Supplemental Information

SUPPLEMENTAL FIGURE 1. Summary of Down syndrome-specific care.

m DS diagnosis with either CVS or amniocentesis prenatally votype postnatally w recurrence risk and offer the family referral to a clinical cist or genetic counselor. barent-to-parent and support group information to the family. DC DS-specific growth charts to monitor weight, length, -for-length, head circumference, or BMI. Use standard charts Il after age 10 years. an echo, to be read by a pediatric cardiologist. g assessment or video study if any: marked hypotonia, weight (<5th %ile weight-for-length or BMI), slow feeding or g with feeds, recurrent or persistent abnormal respiratory oms, desaturations with feeds robjective hearing assessment (may be in NBS protocols) llow EHDI protocols. can't be visualized, refer to otolaryngologist for exam with coope until reliable TM and tympanometry exams are possible fety seat evaluation before hospital discharge. vith differential I, make caregivers aware of risk/signs of leukemia (e.g., easy g/bleeding, recurrent fevers, bone pain) rophylaxis based on AAP guidelines.		All healthcare Any visit Every 3-6 mo By day 3	1 yr visits Up to 6 mo: : : : : : : : : : : : : : : : : : :	5 yr	12 yr	21 yr
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rophylaxis based on AAP guidelines.						
rophylaxis based on AAP guidelines.		At birth (if not in NBS)	Every 5-7 mo		6 mo if antithyroid anti	bodies ever detected
				<u> </u>		
y precautions.				Biennially		
						1
therapy.		Any visit				
g evaluation.		clear				
R, behavioral, ear-specific).		Start at 6mo, every 6 mo until established normal bilaterally by ear-specific testing, then annually				
sabilities.			-		x x <td></td>	
e pain						
pertise in pediatric sleep disorders.						
stands and is following therapy plan at home.		All HMV	1			
or (2) a combination of serum iron and Total Iron Binding ity				Annually		
rician may prescribe iron supplement.				Any visit		
			All HMV, use developmental ly-appropriate criteria	Photoscreen (all HMV); if unable, refer to ophthalmologist annually	Photoscreen (all HMV); if unable, refer to ophthalmologist biennially	Visual acuity or photoscreening at a HMV, or ophthalmology- determined schedul
see text for details).				Any visit		
polysomnogram.		ļ				
s sexual exploitation risks.				At 30 mo At least once	At least once	At least once
					subsequent HMV	-appropriate, then all
					At least once	At least once
s and facilitate transitions: education, work, finance,			All HMV		All HMV starting at	10 yr
	rophylaxis based on AAP guidelines. ss cervical spine-positioning for procedures and atlantoaxial y precautions. s for CAM use, discourage any unsafe CAM practices. children to early intervention for speech, fine motor or gross therapy. lle ear disease occurs, obtain developmentally-appropriate g evaluation. een hearing with developmentally-appropriate methodology & behavioral, ear-specific). to ophthalmologist with experience and expertise in children sabilities. with differential if easy bruising or bleeding, recurrent fevers, e pain s for sleep-disordered breathing; if present, refer to physician xpertise in pediatric sleep disorders. e child is receiving developmental therapies, and family stands and is following therapy plan at home. with differential and either (1) a combination of ferritin and or (2) a combination of serum iron and Total Iron Binding ity lid has sleep problems and a ferritin less than 50 mcg/L, the rician may prescribe iron supplement. screening ild has myelopathic symptoms, obtain neutral C-spine plain see text for details). n polysomnogram. re family for transition from early intervention to preschool. ss sexual exploitation risks. developmentally-appropriate plans for menarche, ception (advocate/offer LARC), and STI prevention. ss risk of DS if patient were to become pregnant. s for any developmental regression. ss and facilitate transitions: education, work, finance, anship, medical care, independent living	ss cervical spine-positioning for procedures and atlantoaxial y precautions. s for CAM use, discourage any unsafe CAM practices. children to early intervention for speech, fine motor or gross therapy. Ile ear disease occurs, obtain developmentally-appropriate g evaluation. seen hearing with developmentally-appropriate methodology R, behavioral, ear-specific). to ophthalmologist with experience and expertise in children sabilities. with differential if easy bruising or bleeding, recurrent fevers, e pain s for sleep-disordered breathing; if present, refer to physician xpertise in pediatric sleep disorders. e child is receiving developmental therapies, and family stands and is following therapy plan at home. with differential and either (1) a combination of ferritin and or (2) a combination of serum iron and Total Iron Binding ity lid has sleep problems and a ferritin less than 50 mcg/L, the rician may prescribe iron supplement. screening id has myelopathic symptoms, obtain neutral C-spine plain see text for details). 1 polysomnogram. re family for transition from early intervention to preschool. ss sexual exploitation risks. developmentally-appropriate plans for menarche, ception (advocate/offer LARC), and STI prevention. ss risk of DS if patient were to become pregnant. s for any developmental regression. ss and facilitate transitions: education, work, finance,	ss cervical spine-positioning for procedures and atlantoaxial All HMV y precautions. 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Ben hearing with developmentally-appropriate methodology t, behavioral, ear-specific). to ophthalmologist with experience and expertise in children solitilities and is following therapy plan at home. with differential of developmental therapies, and family stands and is following therapy plan at home. with differential and either (1) a combination of ferritin and or (2) a combination of serue and erritin less than 50 mcg/L, the rican may prescribe iron supplement. screening the differential is symptoms, obtain neutral C-spine plain see text for details). polysomogram. refamily of therastic size plans for mearty intervention to preschool. s sexuel exploitation risks. s and excited for the details). polysomogram. refamily of therastic plans for mearty intervention to preschool. s and sis foll Si receiving development. s creening All HMV, use developmental by appropriate criteria criteria developmental by appropriate criteria cri

Do once at this age	Abbreviations: DS, Down syndrome; CVS, Chorionic villus sampling; HMV, Health Maintenance Visit; BMI,
Do if not done previously	Body mass index; CDC, Centers for Disease Control; EHDI, Early Hearing Detection and Intervention; NBS,
Repeat at indicated intervals	Newborn screen; CAM, Complementary and alternative medicine; BAER, Brainstem auditory evoked
(border) See report for end point	response; TM, Tympanic membrane; TAM: transient abnormal myelopoiesis