From the Other Side of the Slit Lamp

Keratoconus patients share their experiences in the chair and in life.

By Virginia Pickles, Contributing Editor

If there is a place in the eye care world where making a living and making a difference intersect, contact lens practitioners who manage keratoconus patients may have found it. Boston Update interviewed three patients to find out how their contact lenses—and the people who fit them—improve their lives every day.

Professor by day

Elio Spinello, MPH, EdD: businessman, university professor, bad guy? It’s true. The 50-year-old Valencia, Calif., man owns RPM Consulting LLC, teaches in the Department of Health Sciences at California State University in Northridge, and some evenings and weekends, he plays a “bad guy” for the LA County Sheriff’s Department, one of numerous activities he might have had to abandon if not for GP contact lenses.

Diagnosed with keratoconus in 1999, Elio wore eyeglasses for several years, but as his disease progressed and his prescription became more complicated, the eyeglasses were not working well for him.

He gradually started curtailing his night-time driving until he either didn’t go out at night or he had to ask someone to drive.

“The streaking of headlights from oncoming traffic was so bad, I couldn’t see what was in front of me,” he says. What’s more, his declining vision was interfering with his volunteer work.

“I sometimes participate in training exercises with the Sheriff’s Department,” he explains. “Occasionally, I have to pretend to be a bad guy and get arrested or handcuffed or pulled over. It got to the point where I couldn’t see well enough to react or respond appropriately. I was spending more time squinting and trying to figure out what I was looking at, especially at night. I really couldn’t see well enough to be a good bad guy.”

Considering Elio’s increasing limitations, his ophthalmologist decided it was time to try contact lenses and referred him to an optometrist with experience fitting keratoconus patients. Until recently, when he entered a study of a new lens design, Elio wore keratoconus design GP lenses for 12 to 14 hours a day and achieved BCVA of almost 20/20.

“The transition to contact lenses made a huge difference for nighttime activities,” he says. “For daytime, the biggest difference is that my acuity is much more consistent across my entire field of vision, whereas, with glasses there was a sweet spot, and anything outside of that area was a blur. I have much more consistent, natural vision. The improvement is breathtaking.”

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Elio has nothing but praise for his primary eyecare provider, who diagnosed his keratoconus early and made sure his expectations were realistic.

“He diagnosed the disease well before I was having serious vision problems,” Elio says. “Every time I’d see him, he was very reassuring. By the time he referred me for contacts, I pretty much knew where I was at, what I needed to do next, and what was going to happen next.

“The optometrist who fit me with the keratoconus design GP lenses also was very good. She said, ‘You’re going to be back and forth here for the next 2 to 3 months while we dial in the design.’ In about 6 weeks, she had my prescription close to what it is now. She knew exactly what she was doing and had her plan A, plan B and plan C all set up.”

Teen ambitions

Eighteen-year-old Jensine Eckwall from Sandy Hook, Conn., has ambitious plans. This fall, she will attend the School of Visual Arts in New York City, where she will major in illustration, which should open the door to a career as an art director or illustrator.

Six years ago, Jensine hit a speed bump on the road to college and a career when she was diagnosed with keratoconus. What slowed her down was not so much the disease as an early—and incorrect—assessment that her disease was so advanced that she would not be able to comfortably wear contact lenses or derive any visual benefit from them.

“The doctor said that if Jensine were an adult, we would be talking about a transplant,” recalls Jensine’s mother Randy Eckwall. “This was before anyone had even tried to fit her with a lens. This was traumatic news for a parent to hear.”

Even after her online research, Randy was discouraged. “I paid very little attention to my keratoconus,” she says. “I had a young child and just went on with life as usual. It didn’t happen to me. I was not fully aware of what was happening.”

“I consider Jensine’s contact lens fitter a miracle-worker,” Randy says. “Jensine graduated in the top 2% of her class and has received several scholarships to college. This is a different outcome than I imagined five years ago when I was told she would never be able to wear lenses. Getting well-fitted lenses has changed my daughter’s life in many ways, and I am very thankful that there continue to be people who want to treat patients who have keratoconus.”

