Supplementary material for < Olteanu C, Dimaras, H>, < Enucleation Refusal for Retinoblastoma: A Global Study>, <Ophthalmic Genetics>, <2014>

Supplementary Table 1. Summary of survey responses sorted by country

World Bank Income Status	Geographical Region	Responses (#)
HICs	Asia	
	Japan	1
	Singapore	1
	Australia	
	Australia	1
	Europe	
	United Kingdom	2
	Netherlands	2
	Spain	1
	Austria	1
	Finland	1
	North America	
	Canada	4
	United States	10
Total		24
LMICs	Africa	
	Nigeria	2
	Egypt	2
	Kenya*	3
	Asia	
	Thailand	1
	Malaysia	2
	Iran	1
	Jordan	1
	India	3
	Uzbekistan	1
	Central America	
	Mexico	1
	Honduras	1
	South America	
	Brazil	1
	Colombia	1
	Argentina	1
Total		21

*low income
country

Supplementary Table 2. Factors Influencing Parental Acceptance of Enucleation after Initial Refusal

Theme	Description	Comments (edited for grammar) from Survey Respondents
<i>Education of parents</i>	<ul style="list-style-type: none"> Parental understanding of the disease, benefits of enucleation, and future consequences if eye is not removed 	<ul style="list-style-type: none"> Parental education alone can change the situation When some parents who are initially opposed to enucleation are educated and they become aware of the implications, they often accept it [enucleation] Yes, by explaining the advantages of it [enucleation] Demonstrate the need for enucleation Fear of blindness and facial disfigurement is very strong; for this reason, acquaintance with enucleated patients is my best weapon against enucleation refusal Explain extraocular retinoblastoma and [patient] survival In most cases they [parents] finally approve for fear of their child's death
	<ul style="list-style-type: none"> Use of visuals to answer parents' questions to help them understand disease and prognosis 	<ul style="list-style-type: none"> Give parents all the time they need to talk to the doctor, answer all the questions they have in mind (although they might ask the same question over and over), explain in detail what will happen to their child right after enucleation and long term care Show orthoptic findings about low vision or blindness, RetCam, Ultrasound, MR Images. Explain prognosis.
	<ul style="list-style-type: none"> Enucleation is performed when other therapies do not work 	<ul style="list-style-type: none"> Despite focal therapy, vitreous seeding became evident and parent agreed (multiple images, discussions) [Parents accepted enucleation] after counsel, but mostly after parents have tired of all other treatments
<i>Cross-Consultation</i>	<ul style="list-style-type: none"> Parents have received the same opinion from another specialized centre 	<ul style="list-style-type: none"> [Parents accepted enucleation] after the parents sought second or third opinions [Parents accepted enucleation] but only after 2nd opinion at another hospital Second opinions sometimes help [Parents accepted enucleation] after being advised of enucleation at another specialized center
	<ul style="list-style-type: none"> Discussion, counseling 	<ul style="list-style-type: none"> [Parents accepted enucleation] visits with other enucleated retinoblastoma patients [Parents accepted enucleation] after counseling, or
<i>Family Support</i>	<ul style="list-style-type: none"> Involve other family members or relatives 	<ul style="list-style-type: none"> We let them discuss with other family members and involve the whole family. Be patient. [Parents accepted enucleation] by counseling all family members repeatedly Give the parents few days to think, to accept the idea, get out of denial phase, get another opinion and discuss issues with relatives
	<ul style="list-style-type: none"> Involve support services and support groups 	<ul style="list-style-type: none"> [Parents accepted enucleation] with help of social services and other family members Social assistance system is very important, for example, stepless road, voice guidance [Support] is easy available in our country and offered to all patients and parents Access to prosthesis and low vision services if needed
	<ul style="list-style-type: none"> Meeting other patients who have had 	<ul style="list-style-type: none"> [Parents accepted enucleation] after meeting other affected families

enucleation

- I ask parents who experienced the loss of their child due to retinoblastoma to talk to them.
- Group counseling between a family with a good outcome and the new patient [encourages acceptance of enucleation]

Supplementary Table III. LMIC physician suggestions to facilitate parental acceptance of enucleation.

Theme	Description	Comments (edited for grammar) from Survey Respondents
<i>A team approach to care</i>	• Characteristics of the health care team (supportive, caring, empathetic)	<ul style="list-style-type: none">• We have a team of people who talk to the family and let them know we care• Empathy and careful explanation, provide chances to seek second opinion• Repeated counseling and good communication skills• Good parent-medical relations, self-confidence, information, good team support
	• Family setting during communication with the medical team	<ul style="list-style-type: none">• Gather as many members of patient's family when explaining enucleation, highlighting that it is the only treatment option• For young parents, ask for grandparents to be involved in decision making
	• Involvement of community to raise awareness and social acceptance	<ul style="list-style-type: none">• General awareness about the disease, media involvement in creating awareness in a sensitive way and creating social acceptance of such children and encouragement from responsible societies and government• Education, culturally focused, with support from community and religious leaders
<i>Increased time with parents</i>	• More time to facilitate education and family acceptance of treatment	<ul style="list-style-type: none">• We call the family at least 3 times before giving up.• On several occasions, by giving the parents some time to decide (in the meantime giving the child a few cycles of chemotherapy) could help the parents change their minds and accept enucleation.• Allow sufficient time, multiple consultations, thorough explanations
<i>Transition planning</i>	• Sharing enucleation success stories	<ul style="list-style-type: none">• Give examples of saved and unsaved lives for treated/untreated patients• Need pictures of children with cancer who had enucleation and given prosthesis• Discussing survival stories with parents• [Have parents] talk to patient families with similar pathology

***Improved
supports for the
visually
impaired***

- Cosmetic appearance and prosthetic eyes
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- Improved access and availability
- Additional supports to facilitate education, employment, integration into society

- It is better to give the child a prosthesis so that the face is cosmetically accepted
 - If patients are sure that the surgery will have good cosmetic outcome [they will accept enucleation]
 - There should be more facilities to support the child who needs enucleation and his parents
 - Psychosocial support is very important
 - Special concessions at school, job, etc
 - Need: 1.better social and educational resources for the blind; 2. role-models for the blind; 3. disability-friendly society
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