

# Ophthalmological Care Options



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# Disclosure

Actual commercial or personal interest in some brands mentioned in the presentation

eyeness AG is actually or has been financially supported as consultant, developer or lecturer by:

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*COOPER Vision Inc.*

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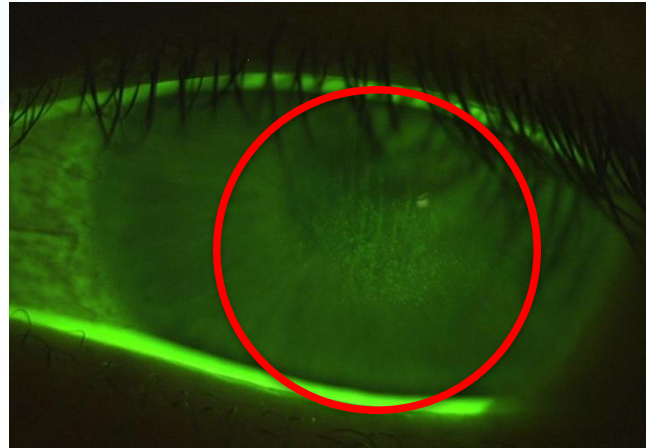
*JOHNSON & JOHNSON Vision Care*

All pictures shown are with the consent of the patients.

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# Introduction

Due to a mutation on the collagen VII-Gen or Keratin 5/14, which is part of the adhesion-complex of the corneal epithelial cells, between **14-35%** *(Tong et al. 1999; Gans 1988)* **of all eyes in EB patients are affected** with painful corneal blisters, corneal scarring, refractive irregularities which can lead to permanent reduced vision.



# Recent “best practice”

“The condition and severity varies between individuals and over time.”

“Calming and pain management are essential.”

ebHandbuch

## AUGEN

### 1. Einleitung

Probleme mit den Augen können in unterschiedlicher Häufigkeit bei den meisten Formen von EB auftreten. Betroffen sein können die Augenlider, die Bindehaut und die Hornhaut. Probleme in diesem Bereich sind besonders unangenehm und oft recht schmerzhaft. Dieser Abschnitt zeigt Ihnen Wege, wie die Häufigkeit von Augenproblemen reduziert werden kann und was zu tun ist, wenn sie auftreten. Darüber hinaus bekommen Sie hier einige Hinweise, die beim Anfertigen einer Brille zu beachten sind.



### Das Wichtigste in Kürze

- Blasen und Verletzungen im Augenbereich können an Augenlidern, Bindehaut und Hornhaut auftreten.
- Häufig bei RDEB, immer wieder bei DDEB, regelmäßig bei JEB,



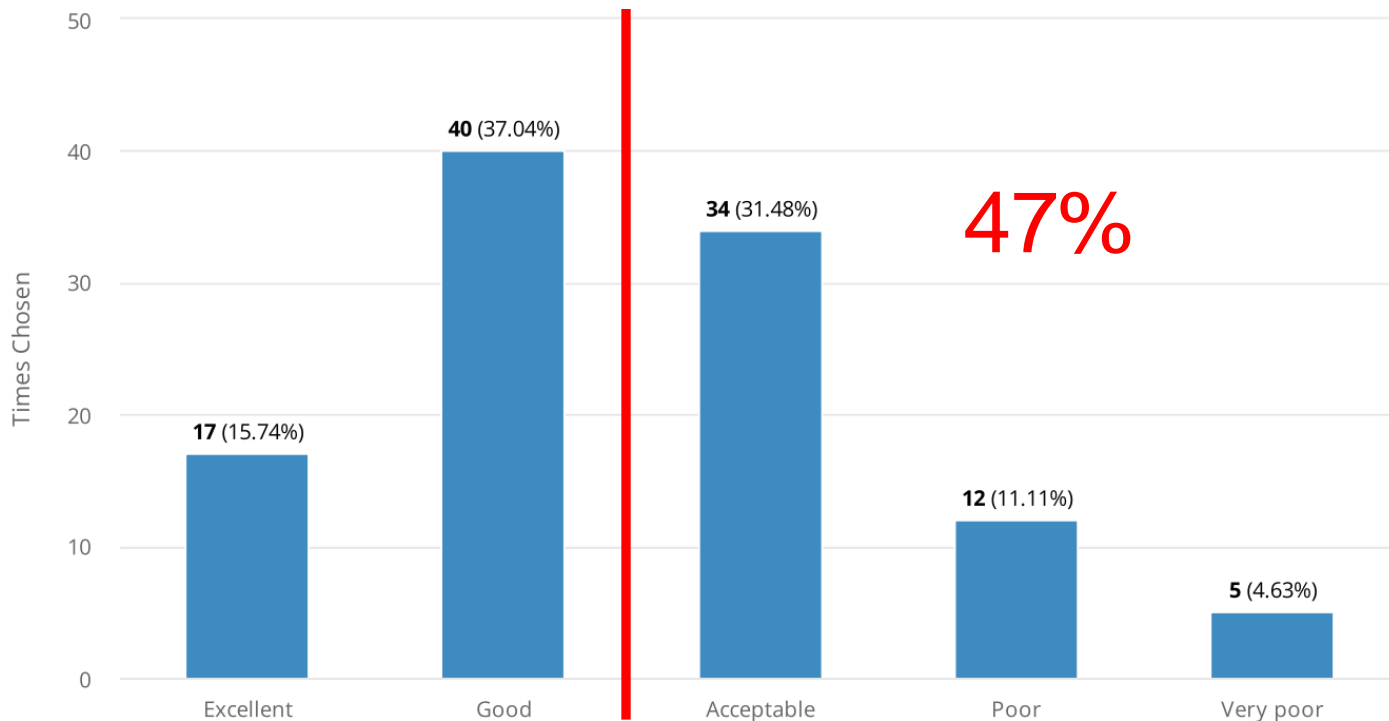
- **Ruhigstellung und Schmerzlinderung sind die wichtigsten Erstmaßnahmen.**

- Alle Maßnahmen sind durch Kontrollen beim Augenarzt zu begleiten!

## 12. How do you, or the person you care for, rate the overall improvement in symptoms after the dry eye and/or vision disorder minimal therapy duration 1 month or more?

Number of responses: 108

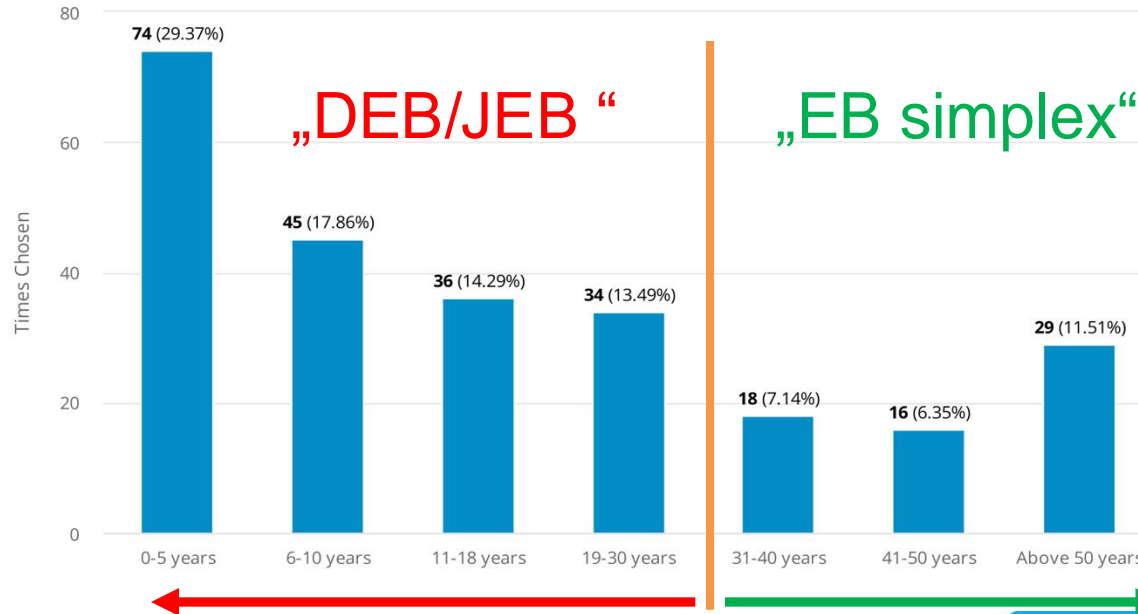
### Eye care survey (DEBRA International 2022)



# Eye care survey (DEBRA International 2022)

## 3. What age group do you, or the person you care for, belong to?

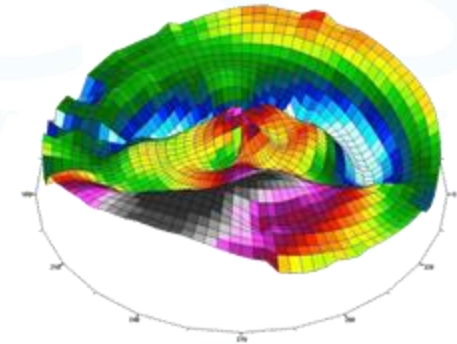
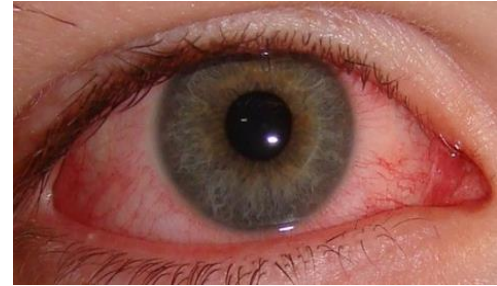
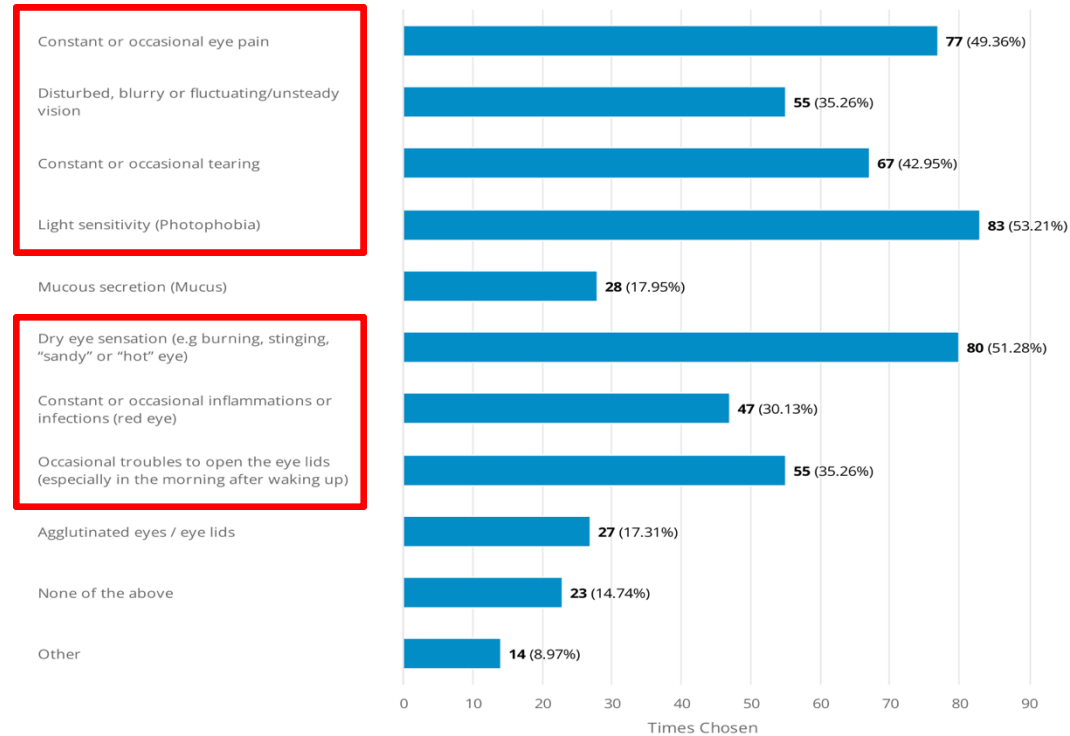
Number of response : 252



