

Down's Syndrome Clinic Proforma
Age 6 months-5 years

Name :

DOB :

Gender : M /F

Rio. number :

Ethnicity:

NHS number :

Mother :

Father:

Parental responsibility:

Address :

Phone:

Mobile:

Email addresses:

Consent given to be contacted using email address: Yes/No

GP:

Consent given to report being shared with GP, allied health professionals, and school/nursery: Yes/No

Using this booklet/guideline

This is **NOT** a patient-held record. Please file in the notes and/or scan into Rio.

This guideline is based on the recommended minimum screening guidelines from the British Down's syndrome Medical Interest Group, and from Whittington Health Guidelines.

Reviews are suggested at 6 months, 1 year and then annually, and in each review, check that the previous screening and tests were done, and then the recommended tests and referrals are suggested at the end.

Please enter blood results on the flow chart on the next page.

Cervical Spine Instability

At each clinic attendance ensure parents are aware of the 'red flags' for cervical spine instability, and that they should seek immediate medical help if they are present.

- Neck pain
- Abnormal head posture
- Torticollis
- Reduced Neck Movements
- Deterioration of gait and/or frequent falls
- Increasing fatigability on walking
- Deterioration of Manipulative skills

Other signs of progressive myelopathy

- Increase in muscle weakness
- Loss of sensation
- Onset of incontinence
- Alteration in muscle tone
- Decreasing co-ordination
- Diminishing kinaesthetic awareness
- Pins and needles.

Appendix

Guidelines for prevention and management of infections

Prophylactic antibiotics

If significant infection history, it may still be appropriate to commence prophylactic antibiotics even if tests normal. These should be considered in children with frequent infections either to be used throughout the year or just September to April.

Options – azithromycin 10mg/kg od 3 days per week
amoxicillin , standard dose tds
co- trimoxazole – single daily dose

The need for prophylactic antibiotics should be reviewed at each visit. If stopping, suggest choose to do this in late spring/early summer.

General management

- Double the length of usual antibiotic course
- Maximise immunity by ensuring appropriate vaccines have been given (as per childhood schedule and any additional vaccines – see below).
- Yearly influenzae vaccine for child and household members
- Pneumococcal vaccines
 - If child is in additional 'at risk group' for pneumococcal infection i.e. because of congenital heart disease, risk of aspiration or neuromuscular complications then to also be offered additional pneumococcal immunisation:
 - o Age 2-5 yrs: single dose of Pneumovax II(at least 2 months after final dose pcv)
 - o Age > 5 years: single dose of Pneumovax II (*)
 - If pneumococcal antibodies are low or concern regarding immunodeficiency discuss further action with Prof M Lakhanpaul

* Pneumovax II should not be repeated within 5 years. If pneumococcal antibodies low despite recent Pneumovax II, please discuss with Prof M Lakhanpaul

PLEASE USE THIS PAGE TO RECORD ANY ADDITIONAL
INFORMATION

Blood test results – flow sheet						
	Full Blood count			Biochemistry		
	Hb	WCC	Plt	U&Es	LFTs	Bone
Birth						
6m						
1y						
2y						
3y						
4y						
5y						
	Thyroid Function				Coeliac testing	
	TSH	T ₄	T ₃	TPO	Coeliac	Total IgA
Birth						
6m						
1y						
2y						
3y						
4y						
5y						
	Immunology tests					
	Immunoglobulins	Functional Antibodies	Prevnar Antibodies	Lymphocyte subsets		
12m or any review as below						
Check the above immunology tests at <ul style="list-style-type: none"> 12 months any review if above test not done at 12m - with ≥ 4 infections in 6 months requiring GP visits/ ill health > 5 days or admission for sepsis any review with unusual infection 				Timing of immunology blood tests is at least 1 month after completion of the 12 month routine Hib/MenC/PCV booster immunisations		

Newborn investigation results

Karyotype result: _____

Guthrie card: Normal ☐ Abnormal ☐

Thyroid function tests: Done - normal ☐ Done - abnormal ☐ Not done ☐

Results : TSH _____ T₄ _____ TPO antibodies _____ T₃ _____

Full blood count: Done - normal ☐ Done - abnormal ☐ Not done ☐

Results : Hb _____ WBC _____ Platelets _____ Blood film _____

Echo.: Done - normal ☐ Done - abnormal ☐ Not done ☐

Newborn hearing screen: Done - normal ☐ Done - abnormal ☐ Not done ☐

[illegible]

Discussed at this clinic visit :

- Red flag symptoms of cervical spine instability ☐
- Need for annual influenza vaccine for child and family ☐
- Need for minimum biennial review of hearing and vision ☐
- Disability living allowance ☐
- Discharge to school nurse and new follow-up arrangements ☐
- Need for annual FBC, biennial TFT ☐
- Symptoms of coeliac disease ☐

Blood tests: FBC, ferritin, TSH, T₄, TPO
Referrals:
School nurse ☐

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.

