Chapter 7
Preoperative Counseling

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Preoperative discussions with caregivers and patients are an essential component of the early phases of care related to childhood cataracts. These conversations are detailed and complex, requiring the physician to set aside appropriate time and participate as both an active educator and listener. The physician will also need to coordinate the interdisciplinary needs of each unique patient. Appropriate expectations should be set, terminology should be introduced, and empathy should be used, particularly in addressing the concerns and needs of each family. The postoperative course after childhood cataract surgery often lasts for decades, so the family must be prepared for long-term care and follow-up. The family should understand that the physician-family-patient relationship will endure both triumphs and challenges requiring short- and long-term support from the medical team. Successful outcomes often require years of individualized vision rehabilitation and lifelong monitoring for complications.

Etiology

Often, the first question families ask is, "Why did my child get a cataract?" Physicians and parents alike have an interest in the answer to this important question. In some situations, the answer is known at the time of diagnosis (e.g., if a child had a family history of childhood cataracts, a congenital infection, or trisomy 21). However, in many instances, there is either no identifiable cause or testing will be

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recommended to help arrive at a conclusive answer. In the early phases of the physician-family relationship, it is important to outline for the family the broad categories of cataract etiology including idiopathic, inherited, secondary to other intraocular pathology, and secondary to a systemic condition. At this point, the physician may offer the most likely explanation for the cataract based on the history and exam findings. In cases where additional lab work is warranted, we recommend describing the occurrence of cataracts as an "important clue" that may help the ophthalmologist identify an underlying systemic issue that would benefit from early treatment. Chapter 1 (Cataract Epidemiology and Genetics) provides a comprehensive discussion of the specific causative examples of congenital cataracts. Table 7.1 highlights the steps in preoperative assessment for cataract causality.

The etiology of congenital cataract can be narrowed according to key clinical features: laterality, family history, syndromic systemic features, exposure history, and associated ocular pathology. A decision tree illustrating how the clinical features and history aid in determining the cause of congenital cataracts is shown in Fig. 7.1. The family, pediatrician, and other subspecialists, such as geneticists, are key participants in this investigation preoperatively. Often, targeted testing at the time of surgery can be arranged by thoughtful collaboration with a multidisciplinary team.

Table 7.1 Preoperative assessment for cataract causality

Physical and ocular exam in clinic	Systemic testing	Interdisciplinary consults
History – family and patient history may reveal the cause of childhood cataract(s)	Blood tests – TORCH infection workup, complete blood count (CBC), chemistry panel (glucose, creatinine, blood urea nitrogen (BUN), phosphorus, calcium), ferritin, red blood cell galactokinase (GALK) activity, other galactosemia tests[a]	Pediatrician
		Geneticist
	Urine tests – reducing substances, amino acids, galactosemia enzymes	Genetic counsellor
Exam – information about laterality, corneal diameter, presence of persistent fetal vasculature or Peters anomaly, B-scan for possible tumor or retinal pathology, signs of trauma	Genetic tests – specific test based upon presumed diagnosis, such as genetic panel (for non-syndromic bilateral congenital cataract), karyotype (for highly recognized chromosomal syndromes), or chromosomal microarray (for bilateral cataracts with less specific syndromic features) [1, 2][b]	Anesthesiologist
Exam of parents, siblings – if positive may help refine a presumed genetic diagnosis or identify siblings with cataracts or other ocular anomalies		Other subspecialists as needed
Continued surveillance: At least once per year, patients with a history of idiopathic bilateral cataract should be re-evaluated for any change or update to the review of systems.		

[a]Classic galactosemia test is part of routine newborn screening
[b]Performed under the guidance of a trained geneticist and genetics counsellor

