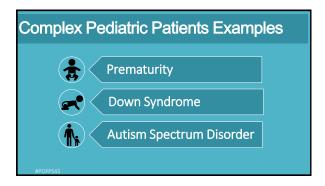
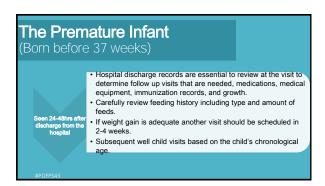
The Care of the Medically Complex Child & Their Transition to Adult Medical Care Diana Kudes, MD Jessica Mayer, DO POFPS 43rd Annual CME Symposium August 3, 2018

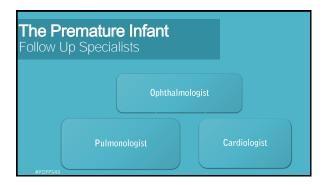
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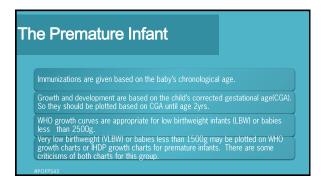
Help family physicians be more comfortable in the care of the medically complex pediatric patient. Help family physicians transition care of the medically complex child to adult care. Help family physicians assume care of medically complex children transitioning from pediatric care.











Br	east Feeding
	Breastmilk is the best nutrition for the premature infant however breastfed infants tend to gain weight slower than formula fed infants.
	In the NICU babies are usually given breastmilk with fortifiers to increase weight gain.
	Evidence for continuing fortification after discharge are small but are recommended by many NICUs. Fortifiers are continued until corrected weight is 25% or greater or 6 months.
	The European Society for Paediatric Gastroenterology, Hepatology, and Nutrition recommends fortification for exclusively breastled infants with subnormal weight for corrected gestation age. ²

Formula fed infants are fed enriched 22cal/oz formula in the NICU for improved growth and nutritional needs. There is no data to support continuation of enriched formula for all former premature infants. Infants who are <10% at NICU discharge are usually discharged on an enriched formula until they are >25% or 6 months old. Infants should usually be allowed to eat on demand every 2-4hrs for a total of 120-150ml/kg/d.

h a	ne Premature Infant: Alivizumab
	Depending on how premature the infant is and other comorbidities the infant may qualify for palivizumab. The AAP has published guidelines for its use and reviews its policy yearly.
I	Infants in the first year of life who were born before 29 weeks qualify but infants born >29 wks may qualify if certain conditions are met.
	RSV Policy Statement —Updated Guidance for Palivizumab Prophylaxis Among Infants and Young Children at Increased Risk of Hospitalization for Respiratory Syncytial Virus Infection. <i>Pediatrics</i> 2014;134(2):415–420 contains the current guidelines

The Premature Infant: Iron Deficiency Preterm infants have low iron stores, decreased erythropoietin production, shortened RBC survival and have often had frequent venipuncture putting them at higher risk of developing anemia. Breastfed preterm infants should be given 2mg/kg of iron from age 1mo to 12mo or until getting adequate iron intake from foods Screen for iron deficiency anemia in all preterm infants between ages 48 months, and then again at 12 and 24 months of age.

The Premature Infant: Development Development should be based on the corrected gestation age and evaluated at every well child check. Any delays should prompt referral to Early Intervention. Referral to Early Intervention surveillance programs may be initiated at NICU discharge. Most NICUs also have follow up clinics which will include development surveillance.

Premature	e Infant:
Premature infants are at higher risk of	 Cerebral palsy Motor and coordination problems Cognitive impairment ADHD
#POFPS43	

The AAP published guidelines for the health supervision of the child with Down Syndrome from birth to age 21 years in 2011. These guidelines include useful information about additional health screenings and anticipatory guidance unique to this population of patients.