Physical Examination :

(plot biometry data on Down's syndrome specific charts)

Height = (centile) Adequate ☐

Weight = (centile) Adequate ☐

OFC = (centile) Adequate ☐

BMI = (centile)

BP = SaO₂ =

General comments :

Cardiovascular :

Respiratory:

Abdominal:

Neurology:

ENT:

Eyes (Cataracts, Strabismus, Nystagmus, Visual behavior):

Developmental observations :

6 month Review – Date :

Attended with :

Doctor Seen by :

Other professionals present :

Current Problems (in order of importance) :

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

Professionals involved and site:

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

[illegible][illegible]

Substance	Reaction

Bladder and Bowel :

Coeliac : Symptomatic ☐ Asymptomatic ☐

Dental:

Snoring: present ☐ absent ☐

Obstructive sleep apnoea: present ☐ absent ☐

Hearing :

Gross motor :

Speech, Language and Communication :

Social / play :

Immunisations :

BCG ☐ DTaP/IPV/HiB/PCV ☐ DTaP/IPV/HiB/Men C ☐
DTaP/IPV/HiB/Men C/PCV ☐
12 month HiB/Men C/PCV ☐ MMR1 ☐ MMR2 ☐ Pre-school
booster (DTaP/IPV) ☐
Pneumovax II (single dose between 2-5 years) ☐
Influenza vaccine: Child ☐ Household members ☐

Comments :

New siblings, changes arising in the family (see previous genogram) :

Education**Social History**

Current Housing :

Current Benefits (DLA etc):

Current Support services / voluntary sector input :

Immunisations :

BCG ☐ DTaP/IPV/HiB/PCV ☐ DTaP/IPV/HiB/Men C ☐
DTaP/IPV/HiB/Men C/PCV ☐
RSV prophylaxis: Indicated ☐ Given ☐
Influenza vaccine: Patient ☐ Household members ☐

Comments :

Genogram and Family History**Social History**

Current Housing :

Current Benefits (DLA etc):

Current Support services / voluntary sector input :

5 year Review – Date :

Attended with :

Doctor Seen by :

Other professionals present :

Current Problems (in order of importance) :

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____

Professionals involved and site:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____

Surveillance since last visit:

(Specify abnormality in problem list above if abnormal)

Formal Audiological testing: Done - normal ☐ Done - abnormal ☐ Not done ☐ (if not done, must be referred urgently today)

FBC & ferritin : Done - normal ☐ Done - abnormal ☐ Not done ☐

Physical Examination :

(plot biometry data on Down's syndrome specific charts)

Height = (centile) Adequate ☐

Weight = (centile) Adequate ☐

OFC = (centile) Adequate ☐

BMI = (centile)

BP = SaO₂ =

General comments :

Cardiovascular :

Respiratory:

Abdominal:

Neurology:

ENT:

Eyes (Cataracts, Strabismus, Nystagmus, Visual behavior):

Developmental observations

Impression/comments :

Discussed at this clinic visit :

- Red flag symptoms of cervical spine instability ☐
- Need for annual influenza vaccine for child and family ☐
- Need for RSV prophylaxis (if indicated) ☐
- Referrals to SLT, physiotherapy and preschool education ☐
- Need for formal audiology testing before 12 months ☐
- Disability living allowance ☐

Recommended surveillance at this clinic visit :

- Blood tests: None
- Referrals:
 - Speech & Language Therapy ☐
 - Physiotherapy ☐
 - Preschool education/education psychologist ☐
 - Audiology ☐

Additional Plan :

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.

Next Follow-up:

PLEASE USE THIS PAGE TO RECORD ANY ADDITIONAL
INFORMATION

Impression/comments :

**PLEASE USE THIS PAGE TO RECORD ANY ADDITIONAL
INFORMATION**

Discussed at this clinic visit :

- Red flag symptoms of cervical spine instability ☐
- Need for annual influenza vaccine for child and family ☐
- Need for pneumovax II (if not already had) ☐
- Need for annual review of hearing ☐
- Disability living allowance ☐

Recommended surveillance at this clinic visit :

Blood tests: FBC, ferritin
Referrals:
None unless indicated

Additional Plan :

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.