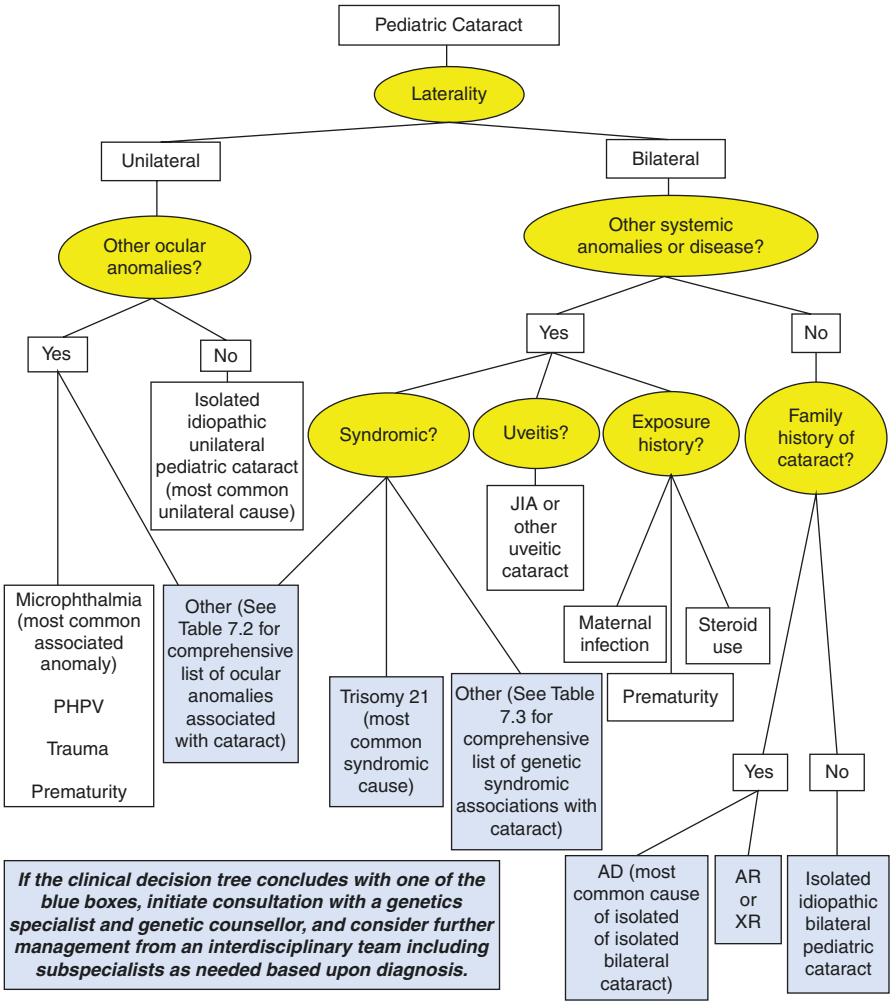

Fig. 7.1 Decision tree pediatric cataracts

Following a careful assessment of cataract causality with the assistance of genetics specialists, a patient-specific multidisciplinary team should be assembled as an essential part of appropriate care for a child with cataracts. Table 7.2 outlines cataract etiology according to the associated systemic manifestation with the greatest morbidity. This organization provides an initial framework for the early stages of developing a medical team that will help care for the child. Ophthalmologists should have a low threshold to refer to colleagues with expertise in managing these complex conditions, thereby ensuring that cataract management does not overshadow the child's global progress.

Table 7.2 Genetic syndromic associations with cataract, grouped according to primary systemic findings[a] [3, 4]

Trisomy	Metabolic	Craniofacial	Dermatologic
21 (Down) 13 (Patau) 14 (mosaic) 15q 18 (Edwards) 10q 20p	Galactosemia Hypoparathyroidism Pseudohypoparathyroidism Diabetes Refsum Hypoglycemia Mannosidosis Wilson's disease Sulfatase deficiency Fabry Glucose-6-phosphatase deficiency	Hallermann-Streiff Rubinstein-Taybi Smith-Lemli-Opitz Pierre Robin Oxycephaly Crouzon Apert	Cockayne Poikiloderma Atrophicans Incontinentia pigmenti Congenital ichthyosis Atopic dermatitis Ectodermal dysplasia Progeria

Central nervous system	Renal	Musculoskeletal	Gastrointestinal	Multisystem
Laurence-Moon Sjogren-Larsson Peroxisomal Zellweger Cerebral gigantism Batten disease	Lowe Alport WAGR Aniridia	Chondrodysplasia Myotonic dystrophy Albright osteodystrophy Potter Chondrodystrophic myotonia Spondylo-ocular syndrome	Cerebrotendinous xanthomatosis (CTX)	Nance-Horan Cockayne Marfan Turner NF2

[a]Note each disease grouped according to most relevant category; many diseases mentioned above have multi-organ involvement

Timing of Pediatric Cataract Surgery

Preoperative discussion regarding the timing of congenital cataract surgery should focus on weighing the risks and benefits of early versus delayed surgical intervention. The optimal age for pediatric cataract surgery is that which reduces the risk of deprivation amblyopia without significantly increasing the risk of secondary postoperative complications. Families should understand that in general, the younger the child is at the time of cataract surgery, the greater the incidence of associated complications. However, delaying surgery increases the risk and severity of amblyopia.

Retrospective and prospective surgical outcome data have helped define a latent period for pediatric cataract surgery beyond which the risk of amblyopia rises significantly [5–11]. There is consensus that surgery for unilateral congenital cataract should be performed when the child is 4–6 weeks old [10]. Beyond this latent period, visual outcomes and rates of amblyopia have been shown to steadily worsen over time [6, 7, 9, 10]. Surgery at an earlier age significantly increases the risk of secondary glaucoma, which carries severe ocular morbidity.

The surgical timing for children with bilateral cataracts is less well defined. Families should be counseled that poorer visual outcomes have been demonstrated in children who have surgery after 8–10 weeks of age [5, 10, 11]. Surgeries for the two eyes are ideally separated by approximately 1–2 weeks. A longer period

between surgeries increases the child's risk of developing amblyopia in the eye undergoing later surgery. Immediate sequential bilateral cataract surgery should be reserved for cases where general anesthesia exposure must be limited due to patient comorbidities [12]. In these cases, families must fully understand that this approach has the theoretical increased risk of bilateral endophthalmitis and is therefore not the preferred method for otherwise healthy children. In cases where a child is systemically unstable, surgery may need to be delayed until the child can safely undergo anesthesia.

Risks of Pediatric Cataract Surgery

Informed consent for pediatric cataract surgery should be discussed on multiple occasions prior to the procedure. Some families are referred to the ophthalmologist with a known diagnosis of cataract and the expectation of surgery, while for others, a cataract is a brand new diagnosis. In either scenario, all families will need a great deal of additional information to be adequately informed. Discussion of the potential benefits of cataract surgery is likely to be readily accepted and understood. However, for children who present at a later age, especially those with unilateral cataract, the risk of limited visual recovery and guarded visual prognosis should be explained in detail. Advantages of lens removal for such patients include enhanced contrast and color, improved peripheral vision, prevention of complications related to end-stage cataracts (phacomorphic glaucoma or phacolytic glaucoma), and improved view of the optic nerve and retina for both ocular health monitoring and cycloplegic refraction. For patients who present in a timely fashion, the potential benefits are even greater, but the risks of perioperative and postoperative complications for all children cannot be understated. This part of the discussion with families typically requires more time as it raises additional concerns and questions that need to be addressed. Table 7.3 outlines the many risks that the pediatric ophthalmologist must anticipate at the time of surgery and at every postoperative visit. While this list is too long to discuss each item in detail during the informed consent process, parents and families should be aware of and understand the very common risks of glaucoma, strabismus, refractive error, and amblyopia following pediatric cataract extraction. The rare but devastating risks of infection, retinal detachment, and anesthesia-related surgical risks must also be described in sufficient detail. Table 7.4 highlights the risk of significant complications related to pediatric cataract surgery.

