

LIGHT FOR SIGHT
ACTIVITY REPORT
2018

**20
18**



LIGHT
FOR SIGHT

Fighting preventable blindness

*The Light for Sight Foundation
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Switzerland
www.lightforsight.org*





LIGHT FOR SIGHT ACTIVITY REPORT

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LETTER FROM
**THE CHAIRMAN
OF THE BOARD**

PROF. DR. DR. FARHAD HAFEZI



February 1, 2019

Dear Friends and Colleagues,

Another eventful year has come to a close, and I am pleased to announce that the foundation is not only growing in terms of collaborators, but also in terms of scientific impact.

The accompanying annual activity report will provide an overview of the activities and efforts that our collaborators and volunteers have performed in the name of the foundation.

It is imperative to not only identify high-risk groups but also provide means to conduct good diagnostic examinations.

The four main pillars of the foundation are outreach and awareness, access to treatment, education & training and research. Of these pillars, the highlights of 2018 were:

- A pilot project in 2018 saw Light for Sight participate in the Swiss national future profession day “Zukunftstag” designed for 5th-grade students. Two of Light for Sight’s clinical ambassadors participated to provide an overview about the importance eye health with a special focus on the risk of eye-rubbing and keratoconus awareness.
- Since the foundation focuses on both outreach and access to treatment, it is imperative to not only identify high-risk groups but also provide means to conduct good diagnostic examinations. Therefore, one patient group that was a priority was cognitively-impaired children.

- A process, PINCO (Process to INcrease Compliance in Ophthalmology), has been developed, tested, and is ready for clinical launch.
- With respect to education and training, the ELZA Institute, in

The annual CXL Experts' Meeting, held in December 2018, reached its all-time high in terms of number of participants, number of countries represented, number of newcomers and it received the highest amount of sponsorship since 2015.

- collaboration with the foundation, held a free keratoconus course designed for optometrists in Biel, Switzerland. In the past, these courses were only available in German. This French course had the highest number of attendees to date.
- The annual CXL Experts' Meeting, held in December 2018, reached its all-time high in terms of number of participants, number of countries represented, number of newcomers and it received the highest amount of sponsorship since 2015.
 - As reported in the 2017 Light for Sight Annual Report, the K-MAP global keratoconus prevalence study is rapidly gaining clinical recruitment sites and enrolling patients. I anticipate that preliminary results will be available at the close of 2019 due to the efforts dedicated to this study in 2018.

Last, but certainly not least, fundraising efforts have been spearheaded and successfully administered by one of our foundation's board members. With the primary focus on research, Nikki Hafezi, has secured a major gifts pledge to also support young researchers interested in preclinical and clinical projects in the field of cross-linking applications and treatment modalities. I have also dedicated all of my speaking honorariums to support the foundation. On a personal note, I hope that other Light for Sight partners will join me and do the same.

Thank you for your interest in the foundation, and a special thanks for making the Light for Sight Foundation your charity of choice!

With gratitude,



FARHAD HAFEZI, MD, PHD

*Professor of Ophthalmology
University of Geneva, Switzerland*

*Medical Director
ELZA Institute AG, Zurich, Switzerland*

*Clinical Professor of Ophthalmology
Roski Eye Institute, Keck School of Medicine,
University of Southern California*

*Visiting Professor
Department of Ophthalmology,
Wenzhou Medical University, China*

LIGHT FOR SIGHT HISTORY

THE LIGHT FOR SIGHT STORY

The concept was simple: outreach to a population group at a high-risk of developing keratoconus (Down Syndrome) and provides access to annual eye screenings for early detection and intervention. In the beginning, this concept was called "Project Light for Sight," next "Light for Sight 21," then finally, "Light for Sight Foundation" in November 2015.

The concept started as a small local project in Geneva but due to the instant demand of clinicians to participate and the great interest in performing collaborative research projects, it needed a more formal structure to allow for growth and have the means to accept support and donations. Also, having a foundation would create a body that could potentially fund research initiatives dedicated to helping the foundation's mission. This body would be reliant on the achievements of the foundation as well as success in traditional fundraising in an

"Since keratoconus is currently classified as a rare disease, most eye care specialists know little to nothing about the disease in terms of its symptoms, diagnosis and treatment methods."

already competitive market.

