS MEETING

[WWW.CXLEXPERTSMEEETING.COM](http://WWW.CXLEXPERTSMEEETING.COM)

A 3-day educational platform to share, debate and learn best practice models for CXL treatment methods and explore future applications



### EYE CARE PROFESSIONAL TRAINING

ELZA EDUCATIONAL COURSES

An educational series dedicated the basics of keratoconus taught in multiple languages



### PATIENT FAMILY EDUCATION

[WWW.LIGHTFORSIGHT.ORG](http://WWW.LIGHTFORSIGHT.ORG)

An online educational tool used to answer the most common questions in an unbiased and clinical and scientifically-based manner

How you will find a collection of frequently asked questions and our answers. Besides, you may find information on the internet and also various groups on Facebook on the topic, the "Keratoconus Group" is the largest, with more than 10'000 members and counting. The website of the ELZA Institute provides useful information on the topic and access to a large number of scientific articles, videos, and popular articles on the topic.

#### What is Keratoconus

Keratoconus is a disease that goes along with a diminished biomechanical stability of the cornea. The cornea becomes too soft, leading to an increased bulging and protrusion of the cornea. Since the cornea represents an important part of the eye's optics, a number of symptoms occur: fluctuations in visual acuity, reduction of visual acuity that cannot entirely be corrected with glasses or even contact lenses, and halos around light sources.

## Ophthalmologist Training: 11th Annual CXL Experts' Meeting

The flagship educational program that the Light for Sight Foundation supported in 2017 was the CXL Experts' 11th Meeting held from November 30 – December 2, 2017, in Zurich, Switzerland.



Two new additions to the program were (1) wet labs / didactic courses on Thursday as a prequel to the scientific program and (2) the “Posters, Wine and Cheese” Session on Friday prior to the banquet dinner.

Both additions were adapted from 2016 participants survey responses. From this survey, we learned that the bulk of the audience has changed from experienced CXL surgeons/ key opinion leaders to newcomers to the field in both research and clinics. Therefore, there was a demand to focus on teaching the CXL technique and highlighting the research that is being conducted.

Since the Thursday wet lab and course sessions were completely new, the organizing committee estimated that there needed to be a total of 15 registrants to cover the hotel related costs. Finally, there were a total of 74 paid individuals attending 134 sessions demonstrating the need for such courses. The 2018 meeting will accommodate for a larger demand than originally estimated in 2017.

Although the Thursday program was a financial and educational success, the changes that will be implemented in 2018 would be:

- Offer two basic wet labs, one in the morning and one in the afternoon to accommodate for the demand
- Provide CXL books for sale during this period, which were also a demand



Best Presentation  
Prof. John Jarstad and Dr. Lindsey McDaniel



Best Poster  
Dr. Robert Herber

With over 180 attendees representing 40 countries, it is the largest international meeting solely dedicated to cross-linking (CXL) technology. The 3-day program provided an educational platform of leading experts and corneal specialists to engage in lively discussions and debates about KC management, research findings, and promising new applications and treatments.

In replacement of the annual Theo Seiler Award that is given to a promising young investigator in the field of cross-linking technologies and applications, two awards were given for “Best Poster” and “Best Oral Presentation.”

## Eye Care Professional Training: ELZA Educational Courses

One of the founders and clinical ambassador, Prof. Farhad Hafezi, launched a pilot project dedicated to educating optometrists and opticians about keratoconus in Zurich, Switzerland. These courses were in response to the feedback from this group of vision healthcare professionals that little to no information is provided about keratoconus or its management during their education and formation.

These eye care professionals are often the first line of care for suspected patients. Therefore, early detection is essential if the professional knows what to look for in terms of symptoms. Therefore, combining the lack of information with the patient need, Prof. Hafezi organized a 2-hour program highlighting the disease, symptoms, at-risk groups, means for diagnosis and treatment options. Education and awareness are key elements for early detection and intervention; so, the long-term goal of this workshop is to develop a referral network of vision healthcare professionals who are able to detect and easily refer patients.

A major obstacle to acknowledge and overcome is the eye care professional's fear of "losing" the patient if the patient is referred to an ophthalmologist for diagnosis and treatment. Hence, the delicate but crucial elements to balance were the patients' needs with the assurance that once the patient has been surgically treated, the patient will be "returned" to the eye care professional. Trust and respect were key to balance these two elements.

These educational courses or rather called the "Light for Sight Associates Referral Program" continued in 2017. However, in 2017, Prof. Farhad Hafezi was invited to give courses at established congresses in Switzerland, and these invited talks were addressing the same individuals, so a congress platform was used instead of individual courses in a clinical setting.



The speaking schedule included:

**Q1**

University of Basel Lecture Series

February 9, 2017 “Cross-Linking der Hornhaut 2017: Technische Neuerungen & Besser Sehen nach CXL”

Audience: Ophthalmologists

**Q2**

FHNW, Olten

April 11, 2017

“Keratokonius”

Audience: Optometrists and opticians

Global Pediatric Ophthalmology Congress, Milan

June 5-6, 2017

“The Window into their Future: Screening & Early Detection of Corneal Disease in Pediatric Patients”

Audience: Pediatric ophthalmologists

*Scientific Program*

**2<sup>nd</sup> Global Pediatric Ophthalmology Congress**

June 05-06, 2017 Milan, Italy

Conference Series - America

One Commerce Center-1201, Orange St. #600, Wilmington, Zip 19899, Delaware, USA  
Toll Free: 1-888-843-8169, P: 702-508-5200, F: +1-650-618-1417

**Day 1 June 05, 2017**

09:00-09:30 Registrations

**Barcelona 2**

**conference**series.com 09:45-10:00 **Opening Ceremony**

**Keynote Forum**

10:00-10:05 Introduction  
10:05-10:35 Title: *The Window into their future: Screening & Early Detection of Corneal Diseases in Pediatric Patients*  
Prof. Farhad Hafezi, ELZA Institute AG, Dietikon / Zurich, Switzerland

**Group Photo**

Networking & Refreshment Break 10:35-10:55 @ Foyer

**The Light for Sight Course on Keratoconus 10:55-11:55**

Prof. Farhad Hafezi, MD PhD - ELZA Institute, Switzerland  
Prof. Cosimo Mazzotta, MD PhD - University of Siena, Italy  
Dr. Miguel Rechichi, MD, PhD, Crosslinking Specialist, Italy

**Q3**

73rd SBAO Congress, Bern  
September 17, 2017

“Die Zukunft des cornealen CXL: extrem dünne Hornhäute und Infektiöse Keratitiden  
Audience: Optometrists & opticians

**73**  
**SBAO  
FACHTAGUNG  
CONGRÈS  
SSOO**  
WORKSHOP AM MONTAG  
ATELIER LE LUNDI  
17.-18.09.2017 | SWISSÔTEL  
ZÜRICH OERLIKON

11:30

**Die Zukunft des cornealen Cross-Linking: extrem dünne Hornhäute und infektiöse Keratitiden**

**L’avenir de la Réticulation aux UV: cornées ultra-minces et kératites infectieuses**

Prof. Dr. Farhad Hafezi  
Geschäftsführer ELZA Institute AG Dietikon (D)



Farhad Hafezi hält Professuren für Augenheilkunde an den Universitäten Genf und USC Los Angeles und sein Forschungslabor an der Universität Zürich. Er ist international anerkannt als Pionier des Cross-Linking der Hornhaut und wurde 2014 wie auch 2016 von seinen KollegInnen unter die 100 einflussreichsten Augenärzte der Welt gewählt.

Das klassische “Dresden-Protokoll” zur Behandlung des progressiven Keratokonus bei Cross-Linking (CXL) ist heutzutage zum

internationalen Behandlungsstandard geworden. Neue faszinierende CXL-Indikationen mit modifizierten Techniken beinhalten (1) CXL bei Keratokonus mit individualisierter Fluence in extrem dünnen Hornhäuten (270 bis 400 µm) und (2) PACK-CXL bei infektiösen Keratitiden bakterieller, fungaler oder gemischter Ursache.

Farhad Hafezi dispense son enseignement aux universités de Genève et USC Los Angeles. Son laboratoire de recherche se trouve par contre à l’université de Zürich. Il est reconnu internationalement comme pionnier de la réticulation de la cornée. En 2014 et 2016, ses collègues l’ont élu comme l’un des cent ophtalmologues les plus influents au monde.

Le “Protocole de Dresde” classique pour le traitement du kéraconie progressif lors de la réticulation (CXL) est devenu de nos jours le standard de traitement international. De nouvelles indications fascinantes concernant la CXL avec des techniques modifiées contiennent 1) CXL lors de kéraconie avec une fluence individualisée avec des cornées très minces (de 270 à 400 µm) et 2) PACK-CXL lors de kéraconie infectieuses bactérielles, fongiques ou de causes mixtes.

20 SBAO Fachtagung (Herbst 2017)

Umbria Optometry Club, Pfäffikon  
September 24, 2017  
“Cornea Update 2017”  
Audience: Optometrists

**Sonntag, 24.09.2017**

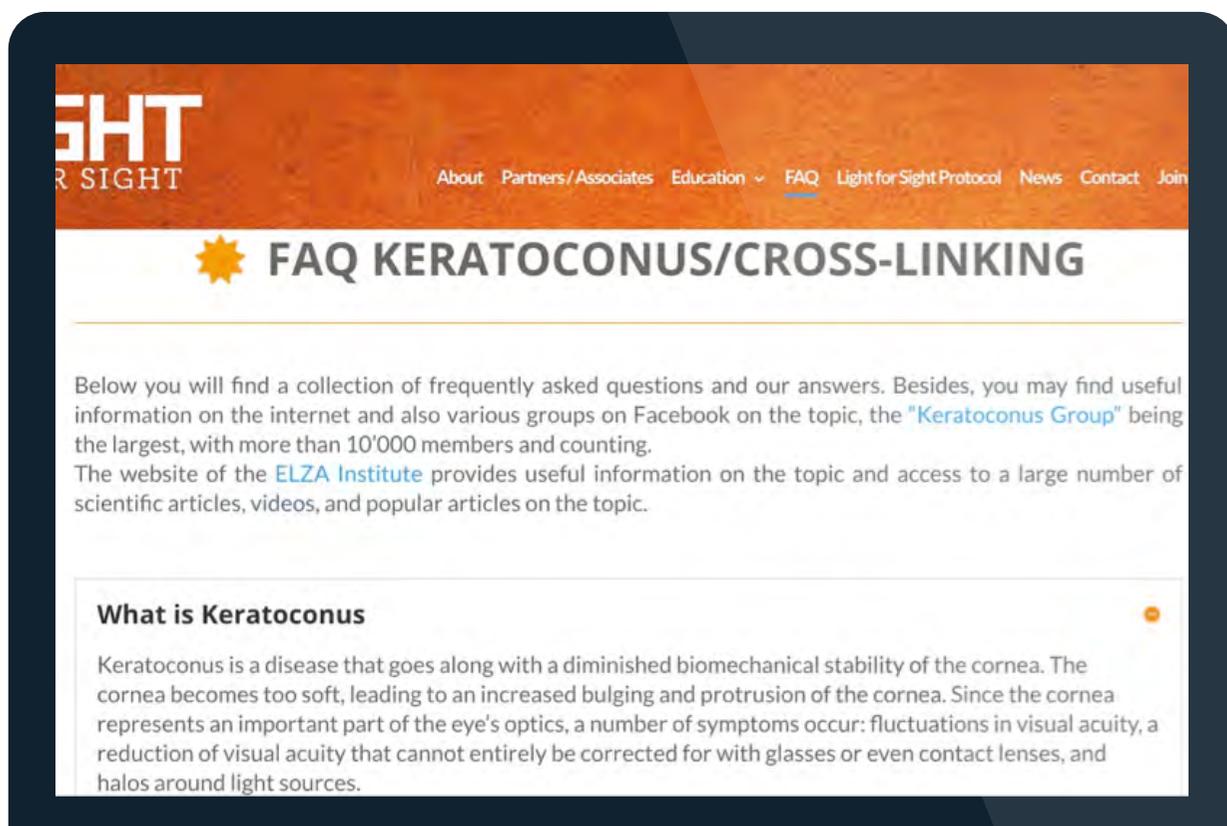
- 09.30 Begrüssung**  
Heinz Dremmel, PhD
- 09.40 Cornea Update 2017 – Teil 1**  
**(Schwerpunkt irreguläre Corneaerkrankungen und Progressionsverläufe)**  
Farhad Hafezi, Prof. MD
- 10.30 Kurze Pause**

