

The
Down Syndrome
Medical Interest
Group

Personal Child Health Record Down Syndrome specific inserts

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**On Behalf of the DSMIG
U.K & Ireland**

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PCHR Down syndrome Self – assessment



1. Were you aware that DS specific PCHR inserts were updated in February 2020?
2. **Heart**: What is the guidance around cardiac checks in CYP who have DS ?
3. **Blood**: What investigations are recommended in the new-born period – extra bonus for time scale
4. **Thyroid**: What is the recommendations for screening a 32 pre-term baby DS for thyroid disorders, what is the schedule for thyroid surveillance in CYP who have DS
5. **Vision**: What checks are recommended in the first year of life and in school age
6. **Hearing**: What is the guidance schedule for a hearing assessment
7. **Hearing**: What is the ideal management for children with a conductive hearing loss in CYP with DS
8. **Toileting**: What is the average age for a child who has DS to achieve day time urinary continence?
9. **Coeliac Ds**: What is the current guidance around screening for CYP who have DS for Coeliac Ds
10. **Breathing disorders**: What is the recommendations around checking overnight saturations in CYP who have DS – 3 part answer
11. **Teeth** – what is different about how teeth erupt in CYP who have DS
12. **Arthritis** – How common is arthritis in CYP who have DS and how does it differ from JIA
13. **Neck instability** – what is the recommendation around trampolining in CYP who have DS
14. What is the guidance around **infections** in CYP who have DS?
15. Do you know how you can obtain a DS specific PCHR?



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History of PCHR & DSMIG

- **1994** Conference at RSM Medical Issues in Down Syndrome Consensus and Controversy- Highlighted need for Guidelines
- **1995** Guideline working group established (Prevention of Disability)
- **1997** DSMIG U.K & Ireland Launched
- **1997** Concept of PCHR insert born, best way of disseminating the good practice described in Guidelines
- **1998** Guidelines working group designed PCHR 1st edition, Funding obtained via the DSA
- **1999** DSMIG set up to distribute and evaluate

Why did the DSMIG make the PCHR Insert?



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- New Parents needed Down syndrome specific information
- Health professionals caring for CYP who have Down syndrome needed guidance
- DSMIG developed guidance and information resources, that needed to be disseminated

What is included in the PCHR



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- General information on Down syndrome
- Developmental Milestones
 - General Moving about: Finding about hands: Finding about words & people
- Health Issues
- Feeding
- Immunisations
- Suggested schedule of health checks
- Sources of Help and Advice
- Infection Alert Page
- Down syndrome specific growth charts

Evaluation of the PCHR inserts



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Formal evaluation 2000 after publication of 1st Edition

- 1st year :Mar 99 – Feb 2000
 - 1615 inserts sent direct to via the DSAs
 - 942 were requested from DSMIG.
- Insert reached over 70% of the target population
- 957 questionnaires were returned in the first 6 months, 40% total inserts distributed in the study year
- 80% of parents responded that they found the information useful and easy to read
- Most useful sections: Growth Charts 37% Development 27%, & Health checks 20%
- 5th Edition Feedback from parents and stakeholders during consultation period

What happened next



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- The 1st edition of the insert was well received by parents
- The insert reached the majority of the target audience
- Health services were prepared to purchase for distribution to new parents
- 2nd Edition 2000 : Production & distribution taken over by Harlow Printing Ltd
- Three further revision, significant changes in 2000, 2011, minor changes in 2015
- Average sales of inserts per year 2019-20: 2094, 2018- 2018: 2553, 2017- 2018: 1642
- Sales: Parents, Trusts, DSA Most commonly 20, Leicestershire 500 inserts!

The 5th Edition



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- Updated health guidance on:
 - Thyroid guidelines
 - Neonatal blood film within the first three days of life
 - Hearing surveillance
 - Arthritis
 - Coeliac screening, Sleep related breathing disorders, Toileting
 - Concerns around atypical presentation of sepsis
- Opportunistically co-consultation with stakeholders involved with Thyroid Guidelines
- Published 2nd February 2020

DOWN SYNDROME - SUGGESTED SCHEDULE OF HEALTH CHECKS

The following are suggested ages for health checks. Check at any other time if there are parental or other concerns.