Case 1

A 4-month-old boy presents to the emergency department for shaking eyes and failure to thrive. His ocular exam is notable for blink to light visual acuity, dense bilateral lamellar cataracts (Fig. 7.2), and an otherwise normal anterior segment.

Table 7.3 Operative risks related to pediatric cataract surgery

Immediate operative risks (intraoperative to week 1 following surgery)	Early risks (week 1 to year 1)	Late risks (after 1 year)
Anesthesia risk (postoperative apnea risk is greatest for patients below 45-week post-menstrual age) Discomfort (dryness and light sensitivity) Damage to nearby ocular structures (lids and lashes) Corneal abrasion Corneal scarring (expected at incision sites) Corneal clouding Wound leak Endothelial toxicity (toxic anterior segment syndrome or TASS) Subconjunctival hyphema or conjunctival injection Retained cortex Hyphema Iris prolapse Iris damage Iris sphincterotomy IOL malposition Vitreous prolapse Lens fragment in vitreous Ruptured posterior capsule Aggressive inflammatory response Infection	Amblyopia Strabismus Glaucoma Endothelial decompensation Iris heterochromia Refractive error Contact lens-related infection Membrane formation Cortical reproliferation Cystoid macular edema Iris synechiae formation Membrane formation or capsular scarring (phimosis or posterior capsular opacification)	Amblyopia Strabismus Glaucoma Retinal detachment Refractive error Potential need for secondary IOL or IOL exchange Contact lens-related infection

Fundus examination could be performed through a crescent of clear red reflex around the cataract with a widely dilated pupil and was normal.

Comment At this time, discussion with our patient's parents centered on the causation of his cataracts and the possibility that they represented an "important clue" into his failure to thrive. A genetics and comprehensive inpatient pediatric admission were recommended to assist in his workup. We discussed the timing and risks of surgery, as discussed above. Due to his presenting nystagmus, visual prognosis was felt to be more uncertain. Nonetheless, it was advised to proceed with surgery. Because of his overall good state of health, surgeries were performed 1 week apart.

Two weeks after presentation, the patient successfully underwent bilateral lensectomy and posterior capsulotomy with anterior vitrectomy. He was given aphakic contact lenses. There was resolution of the nystagmus, and he appeared to intermittently fix and follow with each eye. His eye pressure was 11 in each eye with iCare tonometry, fundus examination was normal, and cycloplegic refraction was +20.0 in each eye. At this point, his systemic workup was unrevealing, and he began gaining weight appropriately.

Table 7.4 Rates of significant complications associated with pediatric cataract surgery

Complication[a]	Risk	Notes
Death	<1–10 deaths per 10,000 anesthetics [13–16]	Studies cited are not specific to ophthalmic procedures, which may have lower risk given the short case duration and hemodynamic stability of eye surgery compared to other organ surgeries. Incidence of anesthesia-related pulmonary and cardiac arrests is highest in neonates [17, 18]
Cardiac arrest	~500 in 1 million anesthetics [19]	Studies cited are not specific to ophthalmic procedures [19–22]
Anaphylaxis	~20 in 160,000 anesthetics [20]	
Laryngospasm/bronchospasm	~5 in 100 anesthetics [21]	
Malignant hyperthermia	~1 in 100,000 anesthetics [22]	
Infection	0.71% [3]	Most commonly diagnosed 48–96 hours after surgery. Gram-positive species are the most common organisms [3]
Retinal detachment (RD)	2.5%, 5-year incidence [23]	Median time to RD 70 months, 5.5% cumulative risk at 10 years [23]
Corneal changes (requiring surgical intervention)	<1% [24]	According to the Infant Aphakia Treatment Study (IATS)
Glaucoma suspect	31% at age ~5 years [25]	
Glaucoma	17% at age ~5 years [25, 26]	Variable rates reported in the literature
Need for additional surgery related to cataract surgery	13% of aphakic patients, 63% of pseudophakic patients [27]	Percentage of patients requiring additional intraocular surgery in the first 12 months. Most of such surgeries are for the purpose of clearing the visual axis [27]
Secondary membrane or proliferation of lens material	80% in pseudophakes less than age 1 year (percentage is lower in older children or children without IOL) [28]	Most frequent long-term post-op complication which can be amblyogenic if visually significant. Risk increases for traumatic cataracts, young children [28–30]

[a]Listed in order of severity

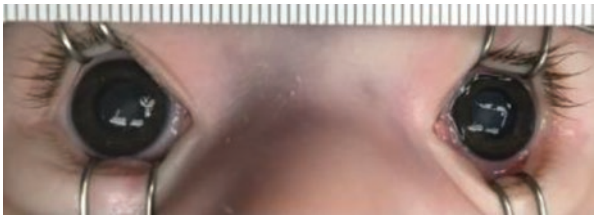

Fig. 7.2 External photo with ruler. Preoperative corneal assessment during examination under anesthesia demonstrates corneal diameters of 11 mm and 10 mm, respectively

Two years later, the patient was able to reliably read single Allen pictures in aphakic contact lenses, and his vision was 20/30 in each eye. Unfortunately, he had developed elevated eye pressures, enlarged corneal diameters, corneal clouding, and a myopic shift bilaterally but worse in the right eye, leading to the diagnosis of glaucoma following cataract surgery. He required surgical treatment for his right eye and topical antihypertensives in his left. He also underwent two strabismus surgeries for esotropia.

