

# CHILDREN WITH DOWN'S SYNDROME IN LANCASTER, KENDAL AND SOUTH LAKES

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## BACKGROUND

Children with Down's syndrome are mainly well, with their main needs being educational and social, but they are at risk of certain conditions and do warrant regular medical review.

In light of recommendations from the Down's syndrome Medical Interest Group<sup>(1)</sup> on medical follow-up of children with Down's syndrome, a form was designed for use in community clinics to act as an aide memoire (see appendix).

Versions of this form are now being used in Lancaster, Kendal and South Lakes. To aid audit, it is updated at the annual clinic visit and is photocopied to the office at Longlands, where the data are entered onto a spreadsheet database in Excel.

## AUDIT OF DOWN'S SYNDROME MANAGEMENT 2004

To audit the management of children with Down's syndrome this database was checked and up-to-date information sought as necessary. The PCIS database was searched for children with Down's syndrome and colleagues were asked for information on any other children known to them.

## RESULTS

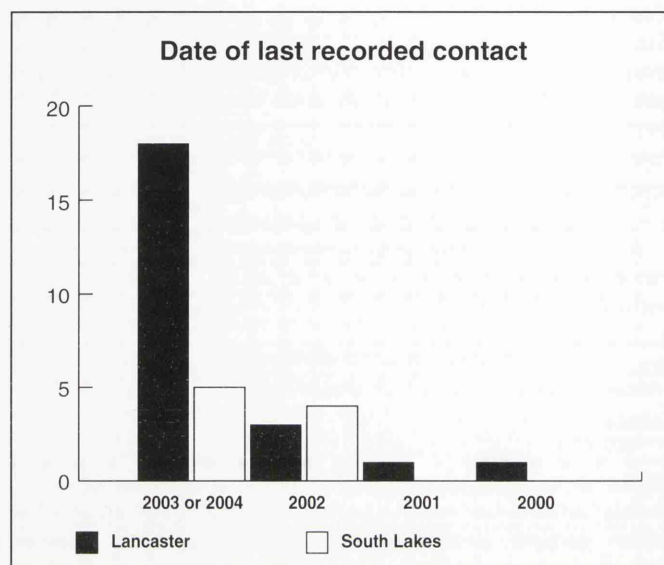
Thirty-two children with Down's syndrome were identified.

Children with Down's syndrome		
	Lancaster	South Lakes
Boys	14	5
Girls	9	4
Total	23	9
Age of children		
Age 0-4	6	3
5-8	5	3
9-12	5	1
13-16	2	0
17-20	4	2

### Frequency of contact

Children should be seen annually and we would expect all children to be seen within 24 months of their last appointment. As this review was carried out in the spring of 2004, all children should have been seen in 2002, 03 or 04.

In Lancaster 91% of children were seen during those years (one family has opted out of follow-up). In South Lakes the figure was 100%.



As a result of the audit we have identified failures in the system and triggered follow-up on those who were overdue.

### Recording of information

Information not recorded			
	Lancaster	South Lakes	Total
Hearing test	1	0	1
Vision check	1	0	1
Echocardiogram	1	0	1
Thyroid function	0	0	0

### Problems identified

Problems identified in 31 children with Down's syndrome			
Problem	Lancaster	South Lakes	Total
Hearing impairment	14	4	18
Visual problem	12	4	16
Heart	16	5	21
Needing thyroxine	1	0	1
Behaviour	6	2	8

All the children had received a neonatal screen of hearing and most had follow-up audiology recorded. In one child in Lancaster hearing testing is not recorded on the database. There was a high incidence of hearing impairment, often due to glue ear.

### Schooling

This was not consistently recorded on the database but 10 children (three from South Lakes) are recorded as attending special school.

## CONCLUSIONS

The database has made the audit rather easier but there were still children not on the database. As a result of this audit we have discovered that one or two young children with Down's syndrome were being followed up entirely within the hospital clinics and were not yet known in the community.

The audit has been useful in identifying children needing follow-up.

Follow-up has improved since the database was set up but we are not reaching our standards.

The high rate of abnormal findings reinforces the need for these children to have regular and thorough review. Once these children leave school their follow-up is left with their GP as there is no equivalent of community paediatricians for adult patients.

## REFERENCES

1 Basic medical surveillance essentials for people with Down's syndrome. Recommendations of the Down's syndrome Medical Interest Group 2000 onwards. [www.dsmig.org.uk](http://www.dsmig.org.uk)

## APPENDIX

### DOWN'S SYNDROME – MEDICAL SURVEILLANCE

NAME:

DOB:																			
<b>DATE</b>																			
<b>AGE</b>																			
<b>WEIGHT</b> Kg every exam																			
Weight centile- Down's chart																			
<b>Height</b> cm Every exam (>2 years)																			
Height centile- Down's chart																			
OFC cm																			
OFC centile																			
<b>Hearing</b> OAE* Distraction 6-10 months Full assessment: 15-18 months Then yearly to 5 years > 5 years – 2 yearly for life	Arranged																		
	Result																		
<b>Vision</b> – red reflex* Ophthalmological review 2nd year of life- at 4 years > 4 years – 2 yearly VA NV	Arranged																		
<b>Heart</b> clinical exam* Echo by 6 weeks (if abnormal ensure written info re antibiotic prophylaxis) Echo early adult life																			
<b>Neck</b> ?pain, posture, torticollis, deterioration in gait, fine motor skills bowel/bladder control																			
<b>TFTs &amp;</b> autoantibodies- neonatal heel prick At 1 year then 2 yearly	Arranged																		
	Result																		
Behaviour problem ? Yes/No																			
Action on behaviour																			
School or nursery-referral to education																			

\*from baby check Code N= Normal