To increase the chance of success, the Light for Sight Foundation expanded its mission to eliminate preventable blindness among all children and adolescents with keratoconus. Keratoconus is one of the leading causes of severe visual impairment in children and adolescents. However, since keratoconus is currently classified as a

rare disease, most eye care specialists know little to nothing about the disease in terms of its symptoms, diagnosis and treatment methods. Early detection and treatment are essential in reducing the severity of symptoms (and the impact these visual symptoms have on their ability to live their lives), so awareness is essential to combat this disease.

The scientific literature indicates that certain groups may show a higher keratoconus incidence rate than the general population. One of these groups is the Down Syndrome population. Given the fact that many of these individuals are deemed low to non-compliant, the eye care specialists who are conducting their vision screening tests may simply deem that the patient is "having a bad day" if the results of are sub-optimal, or worse, give up trying to screen a profoundly non-compliant patient in order to serve the other patients in his or her clinic.

The Light for Sight leadership believes that there are three fundamental ways to increase the awareness about not only the disease, but also the services that the foundation offers to patients and healthcare professionals. These two ways include:

- Building a clinical network of qualified vision healthcare partners to properly diagnosis and treat keratoconus patients
- Establishing working partnerships with patient groups which consist of "high-risk" patients
- Develop/adopt/adapt patient handling methods for non-compliant patients to achieve better screening outcomes and proper diagnoses.



MISSION STATEMENT AND GOALS

Mission Statement:

To eliminate preventable blindness among children
and adolescents with keratoconus

THE LIGHT FOR SIGHT FOUNDATION'S FOUR GOALS:

Outreach

Outreaching to both high-
risk patient groups and
treating clinicians

Knowledge

Training/education and
awareness of the disease
and treatment

Access

Providing access to
treatment for all children
and adolescents with
keratoconus

Protect the Future

Conducting research
to better understand
keratoconus

LIGHT FOR SIGHT FOUNDATION PROGRAM

OUTREACH THAT SAVES SIGHT

During the period between January and December 2018, 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 of the disease, either for screening purposes, referral or treatment. So, “outreach activities” can range from clinical partners providing treatment services, to encouraging high-risk patients to have regular eye screenings or efforts designed for 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 to reducing severe visual impairment due to this disease.

Light for Sight Clinical Network

At the end of 2018, the Light for Sight Foundation proudly lists a total of 33 qualified clinical partners representing 24 countries. All 33 partners agree to comply with the “Light for Sight Protocol”.

Due to the activities that the foundation supports, the recent publications, as well as the exposure that the clinical partners have, presenting on the podiums to the audiences attending international eyecare conferences, there is growing number of clinical partners and non-ophthalmologists who are seeking to partner with the foundation. A goal in 2019 is to sign all qualified partners, especially optometrists, who have expressed interest.

To ensure quality and that the clinical partners abide by the same conditions, the criteria is to remain inclusive and make sure our potential partners are clear about the foundation’s expectations.

Therefore, the four main requirements for clinical partners are:

- Have conducted 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 includes that the clinical partner has access to general anesthesia if the patient is deemed non-compliant*
*“Compliance” refers to the patient’s cooperation level.
- Will accept all pediatric patients, including individuals who are low to non-compliant (e.g. Down Syndrome individuals), for at least screening purposes
- Will waive at least his/her honorarium if he/she deems that the patient is unable to afford the treatment.

To respond to the demand, the clinical partner network is growing its “Associates” partnerships. Associates are both ophthalmologists who do not (yet) qualify as “partners” but still can refer patients. Associates also include optometrists (and opticians) who are unable to surgically treat patients.



Light for Sight Global Information Platform

In a digital world, access to information and international exposure is highly dependent on the visibility of an organization's internet presence – and this applies to Light for Sight too. Accordingly, the board of directors viewed the creation of the Light for Sight website as a high priority, and this was one of the first projects commenced by the foundation. The board of directors continue to dedicate a relatively large amount of resources to the upkeep of the website.

Using the CXL Experts' Meeting as the primary source of material, select presentations were collated and uploaded online. This selection process was based on what information would be the most useful for both clinicians and patients. The goal was to select presentations to help explain the different facets of keratoconus and the state of the art for the treatment method. All presentations are available for any viewers who visit the Light for Sight website.

