

KERNICTERUS SPECTRUM DISORDERS (KSD) DIAGNOSTIC TOOLKIT 1: LIKELIHOOD OR PROBABILITY OF KERNICTERUS

Diagnostic Tool Kit for families or caregivers to determine if an individual has kernicterus.

Child's Name: (Last, First, Middle)	<input type="checkbox"/> Male <input type="checkbox"/> Female	Birth Date:
Parent or Guardian Names: (Last, First)	phone#:	email
Home Address:	Date:	

DIRECTIONS: Please choose the score option (0, 1, 2 or 3) that best fits the child's symptoms.

What was the highest bilirubin level recorded?	SCORE	Your Score
Highest bilirubin level was less than 15 mg/dL	0	(0, 1, 2, or 3)
Highest bilirubin level was between 15 to less than 30 mg/dL; <i>or</i> bilirubin never measured but child thought to be extremely jaundiced by provider or family	1	
Highest bilirubin level was greater than 30 and less than 45 mg/dL	2	
Highest bilirubin level was greater than 45 mg/dL	3	
What are the newborn risk factors?		Your Score
None	0	(0, 1, or 2)
Suspected infection, Rh Disease, "sick", premature less than 35 weeks gestation	1	
Proven viral or bacterial infections, NEC (necrotizing enterocolitis, <i>air in the abdomen</i>), or acidosis (high blood acid level, pH <7.2)	2	
What were the results of the newborn neonatal exam?		Your Score
Normal	0	(0, 1, or 2)
Mild acute bilirubin encephalopathy <i>Lethargy, sleepiness, low or high muscle tone, ±high pitched cry</i>	1	
Severe acute bilirubin encephalopathy <i>Arching of neck and back (opisthotonus), setting sun sign (seeing the "white of the eyes below the eyelids), sometimes with scared looking face, unexplained fever</i>	2	
What were the results at your last follow-up exam?		Your Score
Normal	0	(0, 1, or 2)
Mild Dystonia <i>Setting sun sign ± mild abnormal increase or variably increased or decreased muscle tone (dystonia) ± excessive abnormal movements</i>	1	
Moderate/Severe Dystonia <i>Severe dystonia, setting sun sign ± excessive abnormal movements</i>	2	
When the teeth erupted, how was the enamel?		Your Score
Normal	0	(0 or 1)
Enamel Dysplasia <i>Abnormal dental enamel (dysplasia) of the baby teeth (not the permanent teeth) ± flaking or chipping of the enamel of the baby teeth</i>	1	
What were the results of testing for Auditory Neuropathy Spectrum Disorder (ANSD)?		Your Score
Normal, no ANSD.	0	(0, 1, or 2)
Mild auditory brainstem response (ABR) <i>abnormal but present</i>	1	
Moderate/Severe Absent auditory brainstem response (ABR) ± acts deaf	2	
What were the results of the MRI (Magnetic Resonance Imaging)?		Your Score
Normal	0	(0 or 1)
Probable abnormal MRI with abnormal <i>globus pallidus (GP) ± hyperintensity of subthalamic nuclei (STN) on both sides without other abnormalities</i>	1	
Definite abnormal MRI GP±STN <i>Abnormal hyperintensity of the globus pallidus (GP) bilaterally ± hyperintensity of subthalamic nuclei (STN) without significant involvement of other structures.</i>	2	
Add Your Score Column for Total Score:		

How To Interpret Your Results:	Interpretation:	Total Score:
	Definite Kernicterus	10 - 14
	Probable Kernicterus	6 - 9
	Possible Kernicterus	3 - 5
	Not Kernicterus	0 - 2

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KERNICTERUS SPECTRUM DISORDERS (KSD) DIAGNOSTIC TOOLKIT 2: SEVERITY AND TYPE OF KERNICTERUS

Diagnostic Tool Kit for families or caregivers to determine the severity and type of kernicterus.

Child's Name: (Last, First, Middle)	<input type="checkbox"/> Male <input type="checkbox"/> Female	Birth Date:
Parent or Guardian Names: (Last, First)	phone#:	email
Home Address:	Date:	

DIRECTIONS: Please choose the score option (0, 1, 2, or 3) that best fits the child's symptoms.

How would you describe the auditory symptoms?		SCORE	Your Score
None	No auditory symptoms	0	(0, 1, 2, or 3)
Mild	Mild ANSD (<i>Auditory Neuropathy Spectrum Disorder</i> ; ABR (<i>Auditory Brainstem Response</i>) abnormal but present, may normalize with time), or CAPD (<i>Central Auditory Processing Disorder</i>) ± mild hearing loss; normal or mildly delayed speech	1	
Moderate	ANSD (<i>Auditory Neuropathy Spectrum Disorder</i>) with absent or persistent abnormal ABR, mild/moderate hearing loss, may fluctuate; speech delayed or absent	2	
Severe	ANSD (<i>Auditory Neuropathy Spectrum Disorder</i>) with absent ABR, severe-to-profound hearing loss/deafness	3	
How would you describe the motor symptoms?		Your Score	
None	No motor symptoms	0	(0, 1, 2, or 3)
Mild	Mild abnormal muscle tone ± writhing movements (athetosis); mild gross motor delays e.g. walking; ambulates well, speech is intelligible	1	
Moderate	Moderate abnormal muscle tone ± writhing movements, "athetoid" CP (<i>cerebral palsy</i>); ambulates with or without assistance with abnormal gait with abnormal tone and postures of the hands and feet.	2	
Severe	Severely abnormal tone ± writhing movements, athetoid CP (<i>cerebral palsy</i>); unable to ambulate, feed self, sign, speak; often with episodes of severe increased tone and muscle cramps	3	
Your Auditory Score:			
Your Motor Score:			

How To Interpret Your Results: Circle the subtypes based on the above scores and find the intersection of the two subtypes on the graph below.		Auditory - None	Auditory - Mild	Auditory - Moderate	Auditory - Severe
		<i>Score 0</i>	<i>Score 1</i>	<i>Score 2</i>	<i>Score 3</i>
Motor - None	<i>Score 0</i>	None	Mild Auditory	Moderate Auditory	Severe Auditory
Motor - Mild	<i>Score 1</i>	Mild Motor	Mild Classical	Moderate Auditory Predominant	Severe Auditory Predominant
Motor - Moderate	<i>Score 2</i>	Moderate Motor	Moderate Motor Predominant	Moderate Classical	Severe Mixed, Auditory Predominant
Motor - Severe	<i>Score 3</i>	Severe Motor	Severe Motor Predominant	Severe Mixed, Motor Predominant	Severe Classical

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