CHARGE SYNDROME CHECKLIST: HEALTH SUPERVISION ACROSS THE LIFESPAN (FROM HEAD TO TOE)

*Shaded boxes indicate key assessment points

Clinical alganosis (fallake et al. or Variores or Hale et al. criteria) Genetic counselling Genetic counselling Genetic counselling CAS malformations/Phypoplasis of lifectory bulb/temporal bone (semicircular canal) mildiomations - requires Mith/CT Canal mildiomations - requires Mith/CT Combinary mildiomations - requires - requires mildiomations - requires - requires mildiomations - requires -	INFANCY (0:2 years) CHILDHOOD (3:11 years) ADOLESCENCE (12:17 years) (18+ years)
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Sleep disturbances – consider melatonin Behavior management – self regulation, impulse control, anxiety,	n Plan
Behavior management – self regulation, impulse control, anxiety,	
obsessions, compulsions, anger	I, anxiety,
Toileting skills / support	
Life skills/adaptive behaviour/social skills/social play	
Address sexuality	
Family stress – offer supports and resources	
Medical self-management – work on managing medications, understanding conditions, seeing healthcare provider independently	ions, understanding

CHARGE SYNDROME CHECKLIST: HEALTH SUPERVISION ACROSS THE LIFESPAN (FROM HEAD TO TOE)

Abbreviations Used in Checklist

CGH / comparative genomic FSH / follicle stimulating hormone

hybridization GH / growth hormone

CNS / central nervous system HRT / hormone replacement therapy

CT / computed tomography LH / luteinizing hormone

DEXA scan / dual energy XEray MRI / magnetic resonance imaging

absorptiometry MSK / musculoskeletal

EEG / electroencephalogram U/S / ultrasound

ENT / ear, nose and throat VCUG / voiding cystourethrogram

Resources

 The CHARGE Syndrome Foundation (http://chargesyndrome.org/aboutE charge.asp)

- The CHARGE Informational Pack for Practitioners (SENSE UK)
 (https://www.sense.org.uk/content/chargeEinformationEpackEpractitioners)
- Book E CHARGE Syndrome (Genetics and Communication Disorders), 1st ed.
 Hartshorne TS, Hefner M, Davenport S, Thelin J. 2011
- OMIM Entry #214800 CHARGE Syndrome (http://www.omim.org/entry/214800)
- CHARGE Syndrome International Conference
- CHARGE Syndrome Listserv
- CHARGE Syndrome Facebook Group

Perkins School for the Blind eElearning

(http://www.perkinselearning.org/videos)

- Deafblind International (http://www.deafblindinternational.org/index.htm)
- Open hands, open access: deafEblind intervener learning modules (http://moodle.nationaldb.org)

Key General References

- 1. Blake K, Prasad C. 2006. CHARGE syndrome. Orphanet J Rare Dis 1: 34
- Brown D. 2005. CHARGE syndrome "behaviors": challenges or adaptations? Am J Med Genet Part A 133A: 268E272
- 3. Hsu P, Ma A, Wilson M, Williams G, Curotta J, Munns CF, Mehr S. 2014. CHARGE syndrome: a review. J Pediatr Child Health 50: 504E511