The newest addition to the website was the inclusion of candid interviews with key opinion leaders and Light for Sight Ambassadors about the topic of corneal cross-linking (CXL). The questions for the interviews were collected based on the most frequently asked questions from congresses and from emails from patients. Another aim of the interviews was for young investigators to interview experienced scientists to encourage exchange between the different academic generations.

A total of eight interviews were recorded and posted online in December 2018. Efforts were made to refer past participants of the meeting to the Light for Sight Foundation website and encouraged to enroll in the newsletter. These efforts will aid the future efforts of disseminating information to interested individuals as well as preparing the future project of establishing a membership strategy for the foundation.

EXPERT INTERVIEWS



VIDEOS



ZUKUNFTSTAG 2018

SWISS NATIONAL FUTURES DAY



A new project that was adopted in 2018 was to participate in the Swiss national "Future Day" on November 8, 2018.

Zukunftstag is a national initiative where 5th grade students are responsible for self-organizing a day internship with a professional in a field that interests them. Historically, the mission of this day is to promote gender equality in the workforce, but it has evolved to a day dedicated to empowering young people to start making decisions about their future. Two of the Light for Sight Ambassadors opened their doors to four students from three Swiss cantons: Zurich, Aargau and Zug. There were three main goals of the day:

- To expose the young participants to the different aspects of a busy eye clinic
- To introduce the participants why research is done
- To educate the participants about the harmful effects of eye rubbing.

The ELZA and IROC teams further explained what keratoconus is, how it affects children and adolescents, and how keratoconus is treated (corneal cross-linking). Aside from the administrative and organization aspects of a clinic and research laboratory, the take-home message of the day was that eye rubbing is dangerous and therefore, should avoid rubbing their eyes.

The aim was to educate children about the eye disease so hopefully, they can also share the information with their friends and family. The secondary aim is to empower children with the knowledge that they can also keep their eyes healthy by not rubbing their eyes.

Our goal is to participate in the 2019 Zukunfttag.



TRAINING AND EDUCATION

THE CXL EXPERTS MEETING AND MORE



Training & Education

The Light for Sight Foundation supports the production of educational materials for three main audiences:

- Ophthalmologists (incl. corneal specialists)
- (Referring) healthcare professionals
- Patients/Families.

Ophthalmologist Training: 12th Annual CXL Experts' Meeting

November 29 – December 1, 2018

Mövenpick Hotel – Zurich Airport

Switzerland

www.cxlexpertsmeeting.com

The flagship educational program of the Light for Sight Foundation is the CXL Experts' Meeting, held annually on the first weekend of December. Historically, the CXL Experts' Meeting was called the CXL Congress, but in 2015, a company in the pharmaceutical/medical device industry purchased the naming rights of the Congress, and moved the meeting to Boston, Massachusetts, thereby removing the European focus and location. Due to high demand from former CXL Congress participants, the Light for Sight Foundation started organizing the CXL Experts' Meeting in 2016 under the same fundamental educational principles as the original meeting.

During each CXL Experts' Meeting, the planning committee asks for and collects all suggestions, comments and criticisms of participants and industry. This feedback is thoroughly discussed among the planning committee, and appropriate changes to the program and organization are made. The

committee believes that the meeting serves as an open forum for lively discussion and debate ranging from the preclinical activities to clinical applications of CXL technology. This forum also provides a research platform to encourage multi-center collaborations to advance the field.

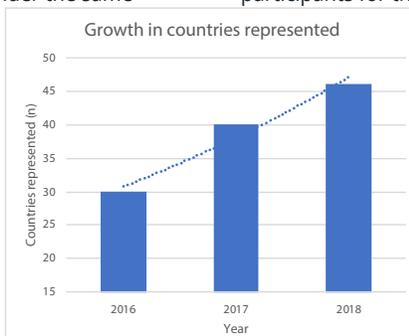
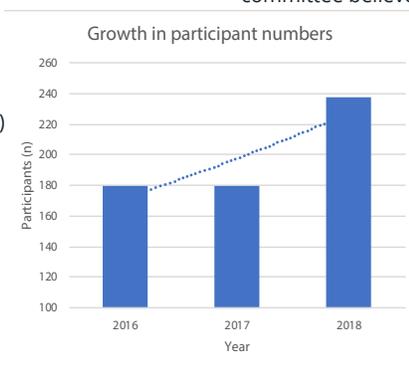
Specifically, the changes that were implemented in 2018 were:

1. Hosting three wet labs (two in the morning and one in the afternoon)
2. Conducting interviews with select speakers
3. Posting the presentations online for participants only
4. Posting select presentations for public viewing, and
5. Hosting a speakers' dinner with young clinicians and researchers at the close of the meeting.

This dinner allowed both young and experienced clinicians and researchers to speak casually with each other about future research projects and career opportunities.

As exemplified in the table, there has been a significant increase in participants for the 2018 meeting. Possible reasons for this increase

of interest include the successful execution of the 2017 meeting in terms of its high-quality scientific program, wet labs and instructional courses and the panel of esteemed invited speakers. An aim for the 2019 meeting is to attract more researchers; one of the ways of doing so is to offer a parallel session focused on corneal biomechanics, which is a very popular topic in the field of cross-linking technology.



2018 CXL Experts' Meeting Advertisement

International **CXL**²⁰¹⁸ Experts' Meeting



Zurich

2018

Nov 29 - Dec 1

Important dates

Abstract Deadline: August 27, 2018
Abstract Notification: September 9, 2018
Early-bird Registration ends: September 29, 2018
Visa Request Deadline: October 26, 2018
Regular Registration ends: October 31, 2018

All experience levels welcome!

Wetlabs and hands-on workshops on Day 1

www.cxlexpertsmeeting.com

The world's largest Cross-Linking congress

The CXL Experts' Meeting is an independent educational forum dedicated to bringing together corneal cross-linking key opinion leaders with newcomers, industry, and students for a lively full 3-day program.

Thursday, November 29

Wetlabs and Workshops:

Light for Sight wetlab, "CXL for Beginners".
The PACK-CXL workshop: treating infectious and non-infectious melting in both humans and animals.
Oculus Workshop, "Screening for early ectatic disease and keratoconus progression".
SCHWIND eye-tech solutions: "Corneal wavefront-guided treatments and CXL using the AMARIS".
The Light for Sight workshop: Identifying, accessing and managing high-risk patients with keratoconus.

Friday, November 30

Wetlabs and Workshops:

Comprehensive and practical CXL applications.

Saturday, December 1

The latest clinical and basic research findings related to diagnostics: High-speed dynamic Scheimpflug imaging, Brillouin microscopy.
Latest CXL protocols: customized, epi-on, iontophoresis, etc.
CXL for ectasia, CXL Plus (combination with refractive surgery).
PACK-CXL for infectious keratitis.
New CXL technologies.

Scientific committee

Farhad Hafezi, Theo Seiler, Paolo Vinciguerra, J. Bradley Randleman, Rohit Shetty

Faculty

Renato Ambrósio Jr, Adel Barbara, Michael Belin, Shihao Chen, Efehan Coskunseven, Mouhcine El Bakkali, Frank Famose, Osama Ibrahim, Sabine Kling, Carina Koppen, John Marshall, Cosimo Mazzotta, Jesper Mortensen, David O'Brart, Simon Pot, Frederik Raiskup, Mohamed Shafik, Mazen Sinjab, Emilio Torres, Ricardo Vinciguerra



2018 CXL EXPERTS' MEETING DELEGATION

KOLS SPEAK ON BEHALF OF LIGHT FOR SIGHT

Eye Care Professional Training: Light for Sight Wet Lab & Workshop (November 29, 2018)

As a continuation of the 2017 pre-congress courses, the Light for Sight Foundation organized two practical courses on Thursday, November 29, 2018.

The morning wetlab was dedicated to ophthalmologists who would like to learn the basics of CXL treatment in a commercial-free environment.

The following workshop was open for any participant interested in identifying high risk groups for keratoconus through certain risk factors. The wetlab and workshops were completely booked (at 100% capacity) and will be repeated in 2019.



Workshops & Wetlabs Thursday, November 29

Light for Sight WetLab "CXL for Beginners"

8.00 am to 10.00 am - **SOLD OUT**

Room: Zurich I

This wetlab will give concise recommendations and guidelines to treat corneal ectasia of various origins. Hands-on course using CXL irradiation devices and porcine corneas. Specifically, accelerated and transepithelial protocols will be discussed including the use of iontophoresis.