# Ocular Symptoms regularly occur

## 1. Do you, or the person you care for, have or have ever had:

Number of responses: 156

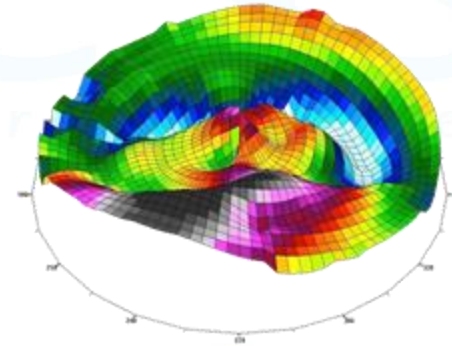
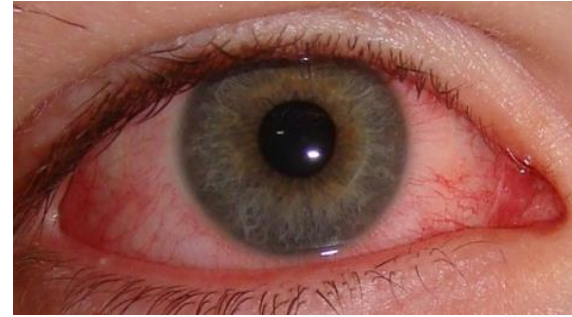




# Ocular Symptoms regularly occur

(according to frequency of naming)

1. Light sensitivity “Photophobia”
2. Dry Eye sensation
3. Chronic (mild to extreme) eye pain
4. Tearing “Epiphora”
5. Reduced, distorted and fluctuating vision
6. Unable or troubles to open the lids (morning)
7. Severe inflamed cornea and conjunctiva
8. Moderate to severe corneal irregularities





## 2. How often do you, or the person you care for, experience the following problems?

Number of responses: 156

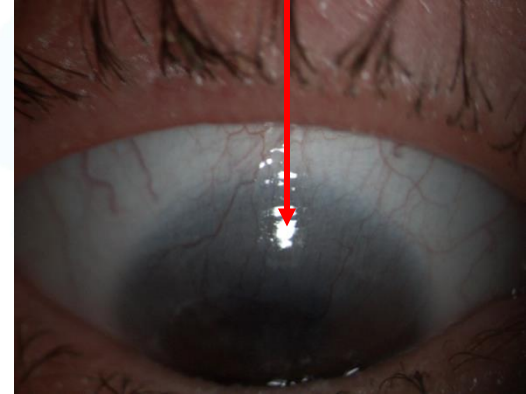
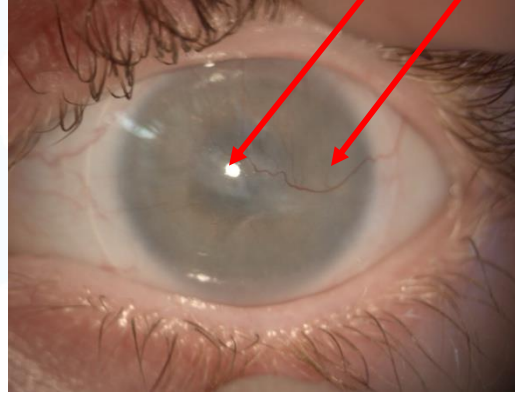
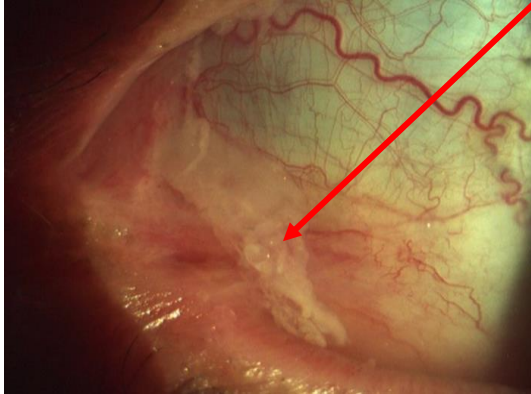


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# Long term complications

- Permanent corneal and/or conjunctival scarring due to inflammatory “healing” process (e.g. synechiae/symblepharon, corneal scarring)
- Chronic visual impairment due to massive neovascularization and pannus



# Surgical Interventions

Frequent medical/surgical interventions needed

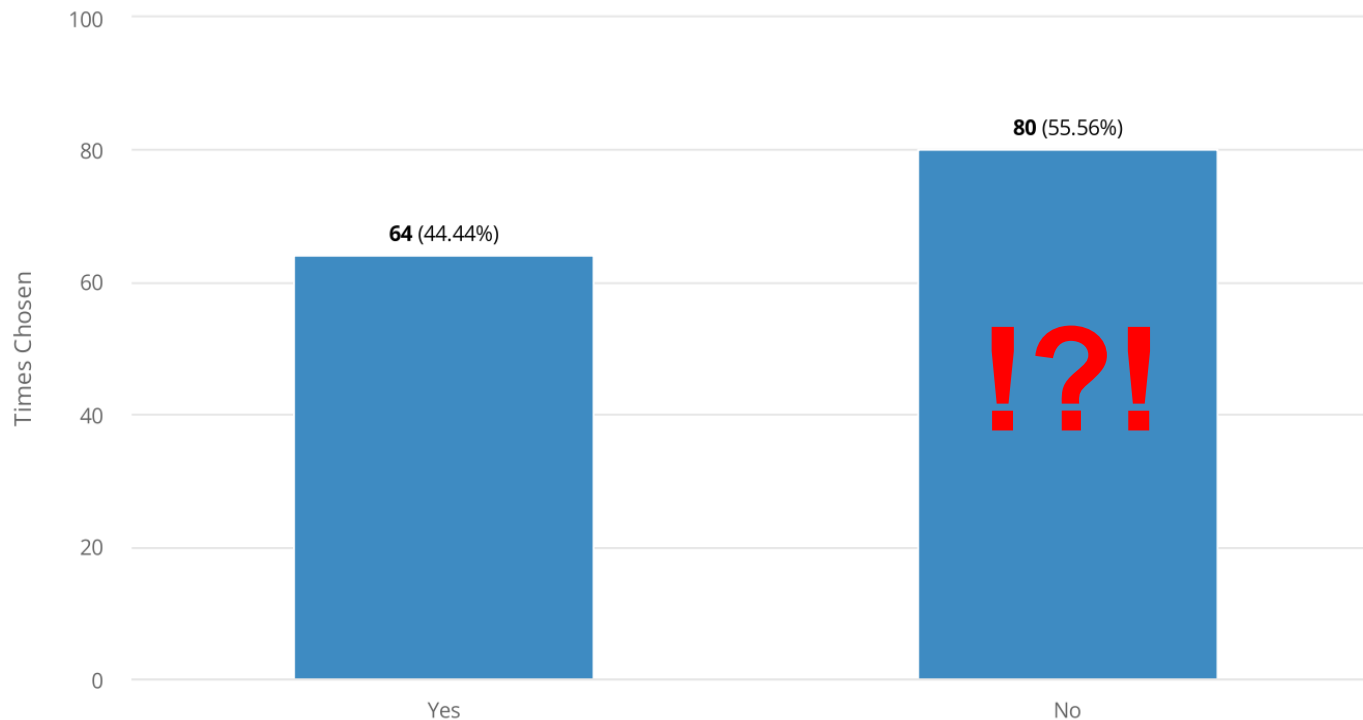


Resection of an ocular adhesion/synechia or pterygium.

