BNSSG Paediatric Shared Care Guidance
Please complete all sections

Section 1: Heading

Drug	Riboflavin
Amber ***three months***	
Indication	Glutaric aciduria type 1, MADD (Multiple acycl-CoA dehydrogenase deficiency), mitochondrial cytopathies, Methylene tetrahydrofoloate reductase (MTFR) deficiency and other disorders of riboflavin metabolism
Speciality / Department	Department for Paediatric Metabolic Diseases
Trust(s)	University Hospitals Bristol NHS Foundation Trust

Section 2: Treatment Schedule

Usual dose and frequency of administration *(Please indicate if this is licensed or unlicensed for this age group and any relevant dosing information)*	50 mg TDS, up to 400 mg/day very occasionally
Route and preferred formulation *(Please indicate licensed or unlicensed preparation)*	PO- capsules (Lamberts Healthcare) Can be opened and dispersed in water if necessary) Must be of a pharmaceutical grade, such as products above used by Bristol Children's Hospital as pharmaceutical quality of the product has been assessed by Pharmacy QC department, UHBristol.
Duration of treatment	Short term to lifelong, until no longer appropriate (as decided by specialist)

Section 3: Monitoring

Please give details of any tests that are required before or during treatment, including frequency, responsibilities (please state whether they will be undertaken in primary or secondary care), cause for adjustment and when it is required to refer back to the specialist)

Baseline tests to be done by secondary care
Appropriate specialised testing in blood or urine depending on the disorder suspected. If appropriate, muscle and skin biopsies performed at diagnosis (or soon after suspected diagnosis) to be undertaken in secondary care. Genetic studies as appropriate. Baseline tests to be organised, performed and reviewed in secondary care.

Subsequent tests - where appropriate *(Please indicate who takes responsibility for taking bloods and interpreting results. If the drug is dosed by weight please also indicate intended frequency of weight monitoring/dose adjustment)*

Test	Frequency	Who by	Action/management
Nil	Nil	Nil	Nil

Frequency of ongoing follow up by secondary care *(Please indicate how often child will continue to be seen by secondary care i.e. at least every 6 months)*	6 monthly

Section 4: Side Effects

Please list only the most pertinent side effects and management. Please provide guidance on when the GP should refer back to the specialist. For everything else, please see BNFc or SPC.

Side effects and management	Side effect	Frequency/severity	Action/management
	Yellow discolouration of bodily fluids e.g. sweat, saliva, urine etc.	Common	Nil
	Nausea and vomiting	Common	Refer to secondary care
Referral back to specialist	Any unexpected/serious side effects.		

Section 5: Other Issues

(e.g. Drug Interactions, Contra-indications, Cautions, Special Recommendations)

Please list only the most pertinent and the action for GP to take (For full list please see BNFc or SPC)

Issues	In neonates, infants and children who are unable to swallow capsules, the capsules can be opened and contents dispersed with water/squash. Large doses can interfere with some laboratory tests.
Reminder to ask patient about specific problems	Nil

Section 6: Advice to the patient

Advice for prescribing clinician to inform patient

Yellow discolouration of bodily fluids e.g. sweat, saliva, urine is harmless

Section 7: Generic principles of shared care for SECONDARY CARE

Core responsibilities

1. Initiating treatment and prescribing for the length of time specified in **section 1.**
2. Undertaking the clinical assessment and monitoring for the length of time specified in **section 1** and thereafter undertaking any ongoing monitoring as detailed in **section 3.**
3. Communicate details of the above in 1 and 2 to GP within the first month of treatment. This information should be transferred in a timely manner.
4. Refer patients to GP and provide information of further action where appropriate e.g. if blood test is

due.
5. To provide advice to primary care when appropriate.
6. Review in frequency specified in **section 3** and adjust dose for child's age/body weight as appropriate.
7. Review concurrent medications for potential interaction prior to initiation of drug specified in **section 1.**
8. Stopping treatment where appropriate or providing advice on when to stop.
9. Reporting adverse events to the MHRA.
10. Reminder to ask patients about particular problems see **section 5.**

Section 8: Generic principles of shared care for PRIMARY CARE

Core responsibilities

1. Responsible for taking over prescribing after the length of time specified in **section 1.**
2. Responsible for any clinical assessment and monitoring if detailed in **section 3** after the length of time specified in **section 1.**
3. Review of any new concurrent medications for potential interactions.
4. Reporting adverse events to the MHRA.
5. Refer for advice to specialist where appropriate.
6. Reminder to ask patients about particular problems see **section 5.**

Section 9: Contact Details

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Section 10: Document Details

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Section 11: Collaboration

Specialists in any one discipline are encouraged to collaborate across the health community in preparing shared care guidance. Please give details

1. Click here to enter details

Section 12: References

Please list references

1. British National Formulary for Children (BNFc). Accessed on 19/09/2018, available from: https://bnfc.nice.org.uk/
2. Evelina Paediatric Formulary. Accessed on 19/09/2018, available from: http://cms.ubqo.com/public/d2595446-ce3c-47ff-9dcc-63167d9f4b80/content/0bd2c4d1-3257-4470-9225-a490842d92f5
3. Alfadhel, M., et. al., 2013. Drug treatmen if inbron errors of metabolism: a systematic review. Arch Dis Chil, 98: 454 461
4. Zschocke and Hoffman, 2004 Vademecum metabolicum: Manual of metabolic paediatrics, 3rd edition, Milupa Schattauer
5. Parikh et. al. 2009. A Modern Approach to Treatment of Mitochondrial Disease. Current Treatement.
6. Saudebray, 2016. Inborn Metabolic Diseases: Diagnosis and Treatement, 6th Edititon. Springer