Frederik Raiskup
University Eye Clinic,
Dresden, Germany



Farhad Hafezi
ELZA Institute, Zürich

Light for Sight Workshop: "Identifying, accessing and managing high risk patients with keratoconus"

2.00 pm to 3.30 pm **SOLD OUT**

Room: Zurich II

This workshop will focus on patients with reduced to missing compliance and how to detect and treat progressive keratoconus in these cases, i.e. in patients with Down Syndrome. Concise recommendations for diagnosis and treatment will be given.



J. Bradley Randleman



Emilio Torres



Farhad Hafezi



Nikki Hafezi

EYE CARE PROFESSIONAL TRAINING ELZA EDUCATIONAL COURSES (EEC)

EDUCATING THE WIDER HEALTHCARE COMMUNITY

One of the founders and clinical ambassador, Prof. Farhad Hafezi, launched a pilot project in 2016 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 of 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 eyecare 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.

While these courses continued in 2018, the difference was that one course was conducted in the French language in Biel, Switzerland. This test course resulted in the highest attended course since 2016. In the Swiss German region, there were between 5–10 participants. However, in Biel, 38 participants registered to attend.

The reasons for the success were:

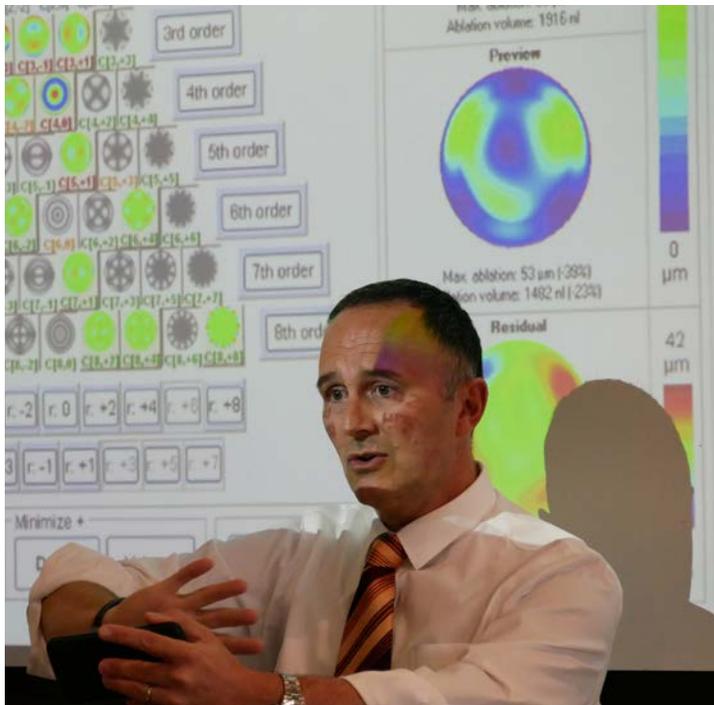
- Providing the presentation and material in the French language
- Coordinating with an existing optometrist who refers patients with keratoconus
- Collaborating with the local optometrist societies for marketing purposes
- Providing national continuing educational credit points
- Making the course to be free of charge
- Hosting on Monday evening, which is typically the free day for optometrists
- Providing food to encourage interaction and discussion after the course

Therefore, in 2019, the educational courses will continue in both German and French. The best practice models learned with the 2018 French course will be repeated with hopefully the same results.



“

One important factor is that the optometrists have their patients 'returned' to them. These seminars are not about poaching patients – they are purely educational, and the attendees appreciate that.



EYE CARE PROFESSIONAL TRAINING: **CONGRESS CIRCUIT**

PRESENTING OUR WORK TO OUR PEERS

Since the Light for Sight Foundation is an international organization, it is essential to educate and train on an international platform. Therefore, all Light for Sight partners and ambassadors are encouraged to present topics related to best practice models for keratoconus detection, treatment and management.