A life uninterrupted

Carolyn Hammett’s resume reflects the wide range of her interests: art historian, musician, world traveler and amateur photographer, to name a few. Carolyn, who lives in Tyler, Texas, was 27 years old, married and the mother of an 18-month-old daughter when she was diagnosed with keratoconus in 1963, but she was much too busy to fret over the news.

“I paid very little attention to my keratoconus,” she says. “I had a young child and just went on with life as usual. It didn’t occur to me that there was anything unusual about my vision except that I had to wear contacts.”

Early on, Carolyn wore PMMA contact lenses for up to 14 hours a day. As her disease progressed, however, her wearing time decreased until, in the 1990s, she could wear her lenses just 2 hours a day or risk an abrasion. At that time, she was an art
history instructor and slide curator for the art department at the University of Texas. She had to “save” her lens-wearing time for classroom lectures. Fortunately, technology caught up with her advancing disease and her contact lens practitioner fitted her with a then-new keratoconus design GP lens. The lenses worked well for her until about 3 years ago, when she started wearing a piggyback lens configuration on her more advanced eye.

Carolyn’s BCVA is 20/30. She wears a toric GP lens on her “good” left eye for 8 to 9 hours a day and a keratoconus design GP lens over a daily disposable lens on her right eye for 4 to 6 hours a day. She wears bifocal spectacles over her lenses.

Now retired from her teaching position, Carolyn and her husband, a retired pathologist, travel extensively. She has had to remove, clean and reapply her lenses in such challenging and diverse locales as a shepherd’s hut at the top of Nimrud Dagh in Eastern Turkey and “just about every museum and church in Italy.”

Carolyn is an eyecare practitioner’s dream. At age 72 and with advanced disease, she is compliant with her contact lens care and wearing schedule, realistic about her “critical seeing time” and enthusiastic about living life to its fullest. Her life as a keratoconus patient, however, has not been without its trials.

“Piggybacking is a pain,” she says. “I’ve never been adept at applying a soft lens, whereas I can apply or remove a GP lens in the middle of the desert in a sandstorm at midnight. There have been times when I thought I was out of options, but each time, new innovations in lens materials or designs have saved the day. I tell some of the young, scared keratoconus patients on the National Keratoconus Foundation online forum that technology is on our side.”

Despite setbacks—for one 6-month period, she had to see “one-eyed” while her practitioner worked on a new lens configuration—Carolyn’s positive attitude prevails. “I have not let keratoconus stop me from anything other than reading music. I have been able to teach at the university level, and my husband and I travel extensively. You can either have patience or pity parties. Most of us probably have both, but when I have a pity party, I think of a young friend in the latter stages of retinitis pigmentosa, and I’m grateful for the vision I have.”

What patients want you to know

For practitioners considering adding keratoconus management to their practices, Elio Spinello has this advice: Study the physiology, the etiology and the epidemiology, and stay current with the constantly changing treatment options and technologies. Accept that fitting lenses is a potentially time-consuming process, and be honest but positive with patients. Do not just put your toe in the water. Jump right in and see as many patients as you can to gain the needed hands-on experience, and try to work with other practitioners who have keratoconus experience.

“If there are doctors out there who feel confident with their skills, I would not want to discourage them from seeing keratoconus patients,” he says. “It’s not going to suck up every last minute of your time, but it is going to require some time investment and a little more work. On the other hand, I think treating keratoconus could be one of the most rewarding things an eyecare practitioner can do.”

NKCF Offers Support for Your Patients

You can obtain reliable information on research and treatment, as well as sensitive yet realistic support for your keratoconus patients at every stage of their disease from the National Keratoconus Foundation in Los Angeles. The NKCF is an outreach program of the Discovery Eye Foundation, a non-profit organization. Resources include:

◊ NKCF newsletter—information about research, new treatment options, new lenses and lens care products, published three times a year.
◊ NKCF Web site—provides information and support, including an online forum for patients to communicate with other patients and eyecare practitioners.