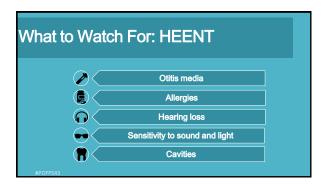
own Syndrome: Growth & evelopment
Infants and children should be monitored closely for growth and development. World Health Organization Growth charts should be used instead of Down Syndrome charts previously recommended because they no longer reflect current population growth.
Children with Down Syndrome are typically of shorter stature and heavier than other children.
Intellectual disability can be mild to severe.
#POFPS43

Down Syndrome: Common medical problems Obstructive sleep apnea Ear infections and hearing loss Cataracts and visual problems Congenital heart disease Thyroid disease Thyroid disease Seizures Hip disorders Congenital Gastrointestinal malformations Autism Celiac disease Hematologics problems: Myeloproliferative disorder, Leukemia Atlanto-Axial instability

	e Screenings and Referrals ewborn Nursery
Refer to Pediatric age 13yrs, then e	Ophthalmologist in the first 6 months. Annual visits ages 1-5 yrs, then every other till very 3yrs.
Repeat Thyroid st	
Refer to Audiology	y at 6 months
Hearing testing an 5-21yrs.	nd tympanometry every 6 months from ages 1-5yrs, then hearing testing annually ages
Hgb annually start	ing at age 1 vr

usn	n Spectrum Disorder
screen	erican Academy of Pediatrics recommends that every child should be id for autism at 18 months and 24 mo using the Modified Checklist for in toddlers revised version or MCHAT-RyF.
eviden	erican Academy of Family Physicians has stated there is insufficient e to screen everyone in lines with the recommendations from the US ative Task Force.
The mo	st recent data from the CDC from 2014 show that 1 in 59 children hav

tism Spectrum Disorder: omorbidities
ASD is more common in children with Down Syndrome, Fragile X syndrome and Tuberous sclerosis.
ASD occurs with another developmental diagnosis 83% of the time.
Psychiatric diagnosis is also present in 10% of children.
Vanderbilt University has a toolkit for Health Care For Adults with Intellectual and Developmenta Disabilities.
About half have an intellectual disability





	n Spectrum Disorder: pintestinal problems	
•Consti	pation	
•Diarrh	ea	
•GERD		
•Food p	preferences	
•Food a	allergies	
•Ask at trying	oout special diets or alternative treatments they may	ay be
#POFPS43		

Autism Spectrum Disorder: Neuro/Muscular - Hypotonia - Seizures - Gross Motor delay - Fine Motor delay - Motor planning problems - Tic disorders

•Poor social skills	
•Wandering	
•Sensory issues	
•Tantrums and self injurious behaviors	
•Depression	
•Anxiety	
•OCD	
•ADHD	

Infectious Disease	
•Otitis media •25% have impaired immunity	
*23% have impalied immunity	



	iltions such as Down Syndrome and Autism special care should be taken to smooth transition
	d to visit the office prior to having their first appointment to be comfortable with ivironment
Providinį anxiety.	g a clear explanation of what to expect during an appointment can help reduce
	be verbal, written or through pictures or a combination. Even patients who are nay benefit from pictures.

Transition to Adult Medical Care During appointments, be sure to explain everything that is about to be done to the patient, even things we may think are routine or have been done to the patient before Be sure to address the patient directly, do not only speak to caregivers Often helpful to schedule longer appointments Important to establish baseline as minor changes may signify significant medical problems Ability to communication symptoms or pain may be limited

Medical Conditions with higher prevalence in Adults with Down Syndrome • In addition to those previously referenced, in adulthood the following medical conditions are more prevalent: • Mental Health Disorders: Depression, Obsessive Compulsive Disorder, Conduct Disorder • Abuse (physical and sexual) • Alzheimer's disease • Testicular cancer • Diabetes •Medical problems tend to manifest as behavioral problems •All standard adult screening should be done

•An adult with Autism or Down Syndrome is considered competent to make their own medical decisions unless specifically declared otherwise

•In cases where guardianship is not appropriate, it is important to address advance directives, especially power of attorney for health care and finance

•Family estate planning is important, frequently a trust needs to be established

#POFPS4

Autism Services in Pennsylvania http://www.dhs.pa.gov/citizens/autismservices Autism Speaks http://www.autismspeaks.org/ Autism Case Training, Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/actearly/autisms/case-modules/index.html General Guide for treating Adults with Disabilities Adults with Developmental Disabilities: A Comprehensive Approach to Medical Care. American Family Physician. 2018;97(10):649-656

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