## Patient/Family Education

General questions about keratoconus (e.g. diagnosis, treatment, risk factors, etc.) were collected from presentations and panel discussions at congresses, patient emails as well as during consultations, and then prioritized based on frequency.

These frequently asked questions (FAQs) were answered by corneal specialists and researchers and posted on the Light for Sight website. Although this section of the website was intended for patients, healthcare professionals like general ophthalmologists and corneal specialists use this educational platform to help explain the disease, symptoms and treatment method to their patients.

Although the website's exposure has not yet been maximized to reach its full potential, beginning discussions about linking to large keratoconus groups (via Facebook, for example), would increase the exposure and make the site more useful for people seeking accurate and unbiased information about the disease.



## **Access to Treatment**

Literature continually shows that some groups of people have a higher prevalence of keratoconus than the general population. One group is the Down Syndrome population. The estimated rate of keratoconus among the Down Syndrome population is reported as high as 1:67 compared to the general population (1:2000, Kennedy et al., 1986).

Despite the relatively low awareness of keratoconus, detection and diagnosis of this disease are even more difficult with cognitively-delayed individuals. In order to properly diagnose a patient, there are a series of tests that require the patients' feedback. If the patient is unable to provide appropriate feedback, often times, the medical professional rules the abnormal findings with the fact that the patient was being non-compliant or did not understand what he/she needed to do. So, instead of repeating the examinations or referring the patient for further tests, the patient simply remains undiagnosed. In the worst case, the patient's symptoms worsen as the disease progresses.

In late 2017, GroupAdvance Consulting GmbH received a mandate to develop a white paper to demonstrate possible best practice models to screen low to non-compliant patients. This white paper would be based on other models working with mentally challenged individuals in clinical settings. Already, the Light for Sight knows that there are:

Three ways to assure the goal of equal access are:

- (1) All clinical partners must be willing to accept low to non-compliant patients or agree to refer them to a nearby Light for Sight clinical partner.
- (2) All clinical partners must have the possibilities of administering general anesthesia for low to non-compliant patients.
- (3) If the treating clinician deems that the patient/patient's family is unable to pay for the costs related to the treatment, then the clinician must waive his/her honorarium. If the family still is unable to pay for the materials, then the clinician would need to contact the foundation for support.

## Light for Sight 21 Vision Agreement

The purpose of having a signed agreement with our partners is to be able to ensure that our partners are providing safe, effective and accessible treatment for all children and adolescents.