Comment The patient did well with improved early visual functioning and excellent acuity 2 years after his surgery. This case demonstrates how good visual outcomes can be achieved with prompt intervention, even if referral is delayed and the patient has signs of damage to the visual pathways (nystagmus) prior to lensectomy. Ongoing discussions with his parents continued to focus on the multiple nuances of recovery and care following cataract surgery.

We had decided on aphakic correction with contact lenses (see below for discussion of intraocular lens (IOL) implantation). The needs for long-term care included a discussion of the risks of amblyopia, strabismus, and glaucoma, among others. While patient age at the time of cataract surgery is a key risk factor for development of secondary glaucoma, delayed surgery (even a significant delay of 3 months) does not universally prevent secondary glaucoma. Due to excellent, consistent follow-up, we were able to diagnosis elevated eye pressure early, optimize our patient's outcome, and minimize risks of vision-threatening complications.

This patient's care was enhanced by consistent communication and collaboration with his pediatrician and our affiliated genetics team. Genetic testing identified a rare deletion previously reported in other individuals with congenital cataracts. This genetic finding offered a presumed genetic diagnosis but did not confirm the association with and etiology for his cataracts. Continued multidisciplinary involvement, including genetics subspecialists and genetic counselors, is an essential component of his ongoing ophthalmic care.

Primary Pseudophakia Versus Aphakia

The discussion of intraocular lens (IOL) implantation should review the risks and benefits specific to this unique surgical situation. Although IOLs have been found to be safe and effective in children, the Infant Aphakia Treatment Study (IATS) did not demonstrate a visual benefit to primary IOL implantation over primary aphakia

Table 7.5 Risks specific to intraocular lens (IOL) implantation

Postoperative complications	
Posterior capsule opacification Anterior capsular phimosis Secondary membrane Pupillary abnormalities	May require surgery to clear visual axis
Lens reproliferation causing IOL decentration Primary decentration IOL repositioning Anterior IOL malposition with or without iris capture exchange Refractive surprise Myopic shift with axial growth	May require or IOL
Inflammation Cystoid macular edema	May require medical management.

with contact lens placement in children with unilateral congenital cataracts. In the IATS, there was an increased rate of adverse events and higher rate of additional surgeries in the IOL compared with the aphakic group [31–33]. Disadvantages of primary IOL implantation that should be discussed include increased ocular inflammation, scarring, and the potential need for additional surgery including lens power changes [28, 32, 34]. Table 7.5 details specific risks related to IOL implantation in children.

It should be explained that the majority of the growth of the eye occurs during the first 2 years of life; however, the eye continues to grow and elongate throughout the second decade. This makes selecting an IOL power to minimize refractive error in young adulthood a challenge due to our limited accuracy in predicting the growth trajectory of each child's eye [34, 35]. Various refractive options should be discussed including aiming for a hyperopic correction to avoid a large amount of myopia later in life versus aiming for emmetropia with the use of a piggyback lens or refractive surgery when the axial length has stabilized [36]. Multifocal IOLs may be considered for older children [35, 37].

If the patient is to be placed in aphakic contact lenses, the management of contact lenses should be discussed in detail preoperatively. Active involvement and participation from the patient's caretaker are critical for success with contact lenses [38]. The caretaker will need to be comfortable with insertion, removal, and cleaning of contact lenses. Families should be counseled preoperatively that adherence to patching and contact lenses is essential for prevention of amblyopia. Disadvantages of contact lenses include the cost associated with frequent replacement due to mucous buildup and change in refractive power [39]. If the physician or family suspects that there are barriers to successful management of aphakic contact lenses that put the patient at risk for poor vision, the physician may in turn select IOL implantation or aphakic spectacles [40].

Long-Term Management

It is important to counsel families that regular ophthalmologic care will extend far beyond the time of the initial cataract surgery and the immediate postoperative period. Preparing families for long-term surveillance allows the ophthalmologist to follow closely for pathology associated with pediatric cataracts and cataract surgery. Amblyopia, secondary glaucoma, and strabismus are three of the most common long-term complications associated with pediatric cataracts. A complete and thorough discussion of these risks should take place. Families should understand that frequent follow-up appointments for patching, refraction, adjustment of spectacles and/or contact lenses, and monitoring of intraocular pressure are an important part of the long-term management and treatment of pediatric cataracts.

Amblyopia

Families should be aware that cataract extraction does not guarantee full visual recovery. Children with cataracts are at high risk for amblyopia [41]. Early cataract surgery reduces the risk of amblyopia; however, postoperative amblyopia therapy is equally as important. Families should be counseled that patching and optical correction, including glasses and aphakic contact lenses, will be needed, with frequent adjustment to account for refractive shifts as the eye grows. The IATS demonstrated that higher socioeconomic status, lower parental stress, and younger age of the child were associated with improved adherence to postoperative patching regimens [42]. These potential factors may help identify parents who require additional guidance in the postoperative period to optimize long-term patient outcomes. It is also important to utilize social support or additional services when needed to help families adhere fully to the prescribed visual rehabilitation regimen.