Next Follow-up:

1 year Review – Date :

Attended with :

Doctor Seen by :

Other professionals present :

Current Problems (in order of importance) :

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____

Professionals involved and site:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____

Surveillance since last visit:

(Specify abnormality in problem list above if abnormal)

Formal Audiological testing: Done - normal ☐ Done - abnormal ☐ Not done ☐ (if not done, must be referred urgently today)

Physical Examination :

(plot biometry data on Down's syndrome specific charts)

Height = (centile) Adequate ☐
Weight = (centile) Adequate ☐
OFC = (centile) Adequate ☐
BMI = (centile)
BP = SaO₂ =

General comments :

Cardiovascular :

Respiratory:

Abdominal:

Neurology:

ENT:

Eyes (Cataracts, Strabismus, Nystagmus, Visual behavior):

Developmental observations :

Immunisations :

BCG ☐ DTaP/IPV/HiB/PCV ☐ DTaP/IPV/HiB/Men C ☐
DTaP/IPV/HiB/Men C/PCV ☐
12 month HiB/Men C/PCV ☐ MMR1 ☐
RSV prophylaxis: Indicated ☐ Given ☐
Influenza vaccine: Patient ☐ Household members ☐

Comments :

New siblings, changes arising in the family (see previous genogram) :

Social History

Current Housing :

Current Benefits (DLA etc):

Current Support services / voluntary sector input :

Immunisations :

BCG ☐ DTaP/IPV/HiB/PCV ☐ DTaP/IPV/HiB/Men C ☐
DTaP/IPV/HiB/Men C/PCV ☐
12 month HiB/Men C/PCV ☐ MMR1 ☐ MMR2 ☐ Pre-school
booster (DTaP/IPV) ☐
Pneumovax II (single dose between 2-5 years) ☐
Influenza vaccine: Patient ☐ Household members ☐

Comments :

New siblings, changes arising in the family (see previous genogram) :

Education**Social History**

Current Housing :

Current Benefits (DLA etc):

Current Support services / voluntary sector input :

Current Parental Concerns / current & recent health :

Current Medication

Medication	Dose	Freq.
<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>
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Allergies

Substance	Reaction
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

Systematic review**Bladder and Bowel :**Constipated : Yes ☐ No ☐Coeliac : Symptomatic ☐ Asymptomatic ☐**Feeding / diet:****Dental:****Sleeping :**Snoring: present ☐ absent ☐Obstructive sleep apnoea: present ☐ absent ☐**Vision :****Hearing :****Development:****Gross motor :****Fine motor :****Speech, Language and Communication :****Social / play :**

Physical Examination :*(plot biometry data on Down's syndrome specific charts)*Height = (centile) Adequate ☐Weight = (centile) Adequate ☐OFC = (centile) Adequate ☐

BMI = (centile)

BP = SaO₂ =

General comments :

Cardiovascular :

Respiratory:

Abdominal:

Neurology:

ENT:

Eyes (Cataracts, Strabismus, Nystagmus, Visual behavior):

Developmental observations :

4 year Review – Date :

Attended with :

Doctor Seen by :

Other professionals present :

Current Problems (in order of importance) :

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____

Professionals involved and site:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____

Surveillance since last visit:

(Specify abnormality in problem list above if abnormal)

Formal Audiological testing: Done - normal ☐ Done - abnormal ☐ Not done ☐ (if not done, must be referred urgently today)Thyroid function check : Done - normal ☐ Done - abnormal ☐
Not done ☐FBC : Done - normal ☐ Done - abnormal ☐ Not done ☐Ophthalmology: Done - normal ☐ Done - abnormal ☐ Not done ☐

PLEASE USE THIS PAGE TO RECORD ANY ADDITIONAL
INFORMATION

Impression/comments :

Discussed at this clinic visit :

- Red flag symptoms of cervical spine instability ☐
- Need for annual influenza vaccine for child and family ☐
- Need for annual review of hearing ☐
- Disability living allowance ☐

Recommended surveillance at this clinic visit :

- Blood tests: FBC, ferritin, TSH, T₄, thyroid peroxidase antibodies,
immunoglobulins, functional antibodies, prenar antibodies,
lymphocyte subsets (immunology 1m after 12m vaccine)
- Referrals:
- Ophthalmology (review before age 2) ☐

Additional Plan :

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.

Next Follow-up:

PLEASE USE THIS PAGE TO RECORD ANY ADDITIONAL
INFORMATION

Impression/comments :

Discussed at this clinic visit :

- Red flag symptoms of cervical spine instability ☐
- Need for annual influenza vaccine for child and family ☐
- Need for pneumovax II (if not already had) ☐
- Need for annual review of hearing and vision ☐
- Disability living allowance ☐

Recommended surveillance at this clinic visit :

- Blood tests: FBC, ferritin, TSH, T₄, TPO
- Referrals:
- Opthalmology (to be seen by age 4) ☐

Additional Plan :

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.

