RETINOBLASTOMA REGISTRY

Office use: Centre: ____ / ____

Where check boxes ☐ are provided, check (√) one or more boxes. Where radio buttons ◯ are provided, check (√) one box only.

i) Hospital / Clinic: _____ **ii) Dr in charge :** _____ **iii) Date of Notification :** __ / __ / ____

SECTION A : DEMOGRAPHICS

1. Patient Name :

2. Identification Card Number : *
If MyKad/MyKid is not available, please complete the Old IC or Other ID document No.

MyKad / MyKid: ____ - __ - ____ *Old IC:* ____

Other ID document No: ____ → *Specify type (eg.passport, armed force ID):* ____

3. Address : Postcode ____ Town / City: ____ State: ____

4. Contact number : Homephone: ____ - ____ H/P: ____ - ____

5. Date of Birth: * d d m m y y

6. Age at presentation: * ____ year(s) ____ month(s)

7. Gender: * ◯ Male ◯ Female

8. Ethnic: ◯ Malay ◯ Indian ◯ Melanau ◯ Iban ◯ Other, specify: ◯ Chinese ◯ Orang Asli ◯ Kadazan/Murut/Bajau ◯ Bidayuh

SECTION B : OCULAR HISTORY AND PRESENTATION

1. Clinical presentation: ☐ Leukocoria ☐ Strabismus ☐ Proptosis ☐ Others, specify: ____

2. Age of onset: ____ year(s) ____ month(s)

3. Duration of disease: ____ month(s)

4. Eye affected: ◯ Right ◯ Left ◯ Both

5. Family History: ◯ Yes ◯ No

6. Vision at presentation:

	Right eye	Left eye
6a. Vision:	Unaided: ____ With glasses/pin hole: ____	Unaided: ____ With glasses/pin hole: ____
6b. Unable to take vision, appear to have:	◯ Normal vision ◯ Impaired vision ◯ Blind	◯ Normal vision ◯ Impaired vision ◯ Blind

SECTION C : REFER TO TERTIARY CENTER

1. Refer to tertiary center: ◯ No ◯ Yes → **Hospital :** ____

SECTION D : INVESTIGATIONS & CLASSIFICATION

1. Imaging:

	Right eye	Left eye
a) CT scan:	◯ No ◯ Yes → ☐ Presence of mass ☐ Presence of calcification ☐ Extraocular extension → ☐ Optic pathway ☐ Orbit and adnexa ☐ Intracranial	◯ No ◯ Yes → ☐ Presence of mass ☐ Presence of calcification ☐ Extraocular extension → ☐ Optic pathway ☐ Orbit and adnexa ☐ Intracranial
b) MRI:	◯ No ◯ Yes → ☐ Presence of mass ☐ Presence of calcification ☐ Extraocular extension → ☐ Optic pathway ☐ Orbit and adnexa ☐ Intracranial	◯ No ◯ Yes → ☐ Presence of mass ☐ Presence of calcification ☐ Extraocular extension → ☐ Optic pathway ☐ Orbit and adnexa ☐ Intracranial

2. Genetic testing (blood): ◯ No ◯ Yes → ◯ + ve ◯ - ve

3. Diagnosis:

Right eye	Left eye
◯ Confirmed Retinoblastoma ◯ Not Retinoblastoma, other diagnosis: ☐ Congenital cataract ☐ Coat's disease ☐ Retinal Dysplasia ☐ Persistent fetal vasculature ☐ Others, specify:	◯ Confirmed Retinoblastoma ◯ Not Retinoblastoma, other diagnosis: ☐ Congenital cataract ☐ Coat's disease ☐ Retinal Dysplasia ☐ Persistent fetal vasculature ☐ Others, specify:

4. Classification: International Intraocular Retinoblastoma Classification (IIRC)

Right eye	Left eye
◯ Group A ◯ Group B ◯ Group C ◯ Group D ◯ Group E	◯ Group A ◯ Group B ◯ Group C ◯ Group D ◯ Group E

SECTION E : MANAGEMENT (to be filled up after 3 months)

1. Chemotherapy: ◯ No ◯ Yes → ☐ Systemic Chemotherapy: ____ cycles ☐ Ocular chemotherapy injection: → ☐ Subtenon Injection: ☐ Intraviteal injection:

	Right eye	Left eye
Subtenon Injection:	____ times	____ times
Intraviteal injection:	____ times	____ times

	Right eye	Left eye
2. Enucleation:	◯ No ◯ Yes → HPE Result - Extension of tumour based on HPE results : ◯ Intraocular (no extraocular extension) ◯ With extraocular extension → ☐ Lamina cribrosa ☐ Bruch's membrane ☐ Superficial choroids ☐ Deep choroids ☐ Sclera ☐ Optic nerve end	◯ No ◯ Yes → HPE Result - Extension of tumour based on HPE results : ◯ Intraocular (no extraocular extension) ◯ With extraocular extension → ☐ Lamina cribrosa ☐ Bruch's membrane ☐ Superficial choroids ☐ Deep choroids ☐ Sclera ☐ Optic nerve end
3. Focal therapy:	◯ No ◯ Yes → ☐ Laser ☐ Cryotherapy	◯ No ◯ Yes → ☐ Laser ☐ Cryotherapy
4. Radiotherapy:	◯ No ◯ Yes → ☐ External beam radiation (EBRT) ☐ Plaque radiotherapy ☐ Intensity modulated radiotherapy (IMRT)	◯ No ◯ Yes → ☐ External beam radiation (EBRT) ☐ Plaque radiotherapy ☐ Intensity modulated radiotherapy (IMRT)

5. Traditional complementary medicine : ◯ No ◯ Yes

SECTION F : OUTCOME & COMPLICATIONS (to be filled up after 1 year)

1. Vision:

	Right eye	Left eye
1a. Vision at the last follow up soon after 1 year:	Unaided: ____ With glasses/pin hole: ____	Unaided: ____ With glasses/pin hole: ____
1b. Unable to take vision, appear to have:	◯ Normal vision ◯ Impaired vision ◯ Blind	◯ Normal vision ◯ Impaired vision ◯ Blind
2. Remission:	◯ No regression ◯ Partial regression → ◯ Complete; Type of regression: ☐ Flat scar ☐ Calcification ☐ Fish-flesh ☐ Mixed	◯ No regression ◯ Partial regression → ◯ Complete; Type of regression: ☐ Flat scar ☐ Calcification ☐ Fish-flesh ☐ Mixed
3. Recurrence:	◯ No ◯ Yes → Duration from first time treatment: ____ month(s)	◯ No ◯ Yes → Duration from first time treatment: ____ month(s)
4. Complications:	◯ No ◯ Yes → ☐ Socket / prosthesis related, specify ☐ Disease related, specify: ☐ Chemo related, specify: ☐ Radiation related, specify:	◯ No ◯ Yes → ☐ Socket / prosthesis related, specify ☐ Disease related, specify: ☐ Chemo related, specify: ☐ Radiation related, specify:

5. Lost to follow up : ◯ No ◯ Yes

6. Outcome by 1 year : ◯ Alive ◯ Death ◯ Unknown