Glaucoma

Secondary glaucoma is a potential and serious complication that should be discussed with families prior to pediatric cataract surgery. Glaucoma occurs in 15–30% of cases and may be detected as early as 2 weeks or as late as 5 years following cataract surgery [29, 43–46]. It is often insidious in onset without the typical hallmark findings of primary congenital glaucoma (buphthalmos, epiphora, corneal clouding). Therefore, close intraocular pressure and optic nerve monitoring by the ophthalmologist are required for detection of glaucoma long after the initial surgery and at every clinical visit postoperatively [46]. Glaucoma after cataract surgery is more common in children with microphthalmia and microcornea and in those who

undergo cataract surgery at a younger age, although it may occur in children without these risk factors. Additional risk factors for developing glaucoma include persistent fetal vasculature, prolonged postoperative inflammation, and the need for multiple operations [46, 47]. As previously mentioned, families should be counseled that the most readily modifiable risk factor for developing secondary glaucoma following cataract extraction is the age at which the child undergoes cataract surgery. Delaying cataract surgery – especially unilateral cataract surgery – significantly increases the risk of amblyopia. Therefore, a degree of postoperative glaucoma risk is most often accepted by the surgeon in order to reduce the risk of amblyopia development.

Strabismus

The majority of children who undergo cataract surgery will develop strabismus, and it is often present at the time of cataract diagnosis [48]. In some instances, parents may have noticed their child's ocular misalignment prior to ophthalmologic evaluation. It is important to counsel parents that almost half of children with pediatric cataracts will require strabismus surgery following cataract extraction [49]. Families should be counseled that success with strabismus surgery in this population is lower compared to children without cataracts and the rate of reoperation may be higher. This is due to amblyopia disrupting binocular functioning required to help drive ocular alignment.

Long-Term Visual Prognosis

Parents will want to know what can be done to ensure that their child has the best possible outcome following cataract surgery. A host of factors impact a child's long-term visual prognosis including, but not limited to, the age of cataract onset and timing of cataract extraction, the density and laterality of the cataract (unilateral versus bilateral), associated ocular and systemic pathology, and the quality of postoperative visual rehabilitation. Children who are of kindergarten age or older when they develop cataracts, and infants who have early surgery for bilateral cataracts, have a superior visual prognosis compared to those with early-onset unilateral cataracts. Major studies such as the IATS can be referenced to explain that almost half the children in the latter group achieved vision better than 20/200 following cataract surgery and the majority acquired some depth perception [6–8]. Close surveillance, possible chronic intraocular pressure-lowering therapy, and, often, additional eye surgeries are often required. Therefore, long-term treatment and support must be offered well after the initial cataract surgery is completed in order to optimize and preserve the child's visual functioning.

Health Literacy and Informed Consent

It is important for physicians to gauge the family's health literacy in order to guide preoperative discussions and to target patient information materials and written consent forms appropriately. Families with limited education levels or literacy skills pose a challenge in preoperative counseling and obtaining informed consent for pediatric cataract surgery. Written and verbal discussions with families should take into account that 50% of the US population cannot read above an eighth-grade level. Even patients with the highest levels of education may have limited health literacy, hindering their ability to understand health information and make appropriate health-related decisions. The National Institutes of Health and American Medical Association recommend that patient educational resources be written at or below an eighth-grade reading level so that the information is accessible to most patients. While the risks and nuances of long-term management of pediatric cataracts may be complex, the surgeon should make every effort to use clear, concise, and simple language in counseling patients and their families [50, 51].

Appendix 1 contains a sample consent form that can be used during the preoperative discussion with families in planning for pediatric cataract surgery. This form is modified from the adult cataract consent form available on the Ophthalmic Mutual Insurance Company web page and is validated through readability indexes to be written at or below an eighth-grade level.

Case 2

An 11-month-old baby boy with trisomy 21 was referred by his pediatrician for dull red reflexes. He presented to the ophthalmology clinic with his parents, who live in a rural area 2 hours away. His mother and father are 17 years old, did not attend high school, and have a history of substance abuse. The patient was found to have visually significant cataracts in both eyes (Fig. 7.3). After thorough discussion with the family regarding the risks and benefits of surgery, the decision was made to pursue bilateral sequential lensectomy, without implantation of an intraocular lens.

Immediate postoperative appointments were uneventful, and the postsurgical course was without complications. Two weeks later, the patient failed to return for follow-up appointments. A pediatric clinical social worker was then recruited to assist in contacting social services, and transportation was provided for appointments. The patient's grandmother was noted to be an involved caretaker, and she was encouraged to attend all clinic appointments along with the parents. The family was educated on the importance of timely follow-up and the risks of vision loss. Given the complex social dynamic and inconsistent follow-up history, aphakic spectacles were prescribed instead of contact lenses.

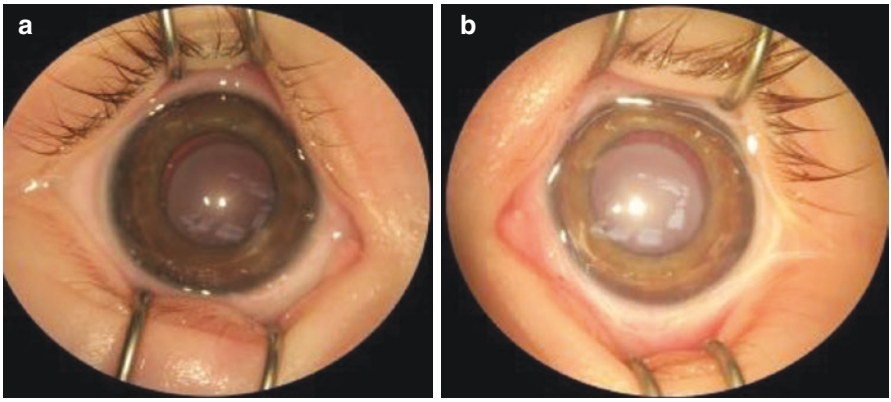

Fig. 7.3 Microscope view bilaterally. Preoperative lens assessment during examination under anesthesia demonstrates bilateral dense lamellar cataracts

After 3 years of follow-up, the patient was 4 years old and demonstrated very good vision. He continued to return for follow-up appointments with the assistance of social services. He is doing well with aphakic spectacles and may be a good candidate for secondary IOL implantation in the future.