Next Follow-up:

Physical Examination :

(plot biometry data on Down's syndrome specific charts)

Height = (centile) Adequate ☐
Weight = (centile) Adequate ☐
OFC = (centile) Adequate ☐
BMI = (centile)
BP = SaO₂ =

General comments :

Cardiovascular :

Respiratory:

Abdominal:

Neurology:

ENT:

Eyes (Cataracts, Strabismus, Nystagmus, Visual behavior):

Developmental observations :

2 year Review – Date :

Attended with :

Doctor Seen by :

Other professionals present :

Current Problems (in order of importance) :

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____

Professionals involved:

- | | |
|----------|----------|
| 1. _____ | 5. _____ |
| 2. _____ | 6. _____ |
| 3. _____ | 7. _____ |
| 4. _____ | 8. _____ |

6

Problems picked up by surveillance:

(Specify abnormality in problem list above if abnormal)

Echo.: Done - normal ☐ Done - abnormal ☐ Not done ☐

(if not done, must be referred urgently today)

Formal Audiological testing: Done - normal ☐ Done - abnormal ☐ Not done ☐

(if not done, must be referred urgently today)

Thyroid function check : Done - normal ☐ Done - abnormal ☐

Not done ☐

Coeliac screening: Done - normal ☐ Done - abnormal ☐

Not done ☐

FBC : Done - normal ☐ Done - abnormal ☐ Not done ☐

Ophthalmology: Done - normal ☐ Done - abnormal ☐ Not done ☐

Immunology tests at 12m: Done – normal ☐ Done – abnormal ☐ Not done ☐

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[illegible]

Substance	Reaction

Bladder and Bowel :

Coeliac : Symptomatic ☐ Asymptomatic ☐

Dental:

Obstructive sleep apnoea: present ☐ absent ☐

Hearing :

Gross motor :

Speech, Language and Communication :

Social / play :

Immunisations :

BCG ☐ DTaP/IPV/HiB/PCV ☐ DTaP/IPV/HiB/Men C ☐
DTaP/IPV/HiB/Men C/PCV ☐
12 month HiB/Men C/PCV ☐ MMR1 ☐ MMR2 ☐ Pre-school
booster (DTaP/IPV) ☐
Pneumovax II (single dose between 2-5 years) ☐
Influenza vaccine: Patient ☐ Household members ☐

Comments :

**New siblings, changes arising in the family (see previous
genogram) :**

Education

Social History

Current Housing :

Current Benefits (DLA etc):

Current Support services / voluntary sector input :

Immunisations :

BCG ☐ DTaP/IPV/HiB/PCV ☐ DTaP/IPV/HiB/Men C ☐
DTaP/IPV/HiB/Men C/PCV ☐
12 month HiB/Men C/PCV ☐ MMR1 ☐
Pneumovax II (single dose between 2-5 years) ☐
Influenza vaccine: Patient ☐ Household members ☐

Comments :

**New siblings, changes arising in the family (see previous
genogram) :**

Social History

Current Housing :

Current Benefits (DLA etc):

Current Support services / voluntary sector input :

Bladder and Bowel :

Coeliac : Symptomatic ☐ Asymptomatic ☐

Dental:

Snoring: present ☐ absent ☐

Obstructive sleep apnoea: present ☐ absent ☐

Vision :

Hearing :

Development:

Gross motor :

Fine motor :

Speech, Language and Communication :

Social / play :

This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are approximately 20 lines visible. The paper has a slight shadow on the right side, suggesting it's resting on a surface.

Current Medication

Medication	Dose	Freq.

Allergies

Substance	Reaction

3 year Review – Date :

Attended with :

Doctor Seen by :

Other professionals present :

Current Problems (in order of importance) :

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____

Professionals involved and site:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____

Surveillance since last visit:

(Specify abnormality in problem list above if abnormal)

Formal Audiological testing: Done - normal ☐ Done - abnormal ☐ Not done ☐ (if not done, must be referred urgently today)

FBC & ferritin : Done - normal ☐ Done - abnormal ☐ Not done ☐

Physical Examination :

(plot biometry data on Down's syndrome specific charts)

Height = () centile) Adequate ☐

Weight = () centile) Adequate ☐

OFC = () centile) Adequate ☐

BMI = () centile)

BP = SaO₂ =

General comments :

Cardiovascular :

Respiratory:

Abdominal:

Neurology:

ENT:

Eyes (Cataracts, Strabismus, Nystagmus, Visual behavior):

Developmental observations :

Impression/comments :

**PLEASE USE THIS PAGE TO RECORD ANY ADDITIONAL
INFORMATION**

Discussed at this clinic visit :

- Red flag symptoms of cervical spine instability ☐
- Need for annual influenza vaccine for child and family ☐
- Need for pneumovax II (single dose age 2-5y) if not had ☐
- Need for annual review of hearing and vision ☐
- Disability living allowance ☐

Recommended surveillance at this clinic visit :

- Blood tests: FBC, ferritin
- Referrals:
- LEA notification ☐

Additional Plan :

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.

Next Follow-up: