

SCD issues across life span – US Sickle Cell Disease Surveillance Workgroup

0 – 6 months	Early Childhood	Pediatric	Adolescent Young Adult	Adult	Older Adults
Mild anemia (thal variants) PCN prophylaxis	Pain Anemia Aplastic crises Hand foot syndrome Splenic sequestration Pneumococcal invasive infection Jaundice	Pain Anemia Stroke Priapism Lung (ACS, PHT, Asthma) Delayed puberty Hearing loss (high frequency) Eye Gallstones Jaundice	Pain, Anemia Stroke Priapism Lung (ACS, PHT, Asthma) Delayed puberty Bone (AVN) Leg Ulcers Pregnancy Eye Gallstones Jaundice	Pain, Anemia Lung (ACS, PHT, Asthma) Bone (AVN) Kidney Heart, Hypertension Pregnancy Leg ulcers Eye Gallstones Jaundice	Pain Disabilities Anemia Gallstones Jaundice Leg ulcers Chronic Organ Damage Lung (ACS, PHT, Asthma) Bone (AVN) Kidney Heart Eye
			Vocation		
		Mental Health			
		Academic Attainment¹			
		Transcranial Doppler			
		Hydroxyurea			
		Transfusions			
		Co-Morbid conditions			
		Infections			
		Neurocognitive Testing¹			
Health Services - Medical Home					
Quality of Life					
Nutrition					
Transplant					
Sickle Cell Trait????					

Neurocognitive and Academic Attainment¹

Neonate Early Infancy	Late Infancy	Toddler Preschool	School Age	Adolescent Young Adult	Adult	Older adult
0-6 months	7-12 months	1-5 years	6-12 years	13-21 years	22-40 years	40+ years
Normal	Decreased performance on Bayley	Decreased performance on Bayley and other neurodev. screens	Impaired EF, Lower IQ Grade retention Resource classes	Impaired EF, Lower IQ Grade retention Decreased HS graduation Decreased college performance	Cognitive deficits Difficulty with work and independent living	More severe cog. deficits Difficulty with work and family