Comment The surgeon should identify any potential barriers to postoperative management and timely follow-up prior to cataract surgery. This may include difficulty obtaining medications, contact lenses, glasses, or attending postoperative appointments. Early involvement of social support services should not be overlooked in its ability to assist in these vital components of post-cataract surgery rehabilitation. For situations where primary caregivers are unable to adequately absorb all duties of the postoperative care, other family members can be recruited. Understanding family dynamics and identifying risk factors can aid in the decision to use aphakic spectacles versus contact lenses or to implant a secondary intraocular lens.

Appendix 1: Pediatric Cataract Surgery Consent Form

What Is a Cataract?

The lens is the clear part of your eye that helps focus images. *A cataract* happens when the lens of the eye becomes cloudy. Cataracts can cause blurry vision or blindness in children. If a cataract is not removed early in life, a child may develop permanent vision loss. This is a serious condition, since vision is important for the brain to develop.

What Causes Cataracts?

Some children are born with cataracts. Other children develop cataracts from medications, infections, eye injuries, or medical diseases. Some cataracts are genetic (can run in families).

How Are Cataracts Treated?

Surgery is the only way to remove a cataract. During cataract surgery, an eye surgeon will remove the cloudy lens. The surgeon may replace the cloudy lens with an "IOL" (intraocular lens, a clear artificial lens). The surgeon may choose to leave your child without a lens (aphakia). In this case, the child may need glasses and/or contact lenses following surgery. In some cases, an IOL can be placed in the eye years after the cataract is removed.

What Are the Major Risks of Cataract Surgery?

Cataract surgery is usually safe and successful. There are risks (problems that can happen) with cataract surgery. While the eye surgeon cannot tell you about every risk, here are some of the common or serious risks:

- *Risks from cataract surgery* include vision loss, blindness, or negative results. Bleeding, damage to parts of the eye, infection, and inflammation can happen. The retina at the back of the eye can pull away from where it is attached (detached retina).
- Your child may need another surgery to take out pieces of the cataract that were not removed.
- *Glaucoma (high eye pressure)* can happen after cataract surgery. Children with glaucoma may need eye drops or glaucoma surgery. Glaucoma can happen whether or not your child has an IOL.
- *It is common for part of the lens to grow back.* This can form a lens membrane or "after cataract." Your child may need a laser procedure or another surgery to remove a lens membrane.
- *Most children will need glasses and/or a contact lens* after cataract surgery.
- *Lazy eye (amblyopia)* is common, and children may need eye patches or drops after cataract surgery.
- *Misaligned eyes (strabismus) and poor depth perception (stereopsis)* can happen, and children may need eye muscle surgery.
- Your child may need frequent eye surgery or exams that require anesthesia.
- *Anesthesia* can cause heart and breathing problems. Very rarely, it can cause death.

- *Other risks.* Cataract surgery only corrects vision problems caused by cataracts. This surgery cannot correct vision problems caused by problems in other parts of the eye. There is no guarantee that cataract surgery will improve your child's vision. It is possible that vision loss, blindness, or even the loss of an eye can occur. These problems can appear weeks, months, or even years after surgery.

Risks from an IOL

Adults with cataracts almost always have an IOL put in their eye. In children, this part of surgery is slightly more risky, so for children with cataracts, an IOL is optional. The good part of an IOL is that it decreases the need for strong glasses or contact lenses. The bad part of an IOL is the slightly increased risk of needing additional future surgery. Most children will be good candidates for putting a lens implant in at a later surgery, when it might be safer or more accurate. As your child's eye grows, the power of the eye changes. The IOL may be too weak or too strong. The eye surgeon may need to replace your child's IOL or make changes to glasses months or years after surgery. An IOL can cause inflammation, glaucoma, scarring, a lens membrane, or other surgery complications.

Acceptance of Risks

I understand that it is impossible for the doctor to inform me of every possible complication that may occur. By signing below, I agree that I have read this form or someone has read it to me, that my doctor has answered all of my questions, and that I understand and accept the risks, benefits, and alternatives of cataract surgery.

I consent for my child to have cataract surgery with an intraocular lens (IOL) in the _____ (state right eye, left eye, or both eyes).

_____ _____
Person authorized to sign for the patient Date

_____ _____
Surgeon Date

References

1. Miller DT, Adam MP, Aradhya S, et al. Consensus statement: chromosomal microarray is a first-tier clinical diagnostic test for individuals with developmental disabilities or congenital anomalies. Am J Hum Genet. 2010;86(5):749–64. https://doi.org/10.1016/j.ajhg.2010.04.006.