To highlight a few presentations conducted in 2018 that were dedicated to the mission of the Light for Sight Foundation:

MAY 8, 2018

Kaiser Permanente Healthcare System (West Coast, USA)

Webinar, host Dr. Michael Waxman

“Corneal Cross-Linking”

Audience: 40 ophthalmologists

JUNE 16, 2018

World Ophthalmology Congress (Barcelona, Spain)

Lecture (Dr. Emilio Torres)

“Assessment of Keratoconus Prevalence in a Pediatric Population in Saudi Arabia”

Audience: 50 ophthalmologists

Lecture (Prof. Farhad Hafezi)

“Prevalence, Detection and Treatment of Keratoconus in Children and Adolescents”

Audience: 150 ophthalmologists

SEPTEMBER 21, 2018

Keratoconus Experts' Meeting (Vienna, Austria)

Lecture (Prof. Farhad Hafezi)

“Diagnosing, treating and managing low compliant pediatric keratoconus patients”

Audience: 80 key-opinion leaders

NOVEMBER 2, 2019

Association Tunisienne de Microchirurgie Oculaire (Sousse, Tunisia)

Lectures (Prof. Farhad Hafezi)

“Cross-Linking dernières avancées en 2018”

Audience: 120 ophthalmologists





INTERNATIONAL COUNCIL of OPHTHALMOLOGY
WOC 2018
 WORLD OPHTHALMOLOGY CONGRESS® | BARCELONA | 16-19 JUNE

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95 MM Covered Lives

17 Dec-17

hmsa



10TH EXPERT MEETING
SURGICAL MANAGEMENT OF KERATOCONUS PATIENTS

VIENNA

FRIDAY 21/09/2018
 5.00-8.30 PM
 REED MESSE - VIENNA
 LEHAR 5

10 RECOMMENDATIONS OF EXPERTS
 IN THE SURGICAL MANAGEMENT
 OF KERATOCONUS FOR
 LESS EXPERIENCED SURGEONS

COVERAGE OF THE EVENT
 THE INTERNATIONAL JOURNAL
 OF KERATOCONUS AND
 ECTATIC CORNEAL DYSPLASIAS

A. ALFONSO SANCHEZ SPAIN	A. CUMINGIOS MEXICO	G. VITAMONIS LITHUANIA	J. TEN SINGAPORE
I. ALLO INDIA	B. EL DINNASOURY SAUDI ARABIA	D. LIN INDONESIA	E. TORRES USA
R. AMBROSIO ITALY	F. HAFEZ SAUDI ARABIA	F. MALLÉGAZE FRANCE	D. TOUBOUL FRANCE
M.C. ARRIELAEZ MEXICO	S. HANNUSH USA	B. MALYUGIN RUSSIA	A. VEGA SPAIN
M. ASSOLINE FRANCE	S. HOLLAND CHINA	C. ROBERTS USA	P. VINCIGUERRA ITALY
M. BALDIS ITALY	O. IBRAHIM EGYPT	T. SELLER SPAIN	L.C. VINGICHEM SINGAPORE
A. BARBARA CANADA	A. VANELLOPOULOS GREECE	M. SHAFIQ SHAHEEN INDIA	M. YOSHINA NUNEZ COLOMBIA
M. BELIN USA	C. KOPPEN USA	M. SRINIVAS INDIA	
E. COSIUNSEVEN TURKEY	B. KRUEGER USA	D. STULTING USA	



ACCESS TO TREATMENT PINCO (PROCESS TO INCREASE COMPLIANCE IN OPHTHALMOLOGY)

FAIR CARE FOR ALL

The Light for Sight Foundation launched a new clinical model initiative intended to increase compliance levels of high-risk patients during routine eye examinations to better identify and diagnose diseases like keratoconus.

To commemorate World Down Syndrome Day on March 21, 2018, the Light for Sight Foundation dedicated this initiative to all Down Syndrome individuals with keratoconus who have been misdiagnosed thanks to the examiner believing that he or she could not obtain accurate readings thanks to low compliance levels.

The literature states that Down Syndrome children and adolescents have a significantly higher risk of having keratoconus than the general population. A Down Syndrome individual also has a higher risk of having attention disorders leading to being socially withdrawn and/or non-compliant. Coupling these two tendencies, special care and thorough examinations are required for this population group.

In clinical partnership with the ELZA Institute (Dietikon), the Light for Sight Foundation is testing a model to help improve compliance among low- to non-compliant patients during eye examinations.