*No surgical intervention for pannus or deep vascularization are available except a risky cornea transplant.*

# 16. Did you receive information about the measures that you, or the person you care for, should adopt to prevent or delay recurrences of dry eye and/or vision disorder symptoms?

Number of responses: 144



# Eye care survey (DEBRA International 2022)

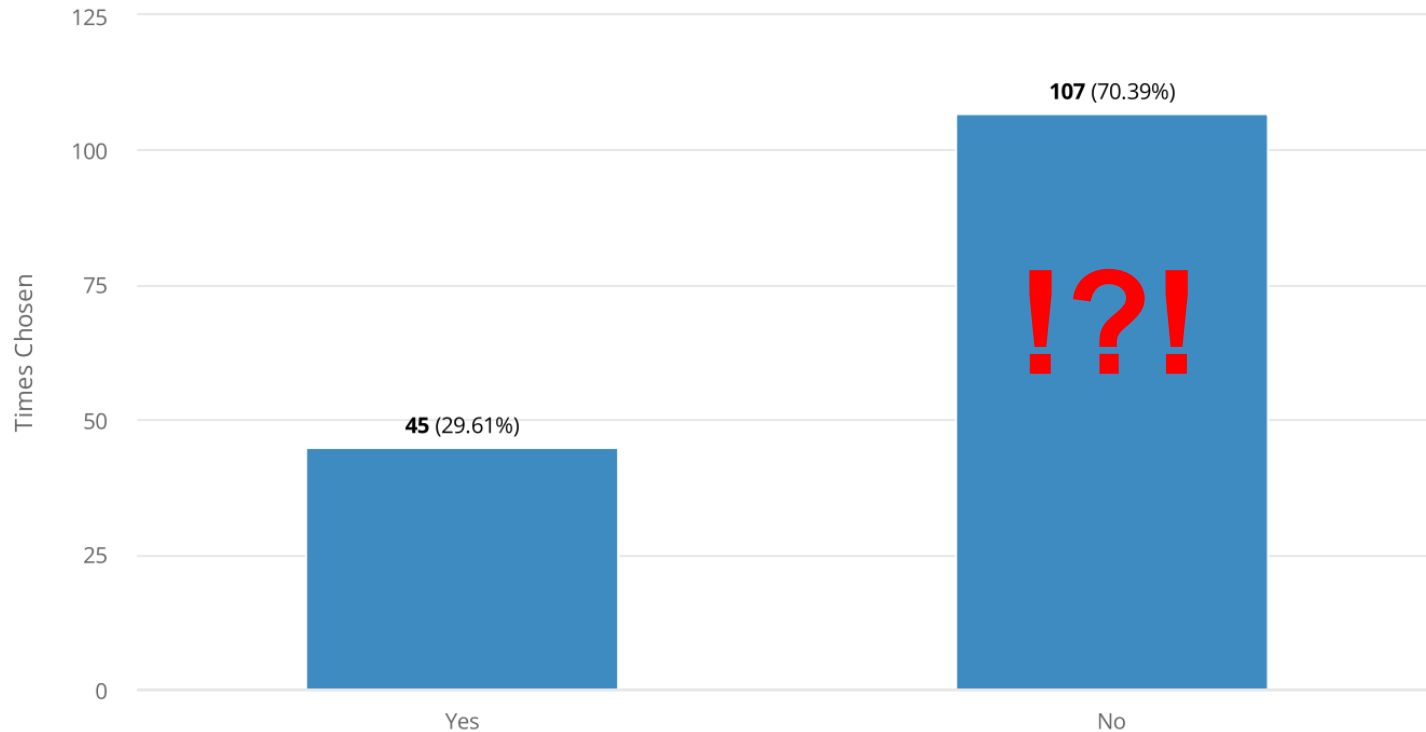
## *Frustrated mother of a young EB patient*

Diagnosis Pannus was established very late. We were explained we cannot remove it, i.e. return to the healthy state. Thus we are destined to treat this issue for all time now in order to prevent further growth. We are very unhappy with the missed diagnosis which we could have prevented if we had known about it. The reason why this happened because our EB dermatologists are not oftalmologists and were unable to diagnose it. They simply said about dry eye and infection therapy, which was not the case with pannus. Our MTD team in

**Not a critic towards dermatology, but a call for consistent multidisciplinary education and cooperation.**

## 8. Did you, or the person you care for, undergo specific dry eye and/or vision disorder management?

Number of responses: 152



## 5. Can you tell us what medication if any was prescribed?

Number of responses: 126

Minor and rare  
Symptoms

Artificial wetting eye drops or autologous serum

79 (62.70%)

Wetting eye gel or ointment

53 (42.06%)

Acute Symptoms

Anti-inflammatory or anti-infection eye medication

39 (30.95%)

Chronic Blepharitis

Lid and/or eye hygiene (cleaning, warm compresses, lid massage)

21 (16.67%)

Acute or chronic  
symptoms  
Prevention !

Bandage or therapeutic contact lenses

16 (12.70%)

Technical therapies or punctal plugs

2 (1.59%)

Unsure? Please write the name(s) of the medication(s) in other section.

5 (3.97%)

Other

**Vyjuvek**<sup>®</sup>  
beremagene geperpavec-svdt  
5x10<sup>9</sup> PFU/mL single-use vial

22 (17.46%)

Future Genetic Tx ?

