**Name:** _____ **Date:**

# Keeping Track of Your Ocular Symptoms

Keeping track of your **ocular symptoms** is a good way for you and your ophthalmologist to know how your symptoms may be changing over time.

- This information will help you document changes in your symptoms.
- You can fill out these symptom trackers regularly and share with your ophthalmologist as changes become noticeable.

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## Photophobia (Light Sensitivity) Tracker

*In the tracker below, write in the date, then put a checkmark ✓ in the space to indicate your level of discomfort in sunlight or bright light.*

**Light sensitivity in sunlight or other bright light**

| DATE | No discomfort or difficulty | Slight difficulty with light that causes occasional eye-blinking | Slight difficulty with light that causes regular eye-blinking | Moderate difficulty with light that requires wearing sunglasses | Severe difficulty with light that requires wearing sunglasses almost all the time | Extreme difficulty with light that requires staying inside due to inability to tolerate natural light even with sunglasses |
|---|---|---|---|---|---|---|
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# Other Eye Symptoms Tracker

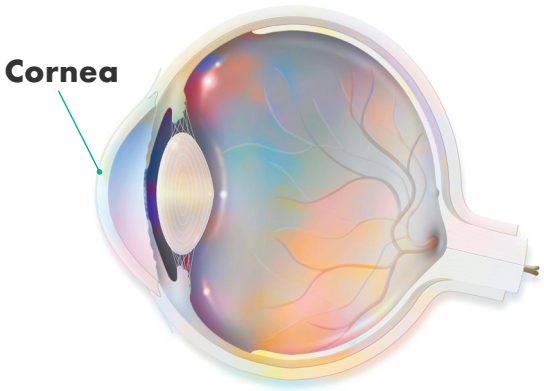
*For each symptom in the table, write the date and put a checkmark ✓ in the space that best indicates how you are experiencing that symptom. There is also a space at the bottom to write in an additional symptom.*

| Other Eye Symptoms | DATE | More Than Before | Same As Before | Less Than Before | None |
|---|---|---|---|---|---|
| **Uncontrollable blinking or spasms of the eyelid muscles** | | | | | |
| **Eye pain** | | | | | |
| **Feeling like there's something in your eyes** | | | | | |
| **Watery eyes** | | | | | |
| **Dry eyes** | | | | | |
| **Blurry vision** | | | | | |
| **Difficulty seeing at night** | | | | | |
| **Difficulty seeing in general** | | | | | |
| **Other:** _____ | | | | | |

# Keeping Track of Cystine Crystals in Your Corneas

Keeping track of the **amount or density of crystals in your corneas** is a good way to let your ophthalmologist know if there are changes over time. The buildup of corneal crystals can lead to uncomfortable and painful symptoms as well as difficulty doing daily activities.

- Your ophthalmologist can use a **slit lamp** to take photos of the crystals in your corneas.
- Based on the slit lamp photos, ask your ophthalmologist to **circle the image** in the tracker below that **corresponds best to the amount of crystals in your corneas**.
- This information will help you document changes in corneal cystine crystal density.
- You can fill out the tracker with your ophthalmologist after every slit-lamp exam.

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## Corneal Cystine Crystals Tracker

*Write in the date and, with the help of your ophthalmologist, circle the image that corresponds best*

| DATE | No Crystals | Some Crystals | Moderate Amount of Crystals | Packed with Crystals |
|---|---|---|---|---|
| | | | | |
| | | | | |
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| | | | | |

# Getting the Most Out of Your Ophthalmology Appointments

Preparing for appointments with your ophthalmologist will help you get the most out of them.

- Decide on the questions you want to ask your ophthalmologist.
- You may want to ask the questions below and also some additional questions.

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## Questions to Ask Your Ophthalmologist

- ❑ How is cystinosis affecting my eyes?
- ❑ What parts of my eyes are affected the most?
- ❑ What is the current density of the cystine crystals in my corneas?
- ❑ Has there been a change in the density of cystine crystals since my last exam?
- ❑ Are my eye symptoms due to the effects of cystinosis in my corneas or on other parts of my eyes?
- ❑ What can I do to prevent long-term complications of cystinosis in my eyes?
- ❑ Do I have other eye conditions that may or may not be related to cystinosis, such as cataracts, retinopathy (a disease of the retina), glaucoma (increased pressure in the eye), or other conditions that can impair vision?
- ❑ _____
- ❑ _____
- ❑ _____
- ❑ _____

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