The organization also offers a “transplant buddy” program, seminars and other programs for patients and clinicians. Visit http://www.nkcf.org or call (800) 521-2524.
Keratoconus Fitting Principles

Patients with keratoconus present many challenges to contact lens practitioners worldwide. In Germany, Hecht Contactlinsen GmbH has had a great deal of experience designing and fitting contact lenses for these patients. Here are some of their insights and strategies.

By Frank Widmer and Dieter Muckenhirn

In newly diagnosed keratoconus, it is important to first evaluate a patient’s visual performance with a spectacle refraction. Contact lenses should be prescribed only when they are necessary to improve visual performance and acuity. The former belief in the therapeutic value of fitting flat rigid lenses in early stage keratoconus has been disproved, and in fact, the friction of a contact lens on a keratoconic cornea may cause disease progression not regression.

Early stage

In early stage keratoconus, we use the “3-point touch fluorescein pattern technique,” whereby the rotationally symmetric contact lens rests mainly on the midperipheral area of the cornea, with minimal touch at the apex (Figure 1). A thin tear film layer must cover the apex and flow over it while the lens moves with each blink. The typical fluorescein pattern shows edge lift of about 0.5mm to 0.7mm.

We also use this fitting technique in patients with highly astigmatic keratoconus corneas by using designs that employ toric surfaces (Figure 2). We have found this technique provides the best visual acuity while maintaining corneal integrity.

We try to maintain a 3-point touch fitting relationship as the keratoconus progresses. We have found this can be best achieved with flexible back-surface designs. However, in advanced keratoconus, this can be difficult.

Progression

Regular follow-up with keratoconus patients is essential to maintain corneal health. As the disease progresses, contact lenses may become too flat in relation to the apex. If these changes are not detected early enough, scars and cell damage may result in subepithelial hyperplasia (Figure 3). In these cases and in cases of grade 4 keratoconus with steep corneas, we need to fit lenses with apical clearance to preserve corneal integrity.

As shown in studies by Zadnik and colleagues in the Collaborative Longitudinal Evaluation of Keratoconus (CLEK) study, the steeper contact lenses are fit, the more they degrade visual acuity and corneal integrity. As a result of these findings in the past several years, we have developed a lens design (Figures 4 and 5) that allows us to increase the sagittal height of the lens, providing better tear volume over the apex to reduce pressure while retaining visual performance. We believe altering the fitting relationship in keratoconus by adjusting the sag height achieves the best fit in these steep, irregular corneas.

Corneal topography

Over the years, videokeratography has become an important tool for fitting contact lenses, especially for irregular corneas (Figure 6). Not only is it valuable for providing information about the contour of the corneal surface, but together with slit lamp observation, it gives practitioners a better understanding of the upcoming challenges when starting to fit these cases. It is also an important tool for creating individual lenses.

In Germany, we use these topographical measurements combined with contact lens design software to calculate toric keratoconus lenses, custom-made aspheric lenses or quadrant-specific lenses. An advantage of this method is that we can simulate the fluorescein pattern and, therefore, the fitting relationship. However, in advanced irregular corneas, it can be difficult to get a reliable topographical measurement. To evaluate the quality of the actual measurement, it is best to apply a rotationally symmetric lens based on the first lens suggested by the topography and compare the simulated and the actual fluorescein pattern. Figures 7 and 8 show a comparison of the computer-simulated fluorescein pattern based on the topography (Figure 6) with the actual on-eye fit, demonstrating how accurate today’s simulation software is. This step is important to decide if the topography of the eye can be used for designing an individual lens with the contact lens design software. This is a great help when special lenses, such as quadrant-specific lenses will be the lens of choice. One can even simulate moving the lens to different positions on the cornea to visualize how the lens will fit when slightly off-center.

First choice

For keratoconus, we mainly use spherical or toric four-curve designs. These are available in two standard versions, and they also can be designed by the fitter. In advanced cases, we use what is termed quadrant-specific designs, using different curves on the back surface to match up with the topography in each of four corneal areas. Most of the quadrant-specific lenses are used for keratoplasty patients or for patients with advanced keratoconus or pellucid marginal degeneration (PMD). The design is based on the corneal topography of the individual patient and is usually aspheric or a four-curved back surface. See Figures 6–10 of the same eye.