**Light for Sight Mission Statement**  
To eliminate preventable blindness among children and adolescents with keratoconus

**To achieve the mission the Light for Sight Foundation aims at four main goals:**

- (1) Outfitting the national vision screening systems
- (2) Providing training and education to medical staff
- (3) Providing access to treatment for all vision impaired patients with keratoconus
- (4) Conducting research to better understand keratoconus

**Light for Sight Clinical Reference Site Agreement**

This collaboration agreement is made on **May 29, 2018** by and between **XXXX (City, Country)** now called "Site" and the Light for Sight Foundation ("LAS") (Zurich, Switzerland).

**The Site**

- will agree to accept children and adolescents (including low to non-compliant e.g. Down Syndrome individuals) in his/her patient consultation for the purpose of screening, detecting, treating and managing keratoconus
- will agree to treat pediatric patients by using a current, safe and effective crosslinking (CXL) treatment method using the Light for Sight protocol when judging the compliance level of the patient with keratoconus
- will agree to treat and care for the pediatric patient despite his/her inability to pay for the treatment and/or refer the patient to another LAS clinical partner site
- has at least access to an operating theatre that can administer general anesthesia in non-compliant patients
- will have a CXL device that is able to perform at least the Dresden protocol when administering CXL treatment
- will provide proof that the treating physician(s) has participated in at least an instructional course(s) on the CXL method (e.g. CXL Experts' Meeting) or had another similar training session by an accredited surgeon (proof of attendance/participation may be required)
- will provide a quarterly report of the number of pediatric patients seen and treated at the Site (e.g. using a web-based reporting system that LAS will provide), when applicable

**Light for Sight Foundation**

- will list the Site on appropriate marketing materials
- will refer patients to the Site when geographically appropriate
- will strive to provide each Site with information about approved training courses for continuing medical education purposes related to keratoconus detection, treatment and management
- will coordinate with LAS industrial partners to provide preferred prices of CXL devices and riboflavin
- will work in collaboration with the Site, to cover any or all of the technical fees associated to the pediatric patient's bill when he/her family was unable to pay
- will organize multi-center study research collaborations and strive to involve the Site where appropriate

In Witness Whereof, the parties hereto have executed this Agreement effective as of the Effective Date written above.

Agreed:

<p><b>Name, Title</b></p> <p><b>Position</b></p> <p><b>Institute/Hospital</b></p> <p><b>City/Country</b></p>	<p><b>Dr. Hafeez, MD, PhD</b></p> <p>Co-Founder and Chairman of the Board of Directors Light for Sight Foundation</p> <p>Professor of Ophthalmology University of Geneva, Switzerland</p> <p>Professor of Clinical Ophthalmology University of Southern California, USA</p>
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## First Down Syndrome Consultation in Switzerland

An estimated 75% of children and adolescents with Down syndrome experience eye-related problems like cataract and keratoconus, so early detection to initiate treatment is essential. And good vision is essential for proper early childhood cognitive development, especially in children with learning disabilities. Any visual impairment would indirectly affect the child's ability to reach its full potential for the rest of its life.

Before 2005, the only means to treat keratoconus was with a corneal transplant. Now a medical procedure called corneal cross-linking (CXL) stops the progression of this disease. CXL now is a global standard of care and was developed in Zurich, Switzerland. CXL has been shown to significantly decrease the need for corneal transplants.

In order to address this high-risk patient group, the ELZA Institute in Dietikon inaugurated the "Light for Sight 21 Eye Health Consultation" on World Keratoconus Day (November 10, 2017). This year-round consultation will be dedicated to detecting, diagnosing and treating the most common eye diseases and conditions that specifically Down syndrome individuals face, including keratoconus.

This national launch was highlighted in different media sources.