This model, which is currently called “PINCO” (Process to Improve Compliancy in Ophthalmology), was developed with a Swiss certified applied behavioral analyst (BCBA). This specialist works specifically with patients diagnosed with autistic spectrum disorder (ASD). Patients with ASD tend to be low to non-compliant and need specialized care. By utilizing positive reinforcement and detecting unwanted behavioral patterns, the model may increase compliancy, which leads to a more comprehensive and thorough examination.

The Light for Sight Foundation is dedicated to working internationally and aims to provide all its clinical partner sites with the final model. However, as the immediate next step, 12 clinical partner sites representing 8 countries have been selected to spearhead the initiative as the next phase of the implementation process. At the annual CXL Experts’ Meeting held in Zurich in December 2018, the Light for Sight Foundation provided training for these Light for Sight clinical partners and staff to help them implement this model at their clinical sites.



It's important to serve the needs of every patient that walks into the clinic to the best of your ability. Non-compliant patients might fail to receive the screening (and therefore the treatment) they need and deserve.

RESEARCH ACTIVITIES

2018 RESEARCH UPDATE



Improved awareness plus access to diagnostic instrumentation (and training) to screen for the disease combined with effective 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 challenging. 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.

University of Antwerp: PhD students (update)

In December 2018, Light for Sight Foundation's first PhD student, Wafa Majed Alotaibi, received her doctoral degree after successfully defending her thesis, entitled "Prevalence of keratoconus among children and adolescents in Saudi Arabia" and was provided by Salus University (USA) and King Saud University (Saudi Arabia). The result from the collective research was that the keratoconus prevalence among the select patient group was 1:21 patients or rather 4.79% (95% CI 2.96 to 6.62). The manuscript in the British Journal of Ophthalmology on January 3, 2018.

Dr. Alotaibi is the first PhD student supported in-kind by the Light for Sight Foundation. The decision to support this PhD student was based on the following criteria:

- The thesis topic fits within the mission and goals of the foundation
- Potential to pursue unique research topics
- The doctoral work is not dependent on the foundation for completion.

Accordingly, the second PhD student supported was selected

in 2018 (thanks to her history and experience in the field of keratoconus and CXL technology) is Mrs. Nikki Hafezi, who was accepted into the department of medical sciences at the University of Antwerp in Belgium. Her thesis will be dedicated to understanding different modulating factors related to keratoconus, with a special focus on the role of oxygen. Since many keratoconus patients are children, pain and infection are risks that need to be addressed. Therefore, having a better understanding of oxygen's role in the cornea may lead to improving clinical applications (e.g. "epi-on" CXL).



The third PhD student is currently planned to commence studies in 2019.

RESEARCH

K-MAP

K-MAP UPDATE

K-MAP: Global Prevalence Study of Keratoconus

In 2018, the K-MAP global study was initiated, and throughout the year, clinical sites were identified. The principal investigator of the study is Prof. Farhad Hafezi (Switzerland).

The hypothesis of the study 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 per site to achieve statistical significance would be 2,995 if the assumed prevalence of the disease is 1:500.

There are five criteria established in order for a site to participate:

- Ethical committee approval (to conduct a clinical study)
- Possession of a Pentacam (to conduct diagnostic measurements)
- An on-site anterior segment specialist
- Signed consent forms from patients
- Signed publication policy related to data and study protocol.

Based on these criteria, six sites have been achieved all requirements. These sites represent the following countries:



5 continents, 11 countries
Goal: > 20,000 eyes

- North America: USA & Mexico
- South America: Peru
- Eurasia: Russia
- Africa: Egypt
- Middle East: United Arab Emirates.

Currently, sites in Australia and South Africa are undergoing the IRB approval process. Ideally, at least one country in Far-East Asia would be greatly add to the impact of the study.

The Russian clinical site will complete their data collection by summer 2019. Preliminary results will follow and may lead to interest from other desired sites from across the globe.

Prevalence of keratoconus in paediatric patients in Riyadh, Saudi Arabia

Emilio Almeida Torres Netto,^{1,2,3,4} Wafa Majed Al-Otaibi,^{5,6} Nikki L. Hafezi,^{2,3} Sabine Kling,^{1,2,3} Haya M Al-Farhan,³ J Bradley Randleman,^{7,8} Farhad Hafezi^{1,2,3,8,9}

Torres Netto EA, Al-Otaibi WM, Hafezi NL, Kling S, Al-Farhan HM, Randleman JB, Hafezi F

Prevalence of keratoconus in paediatric patients in Riyadh, Saudi Arabia.