We are also using more large-diameter lenses, which we call “mini-scleral lenses.” These are typically between 12.5mm...
and 15.5mm in diameter. We choose these lenses when a corneal contact lens cannot be fitted properly, for example, in cases of advanced keratoconus or PMD, or in cases where the lens should show some tear pooling but not much movement due to advanced epithelial dystrophy. We also fit mini-scleral lenses in the cases mentioned above when the patient has symptoms of extensive foreign body awareness when wearing corneal lenses.

**Patient-centric care**

The most important advice we can offer to practitioners is to be vigilant with after-care on a regular basis. Recognizing when it is time to change lens geometry is important to avoid a breakdown of the epithelial tissue, resulting from too much pressure on the apex.

Another important consideration, especially in advanced keratoconus, is that patients are eager to achieve the best vision. This is understandable because these patients know what good vision is. Therefore, we must continue to look for lens designs that will provide the best vision while taking care of the fragile cornea.

Mr. Widmer is involved in the development and introduction of new contact lens products and fitting techniques for Hecht Contactlinsen GmbH. He has written articles and lectured on these topics internationally. He practices at Contactlens-Institute in Hamburg, Germany, the Eyehospital in Basel, Switzerland, and the Contactlens-Institute in Freiburg, Germany.

Mr. Muckenhirn is cofounder of Hecht Contactlinsen GmbH. He has a special interest in topographic measurements of the cornea, and he developed the first aspheric contact lens based on topographic data. He continues to develop new contact lens designs and fitting techniques and writes and lectures on these topics internationally.

**Did you know...**

- It is estimated that keratoconus occurs in 1 out of every 2,000 people in the general population.
- It is believed that genetics, the environment and the endocrine system all play a role in keratoconus.
- Symptoms of keratoconus generally begin in the late teens or the early twenties but can start at any time.
- Keratoconus has no known significant geographic, cultural or social pattern.


**CLMA Honors David Bland**

David Bland, Bausch & Lomb Director of North American Sales, received the Contact Lens Manufacturers Association Industry Enhancement Award for unselfish dedication to the CLMA and the contact lens industry from Janice Schramm of Valley Contax, Springfield, Ore.
Scientists and clinicians have been studying keratoconus for more than 150 years, but only in the last 50 years has our knowledge grown substantially, mostly because of clinical and laboratory research made possible by new technology. In the past year, more than 100 papers have been published in peer-reviewed journals, and countless other articles have appeared in professional publications. A brief synopsis of some of these articles follows.

**General Topics**


  In his Gregg lecture, McGhee provides a highly referenced, wide-ranging overview of historical and contemporary aspects of keratoconus, including:
  - Diagnostic, phenotypic and prognostic factors revealed by large clinical studies
  - Critical diagnostic advances enabled by Placido and slit-scanning computerized corneal topography
  - The emerging roles of higher-order aberration wavefront analysis and corneal hysteresis in delineating early and subclinical keratoconus
  - Inheritance and genetic predisposition to keratoconus
  - Corneal microstructural changes revealed by in vivo confocal microscopy
  - Unifying theories to explain associations between keratoconus, atopy, eye rubbing and keratocyte apoptosis
  - Surgical options for keratoconus, such as corneal transplantation, intrastromal ring segments, collagen cross-linking and keratocyte transplantation.

  McGhee concludes that after 150 years, “Our knowledge of keratoconus remains incomplete, but technological advances should enable us to put together the final pieces of the jigsaw in the foreseeable future.”

- **Keratoconus with high hyperopia.** *Eye Contact Lens.* 2009;35:159–162.

  Although rare, keratoconus may occur in cases of high hyperopia. Management of hyperopic keratoconus with GP contact lenses may be similar to that applied with other cases of keratoconus as illustrated in this case.

  Martin examined a 32-year-old man with severe hyperopia and a 10-year history of daily hydrogel contact lens wear to confirm suspected keratoconus. The patient’s Orbscan topography was consistent with bilateral asymmetric keratoconus, showing asymmetry of central dioptic power, irregular astigmatism, high anterior and posterior corneal elevation values, and corneal thickness in the cones at 450 and 471 microns OD and OS, respectively. Slit lamp biomicroscopy showed Vogt striae OD. The patient was fitted with high-Dk GP contact lenses in a keratoconus design.

