Irish National Register for Children with Downs Syndrome

Version 3.2

Please complete this form for newly diagnosed children with Down syndrome.

Name of Child:	Attach Addressograph Label	Parent/Guardian details at birth: Mother's name: Mother's DOB: DD/MM/YYYY Father's name: Father's DOB: DD/MM/YYYY
Contact Number:		Prenatal Diagnosis Yes / No Pre-natal maternal Blood sampling Yes /No Amniocentesis Yes / No Chorionic Villus Sampling Yes / No
Location:	Urban / Rural (Please circle) County	Family history of Down syndrome: Yes / No
Reporting Centre:		Karyotype result:
Date of Birth	DD/MM/YYYY	Respiratory Syncytial virus Vaccination? RSV Yes / No
Gender:	Male / Female	
Singleton Birth Birth Order:	Yes / No If no please how many were born: ____ ____ (1st, 2nd, 3rd....)	Method of feeding: ☐ Exclusive Breast ☐ Combined feeding ☐ Bottle fed ☐ NG feeds ☐ OG feeds ☐ Peg ☐ TPN (Please tick all that apply)
EDD		
Weight at birth:	____ in kilograms	
Length at birth:	____ in centimetres	
Conception	Natural Yes / No	
	☐ IVF ☐ Donor ovum	Ethnicity:
	☐ IUI ☐ Donor Sperm	Irish Irish Traveller Any other white background African Any other black background Chinese Any other asian background Any other background (incl mixed)
	☐ ICSI ☐ Donor embro	
	☐ Do not wish to discuss	
Type of Delivery	☐ Normal ☐ C-Section ☐ Emergency C- Section ☐ Other_____	
APGAR Score	_____/_____ at 1 minute _____/_____ at 5 minutes	
Medical issues at birth?	Yes / No _____	
Special care needed after birth?	Details: Duration:	
Transferred to a different Hospital?	Age at Transfer: _____ weeks Transferred to: _____ Why:	
Consultant:		
Paediatrician:		

Please return completed forms with the Register copy of the consent form to: Ms Grainne O Connor, Department of Paediatrics, Trinity Centre for Health Sciences, Tallaght University Hospital Dublin 24. Alternatively scan and email documents to Grainne.OConnor@tuh.ie. Many Thanks

Please indicate in results box if tests completed.

Tests	Result Date	Findings
ECG	*Yes / No* DD/MM/YYYY	
ECHO	*Yes / No* DD/MM/YYYY	

In the following sections please tick boxes that apply and use far column for supporting text.

Cardiac Abnormality?	*Yes / No*	**Other related problems**
	☐ Complete Atrioventricular septal defects ☐ Atrial septal defect ☐ Ventricular septal defects ☐ Patent Ductus Arteriosus ☐ Tetralogy of Fallot ☐ Pulmonary Hypertension	
Resuscitation at birth?	*Yes / No*	
	☐ Emergency Transfer ☐ Monitoring of condition ☐ Oxygen Therapy ☐ No treatment necessary	
Gastrointestinal Abnormalities?	*Yes / No*	
	☐ Duodenal Atresia ☐ Imperforate anus ☐ Hirschsprungs disease ☐ Small bowel obstruction ☐ Annular Pancreas	
Thyroid Issues?	*Yes / No*	
	☐ Hypothyroidism ☐ Hyperthyroidism ☐ Medication:_____ ☐ Dosage: _____	
Haematological Abnormalities?	*Yes / No*	
	☐ Transient Myeloid Leukaemia	
Ophthalmology Screening?	*Yes / No*	
	☐ Cataracts ☐ Congenital Glaucoma ☐ Retinopathy due to prematurity ☐ Blindness	
Audiology Screening?	*Yes / No*	
	☐ Conductive hearing loss ☐ Sensor neural hearing loss ☐ Failed hearing assessment unknown cause	
Respiratory Issues?	*Yes / No*	
	☐ Low oxygen saturations due to cardiac issues ☐ Respiratory issues due to hypotonic ☐ Tracheobronchomalacia ☐ Pulmonary hypoplasia ☐ Tracheo-oesophageal fistula ☐ Subpleural cysts	

Form completed by

Print Name: _____ Signature: _____ Date: DD/MM/YY

For office use only: Register ID _____ Date entered: DD/MM/YY

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