	Birth - 6 weeks	Special checks under 2 years	Preschool checks	School age
Thyroid blood tests	Newborn routine heel prick - blood spot test	Age 4-6 months and then every year from the age of 1 year or more often if clinically indicated: Venous thyroid blood test including thyroid antibodies <u>or</u> Fingerprick TSH test		
Eye checks	Newborn routine check including congenital cataract check	Age 18-24 months: Formal eye and vision examination including check for squint, and refraction for long or or short sight	Age 4 years: Formal eye and vision examination including check for squint. Refraction and assessment of near and distant vision and visual acuity	Repeat vision test every 2 years , or more frequently if recommended by optometrist or ophthalmologist or if concerns
	Visual behaviour to be monitored at every review particularly in first year			
Hearing checks	Universal newborn hearing screen	Full audiological review by 10 months including hearing test impedance check	Annual audiological review or more frequently and if indicated 2 yearly audiological review or more frequently if recommended	
Growth monitoring	Length, weight and head circumference should be checked frequently and plotted on Down syndrome growth charts		Height and weight should be checked and plotted on Down syndrome growth charts at least annually (BMI checked if concern regarding overweight)	
Heart checks	By age 6 weeks , formal heart assessment including Echocardiogram	At all ages low threshold for reviewing heart status if signs or symptoms develop		From adolescence onwards as part of routine health checks listen to heart for signs of acquired heart disease
Breathing checks	Enquire at every review for uneven breathing during sleep and poor quality sleep. Screen with an overnight pulse oximetry once in infancy and yearly until the age of 5, or at any age if there are symptoms or concerns. Low threshold for detailed sleep studies if symptoms persist, despite normal tests			
Blood checks	Within the first three days of life, full blood count and blood film to check for a serious blood disorder	If blood film is abnormal treatment or monitoring may be required		

Detailed recommendations for Medical Surveillance Essentials for children with Down syndrome can be found at www.dsmig.org.uk

Infection Alert:



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INFECTION ALERT

This page has been included to highlight to health professionals and parents/carers that children who have Down syndrome may respond differently to infections and need special consideration.

If you are worried that your child may have a serious infection please seek medical advice and show this page.

Children who have Down syndrome are more vulnerable to serious infections and may present atypically. They may not 'appear' to be unwell, so checking with their parents/carers about what is usual for them is important.

If a child who has Down syndrome presents with a possible infection, have a low threshold for:

- Suspecting serious infections such as sepsis or pneumonia and seek prompt paediatric advice
- Starting antibiotics and continuing them for double the length of time, e.g. 10 days instead of 5 days
- Arrange to review the child, if a viral infection is diagnosed and antibiotics are not commenced.

Please offer the recommended universal immunisations as well as, the Flu vaccine every year from the age of 6 months and the Pneumovax II at the age of 2 years.

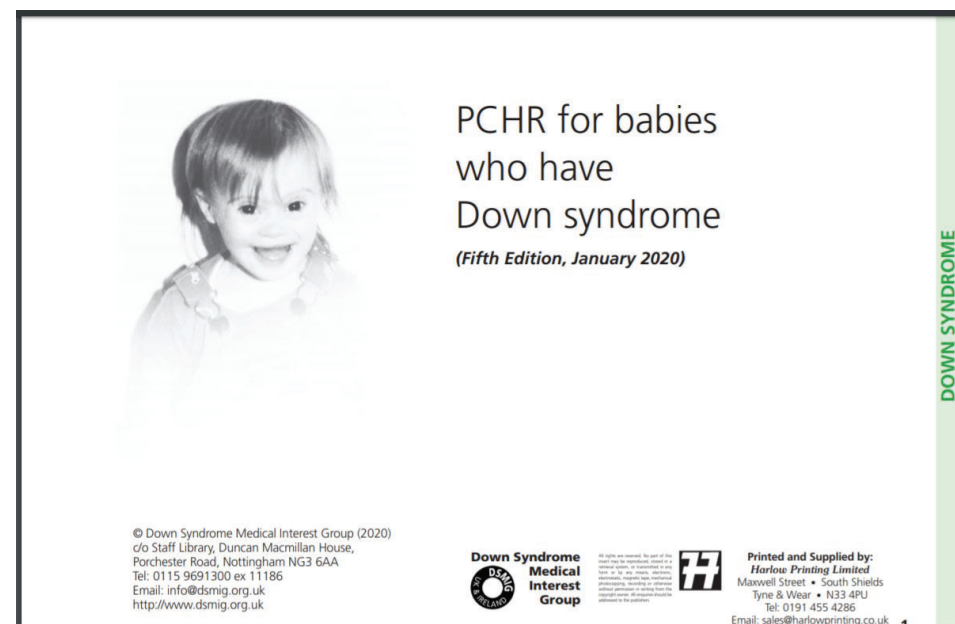
[COVID-19](#)

Thank you & Acknowledgements



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- DSMIG Steering group & Members, DSMIG information officers
- DSA, DSS, DSH, Parent support groups
- Stakeholders from within the Thyroid Guidelines
- Harlow Printing Press
 - Vince Hulme & Clare Turner



The future 2021



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