0 10 20 30 40 50 60 70 80 90

Times Chosen



# Future Gen Therapy for EB Eyes ?

The NEW ENGLAND JOURNAL of MEDICINE

## BRIEF REPORT

### Ocular Gene Therapy in a Patient with Dystrophic Epidermolysis Bullosa

Arianna Tovar Vetencourt, M.D., Ibrahim Sayed-Ahmed, M.D., Jennifer Gomez, Hubert Chen, M.D., M.P.H., Brittani Agostini, B.S.N., Kate Carroll, Ph.D., Trevor Parry, Ph.D., Suma Krishnan, M.S., and Alfonso L. Sabater, M.D., Ph.D.

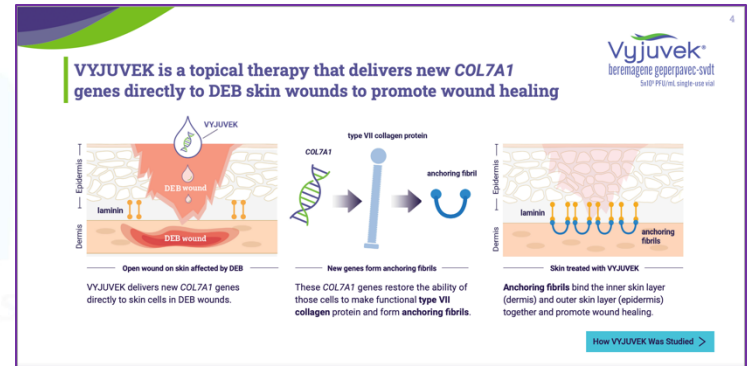
## SUMMARY

From the Bascom Palmer Eye Institute, University of Miami Miller School of Medicine, Miami (A.T., I.S.-A., J.G., A.L.S.); and Krystal Biotech, Pittsburgh (H.C., B.A., K.C., T.P., S.K.).

N Engl J Med 2024;390:530-5.  
DOI: 10.1056/NEJMoa2301244

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Dystrophic epidermolysis bullosa is a rare genetic disease caused by damaging variants in *COL7A1*, which encodes type VII collagen. Blistering and scarring of the ocular surface develop, potentially leading to blindness. Beremagene geperpavec (B-VEC) is a replication-deficient herpes simplex virus type 1–based gene therapy engineered to deliver functional human type VII collagen. Here, we report the case of a patient with cicatrizing conjunctivitis in both eyes caused by dystrophic epidermolysis bullosa who received ophthalmic administration of B-VEC, which was associated with improved visual acuity after surgery.

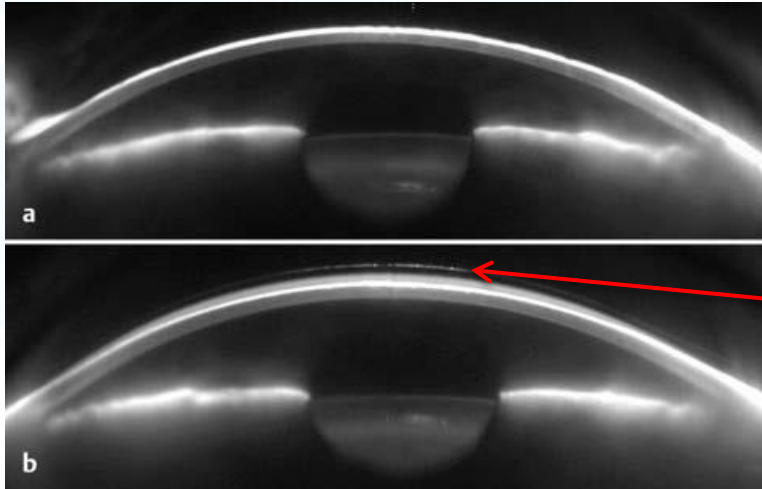


**CAVE: Single case, multiple types of Tx were involved !**



# In severe and recurrent cases, our personal approach of choice

Fitting of therapeutic and refractive effective soft or hard bandage contact lenses as ocular surface protection layer (for EB Px since 2006).



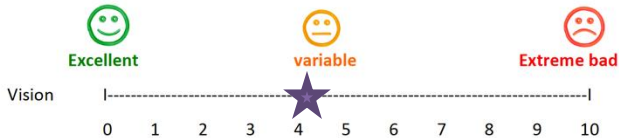
Without contact lens

With protecting contact lens

OCT image of anterior ocular segment

### EBEye Questionnaire (Feel free to optimize the naming, smileys or colors)

This Questionnaire was created to better understand your actual Eye Pain and Vision Situation and over time. Please indicate your personal feelings in the provided Scale.



Created for DEBRA International and cure-eb by Dr. Michael Bärtschi, Eyeness AG, Switzerland; September 2018

# Method/Procedure

## EBEye Questionnaire

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# Bandage Contact Lens Fitting Procedure

## Therapeutic Contact Lens Fitting Suggestions for EB Patients

with recurrent Corneal Blisters/Erosions, Pain Sensation and/or Epiphora

1. EBEye Questionnaire
2. Free Visual Acuity / Corrected Visual Acuity with current Eye Glasses
3. Autorefractor or Sciascopy (*only if Photophobia is not to severe*)
4. Ocular Topography or Autokeratometer
5. Slit Lamp / Biomicroscope Evaluation (*Documented by Photography*)
6. Fluorescein Vital Dye Stain (*Documented by Photography*)
7. Wearing Modality Decision (*Extended/Constant Wear or Daily Wear*)
8. Contact Lens Material Decision (*Silicone-Hydrogel or Scleral Lens*)
9. Basecurve, Over all Diameter and Contact Lens Power Calculation
10. Insertion of Trial Contact Lenses with unpreserved Saline Solution  
*After 5-15 Minutes*
11. Check Trial Contact Lenses for spontaneous Comfort, Centration, Fit and Movement/Tear Exchange
12. Educate proper Contact Lens Handling and Hygiene (*for Daily Wear with unpreserved Peroxid System*)
13. Provide written Handling and Hygiene Instruction (*Brochure*) with Emergency Contact Information
14. Plan Follow-Up Visits depending the Wearing Modality
15. Record Progression by Photography and EBEyes Questionnaire
16. Educate your colleagues about the Possibility of Therapeutic Contact Lenses for EB Patients

## Suggested Soft and Hard Contact Lens Materials for EB Patients

Fundamentals:

- Highest possible oxygen (Gas) permeability for extended or constant wear (EW 24h/7d/30d) up to 30 days and 29 nights. Ideal  $Dk/t > 100$ .
- Lowest protein and oily deposits possible to reduce "biofilm" on lens surface over time and to maintain good eye health.
- Best possible fit and lowest dehydration properties to maintain highest possible long-term comfort and ideal post-lens tear film exchange.