2. American College of Medical Genetics (ACMG and commissioned by the Health Resources and Services Administration (HRSA)). Newborn screening: towards a uniform screening panel and system. Genetic Med. 2006;8(5 Suppl):S12–S252.
3. Hug D. Pediatric cataracts and lens anomalies. In: Nelson L, Olitsky S, editors. Harley's pediatric ophthalmology. 6th ed. Philadelphia: Lippincott Williams & Wilkins; 2014. p. 238–57.
4. Wright KW. Lens abnormalities. In: Wright KW, Spiegel PH, editors. Pediatric ophthalmology and strabismus. 2nd ed. New York: Springer; 2003. p. 451–80.
5. Birch EE, Cheng C, Stager DR, et al. The critical period for surgical treatment of dense congenital bilateral cataracts. J AAPOS. 2009;13:67–71. https://doi.org/10.1016/j.jaapos.2008.07.010.
6. Birch EE, Stager DR. The critical period for surgical treatment of dense congenital unilateral cataract. Invest Ophthalmol Vis Sci. 1996;37(8):1532–8.
7. Birch EE, Stager DR. Prevalence of good visual acuity following surgery for congenital unilateral cataract. Arch Ophthalmol. 1988;106(1):40–3.
8. Brown SM, Archer S, Del Monte MA. Stereopsis and binocular vision after surgery for unilateral infantile cataract. J AAPOS. 1999;3(2):109–13.
9. Jeffrey BG, Birch EE, Stager DR, et al. Early binocular visual experience may improve binocular sensory outcomes in children after surgery for congenital unilateral cataract. J AAPOS. 2001;5:209–16. https://doi.org/10.1067/mpa.2001.115591.
10. Lambert SR. The timing of surgery for congenital cataracts. J AAPOS. 2016;20:191–2. https://doi.org/10.1016/j.jaapos.2016.04.003.
11. Lambert SR, Lynn MJ, Reeves R, et al. Is there a latent period for the surgical treatment of children with dense bilateral congenital cataracts? J AAPOS. 2006;10:30–6. https://doi.org/10.1016/j.jaapos.2005.10.002.
12. Dave H, Phoenix V, Becker ER, Lambert SR. Simultaneous vs sequential bilateral cataract surgery for infants with congenital cataracts: visual outcomes, adverse events, and economic costs. Arch Ophthalmol. 2010;128:1050–4. https://doi.org/10.1001/archophthalmol.2010.136.
13. Gonzalez LP, Pignaton W, Kusano PS, Módolo NS, Braz JR, Braz LG. Anesthesia-related mortality in pediatric patients: a systematic review. Clinics (Sao Paulo). 2012;67(4):381–7. Review.
14. Habre W, Disma N, Virag K, Becke K, Hansen TG, Jöhr M, Leva B, Morton NS, Vermeulen PM, Zielinska M, Boda K, Veyckemans F, APRICOT Group of the European Society of Anaesthesiology Clinical Trial Network. Incidence of severe critical events in pediatric anesthesia (APRICOT): a prospective multicenter observational study in 261 hospitals in Europe. Lancet Respir Med. 2017;5(5):412–25.
15. Murat I, Constant I, Maud'huy H. Perioperative anesthetic morbidity in children: a database of 24,165 anaesthetics over a 30-month period. Paediatr Anaesth. 2004;14(2):158–66.
16. Irita K, Kawashima Y, Iwao Y, Seo N, Tsuzaki K, Morita K, Obara H. Annual mortality and morbidity in operating rooms during 2002 and summary of morbidity and mortality between 1999 and 2002 in Japan: a brief review. Masui. 2004;53(3):320–35. Review. Japanese.
17. Odegard KC, DiNardo JA, Kussman BD, Shukla A, Harrington J, Casta A, McGowan FX Jr, Hickey PR, Bacha EA, Thiagarajan RR, Laussen PC. The frequency of anesthesia-related cardiac arrests in patients with congenital heart disease undergoing cardiac surgery. Anesth Analg. 2007;105(2):335–43.
18. Bharti N, Batra YK, Kaur H. Pediatric perioperative cardiac arrest and its mortality: a database of a 60-month period from a tertiary care pediatric center. Eur J Anaesthesiol. 2009;26(6):490–5.
19. Christensen RE, Lee AC, Gowen MS, Rettiganti MR, Deshpande JK, Morray JP. Pediatric perioperative cardiac arrest, death in the off hours: a report from wake up safe, the pediatric quality improvement initiative. Anesth Analg. 2018;127(2):472–7.
20. Murat I. Anaphylactic reactions during paediatric anaesthesia; results of the survey of the French Society of Paediatric Anaesthetists (ADARPEF) 1991–1992. Pediatr Anesth. 1993;3(6):339–43.