The screenshot shows a Medinside article. At the top left is the Medinside logo, which consists of a blue square with a white letter 'M' inside, followed by the word 'MEDINSIDE' in a sans-serif font. Below the logo is a horizontal line. Underneath the line, there are three small blue squares with white text: 'OPHTHALMOLOGIE', 'ÄRZTE', and 'FORSCHUNG'. The main title of the article is 'Ophthalmologie: Farhad Hafezi lanciert Down-Syndrom Sprechstunde' in a large, bold, black font. Below the title, there are two lines of smaller text: 'Veröffentlicht am: 13. November 2017 10:57, von cm' on the left and 'Letzte Aktualisierung: 13. November 2017 11:27' on the right. At the bottom of the article, there is a bold black headline: 'Das Elza Institut startet die erste augenärztliche Sprechstunde der Schweiz für Menschen mit Down-Syndrom.'

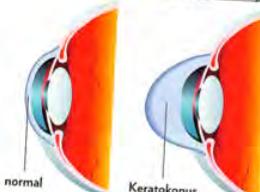
## Switzerland: (Schweizer Illustrierte)

Despite the fact that Switzerland made CXL clinically possible, Switzerland has not accepted the treatment into its national reimbursement policies. Therefore, patients of Prof. Farhad Hafezi have brought this discrepancy to media sources, such as Schweizer Illustrierte, to help increase awareness of the disease but also to demonstrate that the disease affects the youth. And, without proper care of this disease, these children will become visually impaired and/or disabled which will affect the entire society.

It was important to not only demonstrate the importance of screening for early detection, but the fact that through the foundation, all children have access to screening and treatment despite any financial barriers. Although it mainly goes unreported as a respect to the families, many of the foundation clinical partners have informed the foundation that they regularly treat children for free.

**Roy Brügger, Keratokonus-Patient, kann dank der Operation wieder besser sehen.**

Beim Keratokonus ist die Hornhaut ausgedünnt und wölbt sich abnorm vor (rechts).



normal      Keratokonus

Linking, eine Quervernetzung der Hornhaut, auch CXL genannt, ist eine Methode, den Keratokonus mittels UV-Licht und Vitamin B2 zu stabilisieren», erklärt der Augenarzt. Entwickelt wurde die Methode in Dresden, die klinische Weiterentwicklung erfolgte in Zürich. Mit dem Cross-Linking ist es möglich, die Krankheit zu stoppen. Der Eingriff dauert knapp 45 Minuten: Nach einer vorsichtigen Eröffnung der Versiegelungsschicht der Hornhaut werden Vitamin-B2-Tropfen auf die Hornhaut appliziert, um diese zu sättigen. Danach erfolgt eine Bestrahlung mit UVA-Licht. Innerhalb von Minuten wird die Hornhaut um 350 Prozent verfestigt. «Die Erfolgsquote liegt zwischen 93 und 97 Prozent», sagt Prof. Hafezi.

**Vor der Operation** war Roys Sehkraft auf einem Auge 60 Prozent, auf dem anderen zwischen 16 und 25 Prozent. Nach der Operation und mithilfe einer Brille sieht er auf dem rechten Auge jetzt fast 100 Prozent. Die Sehkraft auf dem linken Auge beträgt immer noch nur 25 Prozent. Verbessern lässt sich dieses Resultat noch mit



Spezial-Kontaktlinen. «Die Schweiz ist eines von wenigen Ländern weltweit, die solche Spezial-Kontaktlinen herstellen», sagt Prof. Hafezi. In etwa einem Jahr will Roy es mit den Kontaktlinen versuchen. Um bis zu 50 Prozent lässt sich die Sehkraft mit einer wellenfrontgeführten Excimer-Laser-Behandlung anheben, einer von Prof. Hafezi entwickelten Methode. «Die Behandlung ist nicht vergleichbar mit einer herkömmlichen Laserkorrektur. Es handelt sich dabei um einen komplexen therapeutischen Eingriff», fügt er hinzu. Das von ihm entwickelte Nomoprogramm wird in etwa zwei Jahren weltweit bei Excimer-Lasern in die Software eingespielt werden.

