

My Rb Summary

Name _____

Date of birth _____

NHS number _____



Childhood Eye Cancer Trust
Fighting Retinoblastoma

The Childhood Eye Cancer Trust offer lifelong support to children and families, young people, and adults affected by retinoblastoma (Rb). Rb is a rare cancer and as a result, many healthcare professionals are unfamiliar with its treatment and long-term effects. We have developed this resource for people to document their diagnosis, treatment and late effects, to assist with access to the right healthcare and support services.

Approx date of retinoblastoma diagnosis
Retinoblastoma type (unilateral / bilateral)
Eyes affected (left / right / both)
Genetic status (genetic / heritable or non-genetic / non-heritable)
Other affected family members
Artificial eye (none / left / right / both)
Visual impairment (certified severely sight impaired / blind; partially sighted; other):
Are you registered with a late effects clinic, and if so, which?

Treatments you have received for retinoblastoma:

	Treatment (e.g. chemotherapy, radiotherapy, enucleation)	Approx date of treatment
Treatment 1		
Treatment 2		
Treatment 3		
Treatment 4		
Treatment 5		

Any late effects of treatment / health issues you have experienced / are experiencing linked to childhood retinoblastoma?

Symptom / problem

Part of body affected

Date of onset

How do you treat this symptom?

Symptom / problem

Part of body affected

Date of onset

How do you treat this symptom?

Any second cancers you may have had:

Cancer type and location in body

Date of diagnosis

	Treatment (e.g. chemotherapy, radiotherapy)	Approx date of treatment
Treatment 1		
Treatment 2		

Notes

(e.g. previous / current conditions; treatments; planned procedures; current and past medications etc)