**Corneal Surface Analysis**


  Koller and colleagues recruited 21 patients with progressive keratectasia. One eye per patient was treated with collagen cross-linking (CXL) using the riboflavin/UV-A approach, while the fellow eye remained untreated and served as control. In the 1 year following treatment, researchers reported the following:
  - None of the treated eyes showed topographic progression in contrast to the control group, in which 8 eyes experienced significant progression.
  - Minimal curvature radius increased significantly after 1 year, compared with preoperative measurements; whereas in the untreated fellow eye, it decreased significantly.
  - Minimal corneal thickness was significantly reduced after treatment ($P<0.002$ at 12 months).
  - Corneas showed an evolution toward a more regular shape as indicated by a significant reduction in 4 of 7 keratoconus indices.
  - No complications of CXL occurred in this small study group.

  Researchers concluded that after cross-linking, the corneal shape undergoes a process of regularization, which is active during the first year after treatment and may continue. Longer follow-up is warranted to estimate the full amount of regression of the keratectasia after CXL.

- **Comparison of anterior chamber depth of normal and keratoconus eyes using Scheimpflug photography.** *Eye Contact Lens.* 2009;35:120–122.

  Edmonds and colleagues used Scheimpflug photography to measure the corneal anterior chamber depth (ACD), adjusted by age and sex, of 162 normal and 41 keratoconus patients.

  Univariate analysis showed the mean ACD of 162 normal subjects was borderline significantly less than in 41 keratoconus patients ($3.28 +/- 0.40$ mm; $P=0.079$). However, researchers found that sex ($P=0.001$) and age ($P<0.001$) are significantly related to ACD in all patients. Women with normal eyes had a significantly lower mean ACD than men. Women's eyes with
keratoconus also had a lower mean ACD than men’s eyes with keratoconus. Bivariate regression showed that with each additional year of aging, the ACD was decreased by an average of 0.012 mm in a normal eye and by 0.014 mm in a keratoconus eye. Regression analysis showed that sex \( (P = 0.003) \), age \( (P < 0.001) \) and keratoconus \( (P = 0.003) \) are all significant variables for determining ACD. After adjusting for age and sex, keratoconus eyes had a significantly higher mean ACD (3.34 +/- 0.34 mm) than normal eyes (3.18 +/- 0.28 mm) \( (P = 0.003) \).

Contact Lenses for Keratoconus


A total of 71 patients who wore GP, hybrid or soft toric contact lenses in at least 1 eye completed the Contact Lens Impact on Quality of Life (CLIQ) questionnaire. One eye of each patient was included in the study. Of these, 40 eyes used GP lenses, 20 eyes used hybrid lenses, and 11 eyes used soft toric lenses. In this study, Erdurmus and colleagues found no significant difference among the three groups in self-reported results from the CLIQ questionnaire \( (P = 0.8) \). Regardless of modality, patients reported similar contact lens impact on their quality of life.


Jacobs discusses the use of scleral GP lenses for the visual rehabilitation of ectasia and irregular astigmatism and as a therapeutic option for ocular surface disease. He cites individual cases and case series, as well as a comprehensive article reviewing the history and principles behind current scleral GP lenses, with particular attention to their use in managing ocular surface disorders. Jacobs concludes that clinicians who treat patients with ocular surface disease should consider scleral GP lenses as a therapeutic option for their patients, noting that advances in lens design make these lenses a practical option for an increasing number and variety of patients with corneal disease.


In this retrospective case series, Schornack and colleagues evaluated 5 consecutive patients with severe keratoconjunctivitis sicca (KCS) associated with chronic graft versus host disease. These patients, who could not be managed adequately with conventional therapy, were successfully fitted with Jupiter scleral contact lenses (Mediens Innovations, Front Royal, Va., or Essilor Contact Lens Inc., Dallas, Texas). The researchers evaluated 3 outcome measures: the patient’s ability to tolerate and successfully handle the lenses, improvement in symptoms of KCS and improvement in visual acuity. All patients reported subjective improvements in comfort; and best-corrected vision improved in 7 of the 10 eyes.