Silicon-Hydrogel (soft) contact lens brands with FDA extended/constant wear (EW) and therapeutic use approval:

- Biofinity (COOPER Vision, UK) spheric, toric and multifocal, monthly lens for EW
- Air Optix "Night&Day" (ALCON, USA) spheric, 2 different base curves available, smaller over all diameter for smaller eyes/lid aperture, monthly lens for EW
- Pure Vision (Bausch&Lomb, USA) spheric, 2 different base curves available, monthly lens for EW
- Acuvue Oasys (JOHNSON & JOHNSON, USA), spheric, toric and multifocal, 2 different base curves available, weekly (!) lens for EW
- ORBIS (SwissLens, Switzerland) spheric, broad range of individual BC and (small) Diameters, Definitive 74 (FilconF3), off-label EW for 1-3 months

Rigid Gas Permeable (hard) contact lens brands for Scleral Contact Lenses, only Daily Wear recommended even all of them have a FDA EW approval !:

- Optimum Extreme/Infinite (CONTAMAC, UK) spheric, toric and multifocal
- XO/XO2 (BOSTON, USA) spheric, toric and multifocal
- HDS 100 (PARAGON, USA) spheric, toric and multifocal

# Bandage Contact Lens Fitting Procedure

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Created for DEBRA International and cure-eb by Dr. Michael Baertschi, Eyeness AG, Switzerland; September 2018

## Suggested Soft and Hard Contact Lens Materials for EB Patients

Fundamentals:

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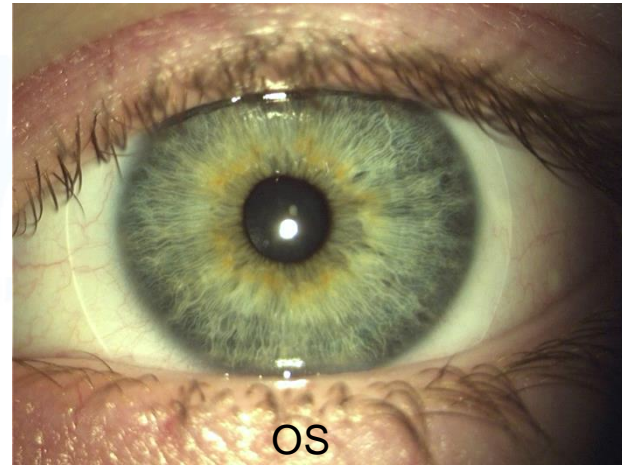
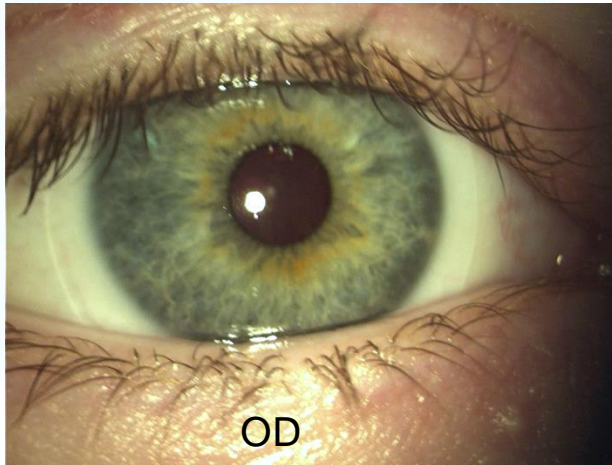
Created for DEBRA International and cure-eb by Dr. Michael Bärtschi, Eyeness AG, Switzerland; September 2018, update 2024.

Extended or constant wear for up to 1-3 months  
with material specially designed for long-term wear.  
(Silicone-Hydrogel or Fluor-Siloxan-MMA)

# Primary Results

“Immediate” elimination of eye pain sensation in minutes or hours.

“Whitening” of the eyes in days due to permanent reduction of ocular stress avoiding recurrent or chronic inflammations.

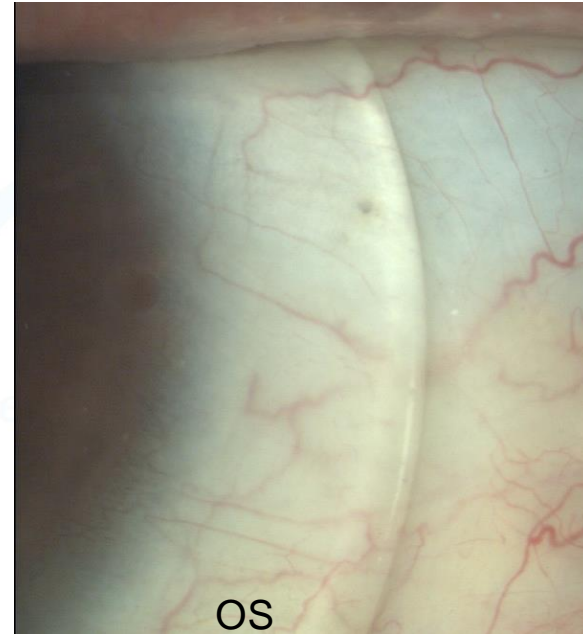
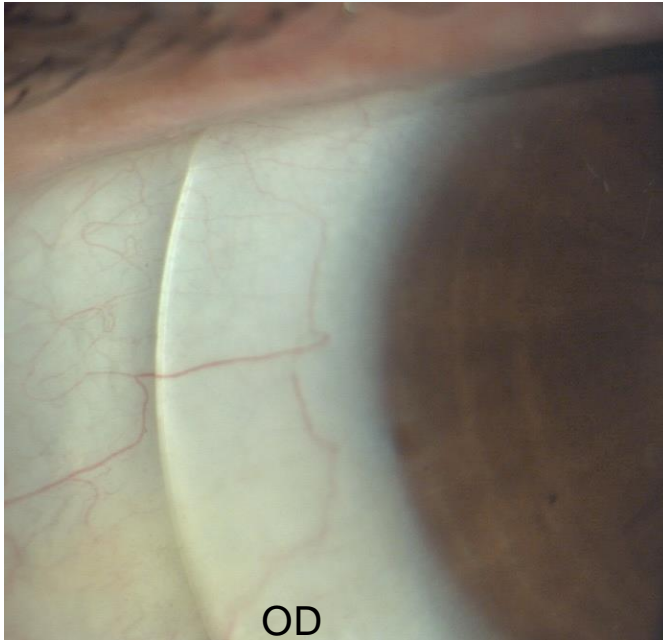


„Soft“ lens example : Silicone-Hydrogel Contact Lenses



# Primary Results

Status after 18 years of contact lens wear



„Hard“ lens example: Scleral Contact Lenses



# Secondary Results

Rehabilitation of permanent and stable vision in a few weeks.