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ABSTRACT
Background/Aim Keratoconus (KC) is an ectatic corneal disorder with marked progression during childhood and puberty that may lead to severe visual loss. In addition to KC prevalence, estimate shows major geographical variations; recent studies using Scheimpflug technology are in contrast to the 1980s and 1990s literature. The present study aims to determine the prevalence of KC in paediatric patients in Riyadh, Saudi Arabia (KSA).
Methods This prospective, cross-sectional, observational, multicentre study collected data from paediatric patients from 6 years and 21 years of age who were seen at multiple non-ophthalmic emergency departments within KSA. Bilateral corneal measurements were performed using a rotational Scheimpflug corneal tomography system. Two masked examiners established the diagnosis of KC using both objective and subjective screening criteria. Cohen's kappa coefficient (κ) was used to qualitatively analyse the interexaminer agreement.
Results There were 522 patients (1044 eyes) evaluated, with an average age of 16.8±4.2 years (range 6–21 years). KC prevalence was 5.56% for examiner 1 and 3.83% for examiner 2. The κ was 0.81 (almost perfect agreement), with discrepancy in nine cases, which were jointly evaluated and consensus obtained. Final KC prevalence was 4.79% (95% CI 2.96 to 6.62) or 1.21 patients.
Conclusions The prevalence of KC among paediatric patients in the KSA is considerably higher than numbers reported from earlier studies and from similar studies in other countries. This increase might be due to geographical variations in disease prevalence or due to the ability of screening technology to detect undiagnosed KC with greater accuracy.

found a prevalence of 54.5 per 100,000 individuals (0.05%) in a population of the USA. Although performed with limited examination techniques (irregular light reflexes or irregular keratometry mires) that would only identify advanced disease, this study still remains one of the most cited studies. More recently, a number of studies have found a higher prevalence and incidence of KC, especially in the Middle East^{1–10} and Asia^{11–13} (range 0.76%–3.10%), probably also due to the increased ability to diagnose KC with the improvement of modern corneal imaging.
Determining true KC is critical for several reasons. Public health programmes, campaigns for screening and predicting treatment costs are usually based on the prevalence of a disease in a given population. Moreover, early diagnosis brings the possibility of providing optimal treatment by reducing progression to more advanced stages of vision loss. Procedures such as corneal cross-linking are performed worldwide and have already reduced progressive visual loss and the need for corneal transplantation based on early population-based data.¹⁴ Therefore, early diagnosis of KC would allow a better understanding of the population, but more importantly, it could allow appropriate treatment in time for visual acuity not to be greatly impaired.¹⁵
The purpose of this study was to evaluate the prevalence of KC identified using Scheimpflug imaging in a paediatric population in Riyadh, Saudi Arabia (KSA).

MATERIALS AND METHODS
This prospective, cross-sectional, observational, multicentre study collected data from subjects between 6 and 21 years of age who were seen at emergency rooms for non-ophthalmic appointments at four different locations in the KSA. After individual confirmation of ancestry through a brief question, only patients of Saudi descent were included. All patients with pre-existing ocular disease other than corneal ectasia or history of ocular surgery were excluded. While not excluded, no patients had a known diagnosis of KC or any related ectatic corneal disorder at the time of their evaluation in this study. For the purposes of this study, we did not attempt to differentiate between KC and other related corneal ectatic disorders such as pellucid marginal degeneration.

All subjects had bilateral corneal evaluations performed using a rotational Scheimpflug system (Pentacam HR, Oculus, Wetzlar, Germany) by the same well-trained individual (WMA). The

INTRODUCTION
Keratoconus (KC) is a progressive ectatic corneal disorder characterised by corneal thinning, irregular astigmatism and protrusion of the cornea that may lead to severe visual loss. Both eyes are usually affected, frequently in an asymmetric manner.^{1,2} Epidemiological studies show that KC affects both sexes and that the disease is more severe in younger patients with marked progression during puberty.^{1,4} KC prevalence estimates show major geographical variations.⁵ It is still unclear to what extent these variations are due to differences in genetic, environmental or geographic factors. Moreover, different diagnostic tools and age groups used in the various studies probably contribute to this variation. In a study conducted over 45 years, Kennedy *et al*⁶



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