**Ganz wichtig beim Keratokonus** ist die Früherkennung. Denn mit dem Cross-Linking gibt es ein Mittel, die Krankheit zu stoppen. Das Problem ist, dass die speziellen Untersuchungsmethoden noch nicht Teil eines allgemeinen Screening-Programms an Schweizer Schulen – und anderswo in Europa – sind. Die Krankenkassen bezahlen Cross-Linking nicht, dafür aber die Hornhautverpflanzung, das Mittel der letzten Wahl. Augenchirurgen sind mit dieser Indikation bei Kindern und Jugendlichen allerdings zurückhaltend. Die Krankheit kann nach zehn bis fünfzehn Jahren ins Transplantat zurückkehren. Prof. Hafezi ist darum überzeugt: «Das beste Gewebe ist das eigene. Je länger wir die eigene Hornhaut erhalten können, desto besser.»

**STIFTUNG**

**«Light for Sight»-Initiative**

Bei der Augenkrankheit Keratokonus besteht nicht nur in der Schweiz, sondern global ein grosser Informationsmangel. Ganz besonders besteht das Manko bei Kindern mit Down-Syndrom, die häufiger betroffen sind. Farhad und Nikki Hafezi haben deshalb 2011 die «Light for Sight»-Initiative in der Schweiz gegründet. Inzwischen ist die Stiftung in mehr als 25 Ländern vertreten. Die Stiftung hat folgende Ziele:

- Screeningprogramme an Schulen und Schulungsstätten für Menschen mit Down-Syndrom.
- Betroffene und ihre Familien über die Erkrankung und Behandlungsmöglichkeiten aufklären.
- Den Betroffenen einen Zugang zur Therapie eröffnen.
- In Härtefällen finanzielle Unterstützung bei den Behandlungskosten ermöglichen.
- Die klinische und Grundlagenforschung auf dem Gebiet aktiv unterstützen.

Mehr Infos: [www.lightforsight.org](http://www.lightforsight.org)

## RESEARCH

Improved awareness, means to diagnosis, and access to treatment will help reduce the deleterious effects this aggressive disease can have. However, the ultimate goal is to understand the disease to a point where it can be prevented before the symptoms even start.

Supporting research is essential to achieve the long-term goals and mission of the Light for Sight Foundation. However, quality, meaningful and high impact research takes time. Research is expensive and raising funds to support the personnel needed to conduct the studies is difficult. So, the Light for Sight Foundation, from the start, decided to invest time and energy to identify collaborators who shared the same mission. This way, the investigators would also invest their time and energy in collaborative research projects in support of the mission.

### **Salus/Kind Saud University: PhD Student No. 1 (update)**

In 2015, Light for Sight Foundation's first PhD student was instructed on how to achieve a statistically sound prevalence of keratoconus among Saudi children and adolescents. The hypothesis was that the prevalence is significantly higher than the currently cited publications, most likely due to genetic disposition and climate (dry and windy). The clinical trial enrolled 522 subjects (1044 eyes) and was submitted to the British Journal of Ophthalmology in September 2017.

To summarize the final keratoconus prevalence among this patient group was 1:21 patients or rather 4.79% (95%CI 2.96 to 6.62). The manuscript was published on January 3, 2018.

Currently, the PhD doctorand is preparing her thesis and is tentatively scheduled to defend only in late 2018 due to familiar reasons.

## K-MAP: Global Prevalence Study of Keratoconus

As a reaction to the significant finding in Riyadh, a global prevalence study has been launched. Based on constructive criticism of the publication reviewers of the pilot study, certain aspects of the exclusion criteria and patient questionnaire have been revised. The goal of the global study (“K-MAP”) is to determine the global prevalence of the disease among children and adolescents in various regions of the world using modern tomographic imaging methods.

Our hypothesis is that the prevalence of the disease is much higher than what is currently being reported. If found to be true, then the results of the study will have a direct impact on the future need and development of screening programs for keratoconus.

Currently, the estimated number of patients needed to achieve statistical significance would be 2,995 if the assumed prevalence of the disease is 1:500.