Using Large-Diameter GPs to Improve Comfort: These four cases demonstrate that larger diameters offer many benefits when fitting GP lenses.

In this article, published in the May 2009 issue of *Contact Lens Spectrum*, John Laurent, OD, PhD, notes that despite the improved physiology of today’s GP lenses, “patient discomfort with these lenses is essentially the same as it was with PMMA lenses,” primarily because of the sensation patients experience when their eyelids touch the edges of the lenses. Laurent presents cases of keratoconus patients whose chief complaint was discomfort. He describes his fitting process and the positive outcomes he achieved using large-diameter GP lenses.

Laurent notes: “The semi-scleral lenses I fit on these patients were more comfortable than their previous corneal lenses because of the reduced interaction between the eyelid and the contact lens. The comfort of a large-diameter GP lens that fits under the eyelid can approach the comfort achieved with soft lenses.”

Refitting Keratoconus Patients: Explaining The Missing Dioptr

In this article, published in the May 2009 issue of *Contact Lens Spectrum*, Bezalel Schendowich, OD, FIACLE, discusses shape changes, sometimes induced by contact lens wear, in the keratoconic cornea. Citing a 2002 publication by Mountford and Noack in which they report an unexpected diopter overrefraction after the first week of contact lens wear in approximately 15% of cases, Schendowich offers an explanation for this phenomenon and describes how he refits his keratoconus patients with this in mind. Schendowich describes common refitting scenarios and offers practical advice on fitting and patient management.

Contact Lens Options for Managing Keratoconus: By knowing your options you can meet the goals of a successful contact lens fit and patient satisfaction.

In this article, published in the April 2009 issue of *Contact Lens Spectrum*, Nicky Lai, OD, MS, FAAO, reviews the basic principles for diagnosing keratoconus and discusses current contact lens options—soft, GP, hybrid and piggyback—for these patients. He includes a table of lens options and fitting strategies for various patient types.

Lai’s comprehensive review covers lens designs, fitting strategies and troubleshooting techniques. He notes: “These options aren’t presented as a progression of lenses throughout the disease, but as a survey of some alternatives. What is successful for one patient may not be to another, so different strategies can increase success.”

![Craig Norman](https://example.com/craig-norman.jpg)

Craig Norman is director of the Contact Lens Section at the South Bend Clinic in South Bend, Ind. (USA). He is a fellow of the Contact Lens Society of America and an advisor to the GP Lens Institute. He is a clinical and educational consultant to Bausch & Lomb.
Suplementos Ópticos Hosts Boston Products Update Seminar

Pictured from left to right are eyecare practitioners Claudia Morales, Rocio de Morales, David Ocampo and Brenda Ocampo, who were among the attendees at a seminar hosted by Suplementos Ópticos in Guatemala City. These brief monthly meetings are designed to enhance practitioners’ expertise in solving vision problems with Boston products. Instructors were Luis Noriega and Jorge Jurado. Photo by Jaime Cabrera.

Moscow Optic Exhibition

At the Moscow Optic Exhibition, DoctorLens promoted Boston buttons and solutions, as well as various specialty GP lens designs. Left to right: Dr. Dmitry Mirsayafov, orthokeratology expert and owner of DoctorLens; Dr. Oxana Anikeeva, RGP and ortho-k lens fitter; Marcel Kopito.

Opti Munich

Opti Munich, the largest optical trade exhibition in Germany, attracts visitors from Austria, Germany, Switzerland and the Netherlands. Left to right: Peter Bruckmann, President of the WVAO Germany, Marcel Kopito, Dee Kerr, Eduard Bosshard, optometrist in Switzerland.

British Contact Lens Association

Dee Kerr congratulates incoming BCLA president William Thomas at the 2009 BCLA Gala Dinner.

Shanghai International Optical Fair

Dr. Tom Tao (left), owner and CEO of Autek, and Jackson Leung at the Hefei Autek booth.

Ms. G.F. Wang, RGP Manager for Oculus, and Jackson Leung at the Oculus China booth.