21. Tait AR, Malviya S, Voepel-Lewis T, Munro HM, Seiwert M. Risk factors for perioperative adverse respiratory events in children with upper respiratory tract infections. Anesthesiology. 2001;95(2):299–306.
22. Brady JE, Sun LS, Rosenberg H, Li G. Prevalence of malignant hyperthermia due to anesthesia in New York State, 2001–2005. Anesth Analg. 2009;109(4):1162.
23. Agarkar S, Gokhale VV, Raman R, et al. Retinal detachment after pediatric cataract surgery. Ophthalmology. 2018;125:36–42.
24. Morrison DG, Lynn MJ, Freedman SF, Orge FH, Lambert SR, Infant Aphakia Treatment Study Group. Corneal changes in children after unilateral cataract surgery in the IATS. Ophthalmology. 2015;122(11):2186–92.
25. Freedman SF, Lynn MG, Beck AD, Bothun ED, Orge FH, Lambert SR. Glaucoma-related adverse events in the first 5 years after unilateral cataract removal in the Infant Aphakia Treatment Study. JAMA Ophthalmol. 2015;133(8):907–14.
26. Mataftsi A, Haidich AB, Kokkali S, Rabiah PK, Birch E, Stager DR Jr, Cheong-Leen R, Singh V, Egbert JE, Astle WF, Lambert SR, Amitabh P, Khan AO, Grigg J, Arvanitidou M, Dimitrakos SA, Nischal KK. Postoperative glaucoma following infantile cataract surgery: an individual patient data meta-analysis. JAMA Ophthalmol. 2014;132(9):1059–67.
27. Plager DA, Lynn MJ, Buckley EG, Wilson ME, Lambert SR, Infant Aphakia Treatment Study Group. Complications, adverse events, and additional intraocular surgery 1 year after cataract surgery in the Infant Aphakia Treatment Study. Ophthalmology. 2011;118(12):2330–4.
28. Plager DA, Yang S, Neely D, et al. Complications in the first year following cataract surgery with and without IOL in infants and older children. J AAPOS. 2002;6(1):9–14.
29. Trivedi RH, Wilson E. Posterior capsule opacification in pediatric eyes with and without traumatic cataract. J Cataract Refract Surg. 2015;41:1461–4.
30. Peterseim MW, Wilson ME. Bilateral intraocular lens implantation in the pediatric population. Ophthalmology. 2000;107:1261–6.
31. Lambert SR, Lynn MJ, Hartmann EE, et al. Comparison of contact lens and intraocular lens correction of monocular aphakia during infancy. JAMA Ophthalmol. 2014;132:676. https://doi.org/10.1001/jamaophthalmol.2014.531.
32. Plager DA, Lynn MJ, Buckley EG, et al. Complications, adverse events, and additional intraocular surgery 1 year after cataract surgery in the Infant Aphakia Treatment Study. Ophthalmology. 2011;118:2330–4. https://doi.org/10.1016/j.ophtha.2011.06.017.
33. Wilson ME, Trivedi RH, Morrison DG, et al. The Infant Aphakia Treatment Study: evaluation of cataract morphology in eyes with monocular cataracts. J AAPOS. 2011;15:421–6. https://doi.org/10.1016/j.jaapos.2011.05.016.
34. Plager DA, Lipsky SN, Snyder SK, et al. Capsular management and refractive error in pediatric intraocular lenses. Ophthalmology. 1997;104:600–7. https://doi.org/10.1016/S0161-6420(97)30264-4.
35. Wilson ME, Trivedi RH, Burger BM. Eye growth in the second decade of life: implications for the implantation of a multifocal intraocular lens. Trans Am Ophthalmol Soc. 2009;107:120–4.
36. Hug D, Nelson L. Harley's pediatric ophthalmology. 6th ed. Lippincott Williams & Wilkins. Philadelphia; 2014.
37. Wilson ME, Trivedi RH. Choice of intraocular lens for pediatric cataract surgery: survey of AAPOS members. J Cataract Refract Surg. 2007;33:1666–8.
38. Cromelin CH, Drews-Botsch C, Russell B, Lambert SR. Association of contact lens adherence with visual outcome in the infant Aphakia treatment study. JAMA Ophthalmol. 2018;136:279. https://doi.org/10.1001/jamaophthalmol.2017.6691.
39. Lambert SR, Kraker RT, Pineles SL, et al. Contact Lens correction of Aphakia in children. Ophthalmology. 2018;125:1452–8. https://doi.org/10.1016/j.ophtha.2018.03.014.
40. Awad AH, Mullaney PB, Al-Hamad A, et al. Secondary posterior chamber intraocular lens implantation in children. J AAPOS. 1998;2:269–74. https://doi.org/10.1016/S1091-8531(98)90082-9.

41. Lambert S, Lyons C. Childhood cataracts. In: Lambert SR, Lyons CJ, editors. Taylor & Hoyt's pediatric ophthalmology and strabismus. 5th ed. London/New York: Elsevier; 2017. p. 346–61.
42. Drews-Botsch CD, Hartmann EE, Celano M. Predictors of adherence to occlusion therapy 3 months after cataract extraction in the Infant Aphakia Treatment Study. J AAPOS. 2012;16:150–5. https://doi.org/10.1016/j.jaapos.2011.12.149.
43. Beck AD, Freedman SF, Lynn MJ, et al. Glaucoma-related adverse events in the infant aphakia treatment study: 1-year results. Arch Ophthalmol. 2012;130:300–5. https://doi.org/10.1001/archophthalmol.2011.347.
44. Freedman SF, Lynn MJ, Beck AD, et al. Glaucoma-related adverse events in the first 5 years after unilateral cataract removal in the infant aphakia treatment study. JAMA Ophthalmol. 2015;133:907–14. https://doi.org/10.1001/jamaophthalmol.2015.1329.
45. Mataftsi A, Haidich AB, Kokkali S, et al. Postoperative glaucoma following infantile cataract surgery: an individual patient data meta-analysis. JAMA Ophthalmol. 2014;132:1059–67. https://doi.org/10.1001/jamaophthalmol.2014.1042.
46. Rabiah PK. Frequency and predictors of glaucoma after pediatric cataract surgery. Am J Ophthalmol. 2004;137:30–7. https://doi.org/10.1016/S0002-9394(03)00871-7.
47. Papadopoulos M, Khaw P. Childhood glaucoma. In: Lambert SR, Lyons CJ, editors. Taylor & Hoyt's pediatric ophthalmology and strabismus. 5th ed. London/New York: Elsevier; 2017. p. 362–77.
48. Bothun ED, Lynn MJ, Christiansen SP, et al. Sensorimotor outcomes by age 5 years after monocular cataract surgery in the Infant Aphakia Treatment Study (IATS). J AAPOS. 2016;20:49–53. https://doi.org/10.1016/j.jaapos.2015.11.002.
49. Bothun ED, Lynn MJ, Christiansen SP, et al. Strabismus surgery outcomes in the Infant Aphakia Treatment Study (IATS) at age 5 years. J AAPOS. 2016;20(6):501–5.
50. John AM, John ES, Hansberry DR, et al. Analysis of online patient education materials in pediatric ophthalmology. J AAPOS. 2015;19:430–4. https://doi.org/10.1016/j.jaapos.2015.07.286.
51. Morrison AK, Glick A, Yin HS. Health literacy: implications for child health. Pediatr Rev. 2019;40:263–77. https://doi.org/10.1542/pir.2018-0027.