Continuous support of healing and stabilizing process of the corneal epithelium for months/years.

„Permanent“ restoration of the irregular corneal surface.

Comparison:

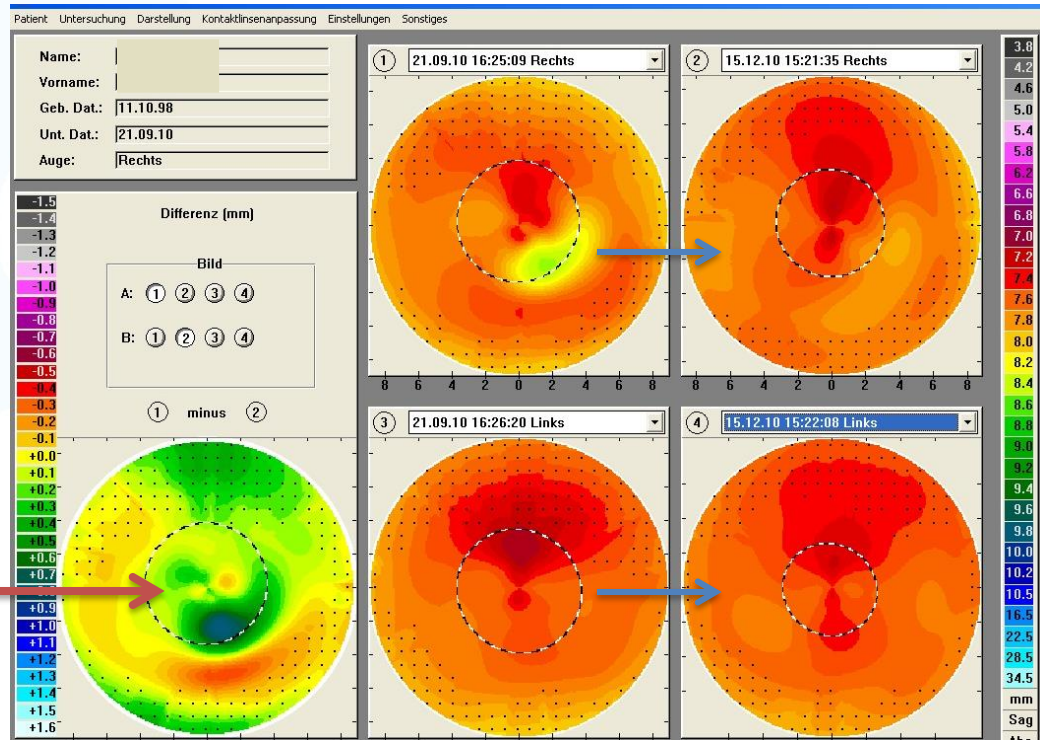
OD 1 -> 2

OS 3 -> 4


Differential map:


OD 1 -> 2

before and after treatment



# Publications: 2015-19


**Universitätsklinik Basel**


  
**UNIVERSITÄT BASEL**

2015

**Einsatz therapeutischer Kontaktlinsen bei rezidivierender Erosio corneae aufgrund Epidermolysis bullosa**

Huebner S<sup>1</sup>, Baertschi M<sup>1,2</sup>, Beuschel R<sup>1</sup>, Wyss M<sup>2</sup>, Itin P<sup>3</sup>, Goldblum D<sup>1</sup>

<sup>1</sup>Augenklinik, Universitätsklinik Basel; <sup>2</sup>Eyeness - Kontaktlinsenstudio Baertschi Bern; <sup>3</sup>Dermatologie, Universitätsklinik Basel

**Hintergrund:** Wir berichten über zwei Patientinnen mit rezidivierender Erosio corneae sowie Hornhaut-irreguläritäten aufgrund Epidermolysis bullosa dystrophica vom Non-Hollopau-Siemens-Typ, die mit therapeutischen Kontaktlinsen versorgt wurden. Der Erbgang dieser Grunderkrankung ist rezessiv. Mutationen im Kollagen-VII-Gen (COL7A1) führen zu molekularen Defekten von Kollagen VII und Abnormalitäten der Verankerungsbrillen. Es kommt zur Blasenbildung. Die Blasen sind schon bei der Geburt vorhanden und bleiben in der Regel lebenslanglich bestehen. Das klinische Bild kann sehr variabel sein. Bei einigen Patienten ist der Befall generalisiert, bei anderen Betroffenen überwiegen akrale Blasen oder es werden die inversen Regionen bevorzugt. Alle Blasen heilen mit Narben und Milien ab. In diesem Rahmen ist auch ein Augenbefall mit rezidivierenden Erosionen möglich.

**Anamnese und Befund:** Eine 49-jährige sowie eine 70-jährige Patientin stellten sich aufgrund rezidivierender Erosionen corneae bei uns vor. In der Spaltlampenuntersuchung zeigte sich bei beiden Patientinnen eine klare Hornhaut mit subepithelialen Bläschen (Abb. 1). Bei Patientin 2 waren subepitheliale Narben sowie ein unregelmäßiges Epithel zu sehen. Beide Patientinnen litten unter der Grunderkrankung einer Epidermolysis bullosa dystrophica.

**Therapie und Verlauf:** Wir wiesen beide Patientinnen einem Kontaktlinsenoptiker an, der die Anpassung therapeutischer Kontaktlinsen vornahm. Patientin 1 wurde aufgrund der glatten Hornhaut mit weichen Verbandlinsen versorgt. Bei Patientin 2 kamen aufgrund der Irreguläritäten der Cornea nur Scleralinsen in Frage. Abb. 2 zeigt die Pentacam-Untersuchungen vor und nach Kontaktlinsenversorgung am rechten Auge. Man kann deutlich erkennen, dass die unruhige Oberfläche durch den Tränenfilm unter der Sclerallinse ausgeglichen wird. Seither ist es zu keinen Rezidiven gekommen und die Patientinnen sind beschwerdefrei.

**Schlussfolgerung:** Die Kontaktlinsenversorgung stellt eine sehr gute Therapieoption bei rezidivierenden Erosionen bei Patienten mit der Grunderkrankung Epidermolysis bullosa dar. Je nach Hornhautbeschaffenheit kommen verschiedene Arten von Kontaktlinsen in Frage.

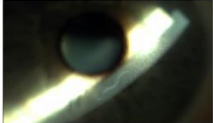


Abb. 1: Hornhautbefund Patientin 1




Abb. 2: Verengung mit Scleralinse

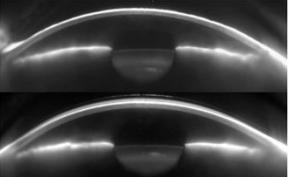


Abb. 3: Pentacam Untersuchung des rechten Auges a) vor und b) nach Verengung mit Scleralinse

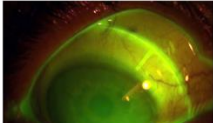



Abb. 4: Scleralinse nach Applikation von Fluorescein

**Publikation (Hintergrund):**  
 Sie werden hier in Englisch oder spanisch übersetzt in any language or other languages.  
 Website: [www.eyeness.ch](http://www.eyeness.ch)


**Ocular Immunology and Inflammation**



2019

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**Extended Wear Bandage Contact Lenses Decrease Pain and Preserve Vision in Patients with Epidermolysis Bullosa: Case Series and Review of Literature**

Ramy Rashad, Matthew C. Weed, Nicole Quinn & Vicki M. Chen

To cite this article: Ramy Rashad, Matthew C. Weed, Nicole Quinn & Vicki M. Chen (2019): Extended Wear Bandage Contact Lenses Decrease Pain and Preserve Vision in Patients with Epidermolysis Bullosa: Case Series and Review of Literature, Ocular Immunology and Inflammation, DOI: 10.1080/09273948.2019.1587472

To link to this article: <https://doi.org/10.1080/09273948.2019.1587472>

380
**Der interessante Fall**

Einsatz therapeutischer Kontaktlinsen ... Klin Monatsbl Augenheilkd 2015; 232: 380–381

**Einsatz therapeutischer Kontaktlinsen bei rezidivierender Erosio corneae aufgrund Epidermolysis bullosa dystrophica**

**Use of Therapeutic Contact Lenses for the Treatment of Recurrent Corneal Erosions due to Epidermolysis Bullosa Dystrophica**

**S. Huebner<sup>1</sup>, M. Baertschi<sup>1,2</sup>, R. Beuschel<sup>1</sup>, M. Wyss<sup>2</sup>, P. Itin<sup>3</sup>, D. Goldblum<sup>1</sup>**

<sup>1</sup>Augenklinik, Universitätsklinik Basel, Universität Basel, Schweiz (Direktor ad interim: Dr. Norbert Spörig)  
<sup>2</sup>Eyeness-Kontaktlinsenstudio Baertschi, Bern, Schweiz  
<sup>3</sup>Dermatologie, Universitätsklinik Basel, Universität Basel (Chefarzt: Prof. Peter Itin), Schweiz

SPEZIAL
Prothetische Kontaktlinsen

die **KONTAKTLINSE** 7-8/2019

**Anpassung und Materialwahl von protektiv, therapeutisch und visuell rehabilitierend wirksamen Kontaktlinsen bei Epidermolysis Bullosa**

Michael Baertschi<sup>1</sup> | Agnes Schwieger-Briel<sup>2</sup>

**Die Epidermolysis Bullosa (EB)** umfasst eine Gruppe seltener angeborener Hauterkrankungen, die durch eine erhöhte Hautfragilität charakterisiert sind. Je nach genetischem Defekt ist auch die Augenoberfläche dieser Patienten betroffen, wodurch es zu rezidivierenden schmerzhaften Hornhautverletzungen und Vernarbungen mit langfristiger Einschränkung der Sehfähigkeit kommen kann. Prophylaktisch werden v.a. benetzende und pflegende Augentropfen/-salben eingesetzt. Bezüglich der Verwendung von Kontaktlinsen besteht hingegen aufgrund der bestehenden Hautfragilität bisher noch eine gewisse Unsicherheit. In diesem Artikel soll anhand einer Fallbeschreibung aufgezeigt werden, wie protektive Schutzverbandslinsen helfen können, die Häufigkeit der Erosionen zu reduzieren und damit die Lebensqualität der Betroffenen nachhaltig und effektiv zu verbessern. **Schlüsselwörter** | Epidermolysis bullosa, Korneaerosionen, Schutzverbandslinsen, Prävention, Protektion, Rehabilitation

**The term Epidermolysis bullosa (EB)** describes a group of rare genetic disorders presenting with skin blistering and wounds. Depending on the underlying genetic defect, the ocular surfaces can be affected leading to recurrent and painful corneal erosions, scarring, and reduced vision. As an attempt to reduce the occurrence of these erosions, moisturizing eye drops and creams are being employed. However, contact lenses are only hesitantly used as the skin fragility is thought to be a contraindication. In this article, we present a patient with EB where the use of protective lenses helped to minimize superficial corneal lesions and consequently increasing the patient's quality of life sustainably and effectively. **Keywords** | Epidermolysis bullosa, recurrent erosions of the cornea, therapeutic contact lenses, prevention, protection, rehabilitation

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## Long term complications in severe cases without CL

- Permanent corneal and/or conjunctival scars due to inflammatory “healing” process (e.g. synechiae/symblepharon, neovascularization, corneal scarring)



- Chronic visual impairment due to massive neovascularization and pannus
- Frequent medical/surgical interventions needed



# Call: be protective !

Therapeutic or protective bandage contact lenses are an easy, quick and effective method to eliminate pain sensation, restore vision and ocular surface regularity on a “permanent” base.



Ilija, contact lenses since the age of 15 months

# Summary & Take-Home

- Minor wetting problems = long lasting artificial tears or eye gel during the day and ointment at night; eyelid hygiene as preventive measure
- In case of infection risk = Antibiotic eye drops and ointment
- In case of acute or chronic inflammations = steroid eye drops (or Ciclosporin A ?)
- Acute or chronic epithelial lesions = Protective bandage contact lenses  
*(sometimes combined with antibiotic and/or steroid or autologous eye drops)*
- Synechiae or adhesions = Surgical intervention *(covered with amniotic membrane)*

