

Pediatric and Adult Preventive Care In Rett Syndrome

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Points of Discussion

- **Child and adult preventive care**
- **Vaccinations**
- **Child, adolescent and adult nutrition**

Childhood Preventive Care

- Well child visits with primary care provider
- Dental care every 6 months or as needed
- Vision and hearing as indicated
- Vaccinations as per AAP guidelines
- Rett syndrome specific considerations
 - EKG screening at dx, then every 1-2 years
 - Scoliosis screening at age 4, then as indicated
 - Nutritional assessment including BMI
 - Bone health by xray or DEXA if at risk
 - Physical therapies and seating assessments

Why Vaccinate?

- **Vaccinations work**
 - Used for over 50 years
 - Save lives and decrease disease
- **Vaccinations are safe**
 - Monitored by FDA, CDC, AAP, AAFP
 - No credible evidence of linkage to autism
- **Vaccinations are necessary**

Without Vaccinations

- Polio would paralyze 10,000 children
- Rubella (German measles) would cause birth defects and mental retardation in 20,000
- Measles would infect 4 million children, killing 3,000
- Diphtheria would be one of the most common causes of death in school-aged children
- Haemophilus influenzae type b (Hib) would cause meningitis in 15,000 children
- Pertussis would kill thousands of infants

Vaccine FAQ's

- **Do vaccines weaken/overwhelm the immune system?**
 - **NO**
- **Does MMR cause autism?**
 - **NO**
- **Does thimerosal cause autism?**
 - **NO**
- **Are vaccines safe?**
 - **YES**

Vaccine FAQ's

- **What are the side effects?**
 - **Common - mild swelling, redness, tenderness, slight fever, fussy; Uncommon – high fever, hives, seizures related to fever**
- **Special considerations**
 - **No live virus vaccines with cancer, oral or injected steroids, immune deficiency**
 - **May delay pertussis part of DTaP with recent history of seizures**
 - **Safe to immunize with low grade fever (<100.4), ear infection, cough, runny nose or mild diarrhea**

Nutrition in Young Females

general recommendations per day

- **Calories –1500 kcals – variable with activity**
- **Protein - 18 gm**
- **Calcium - 800 mg**
- **Vitamin D – 400 IU**
- **Iron – 10 mg**
- **Zinc - 12 mg**
- **Folate - 200 µg**
- **Adequate fluids – 5-6 cups**
- **Average BMI at 4 years – 15.4**

Nutrition in Adolescent Females

general recommendations per day

- **Calories - 2000 kcals**
- **Protein - 46 gm**
- **Calcium - 800 to 1300 mg**
- **Vitamin D - 400 IU**
- **Iron - 8mg**
- **Zinc - 7 mg**
- **Folate - 330 µg**
- **Vitamin A - 485 µg**
- **Vitamin B₆ - 1 µg**
- **Adequate fluids - 6 to 8 cups -more in hot weather**
- **Adequate fiber - Age plus 5 gm**
- **Average BMI at 10 years - 17**

2004 Food and Nutrition Board - National Academy of Sciences

Adult Preventive Care

- **Cancer screening**
 - Skin
 - Breast exams - Monthly “at home” exam; mammography
 - Gynecological exams -
 - Rectal exam for mass and occult blood or ultrasound every 2-3 years if low risk.
 - No need for pelvic or PAP unless increased risk or symptomatic
 - Screening for ovarian cysts if high risk
 - Exam may require sedation
- **Dental**
- **Vision and hearing**

Adult Preventive Care

- **Immunizations**

- Influenza 18-50 if desired; recommended annually after 50
- Zoster (shingles) after age 60 regardless of hx of chicken pox
- Meningococcal polysaccharide after age 55
- Others depending on childhood vaccination history

- **Infectious disease screening**

- Hepatitis C – if high risk
- TB – if high risk

- **Other recommended screenings**

- Cholesterol
- Diabetes type 2
- Hypertension

Adult Preventive Care

- **Rett syndrome specific considerations**
 - **EKG screening every 1-2 years**
 - **BMI and nutritional assessment annually**
 - **Bone mineralization by xray or DEXA**
 - **Physical therapies**
 - **Mental health – depression**

Nutrition in Adult Females

general recommendations per day

- **Calories - ~1500 kcal - variable**
- **Protein - 46 gm**
- **Calcium - 1000 mg - 1200 mg after menopause**
- **Vitamin D - 400 minimum - 1000 IU**
- **Iron - 5-8mg (depending on age)**
- **Zinc - 7 mg**
- **Folate - 330 µg**
- **Vitamin A - 485 µg**
- **Vitamin B₆ - 1 µg**
- **Adequate fluids - 6 to 8 cups-more in hot weather**
- **Adequate fiber- 25 gm**
- **Average BMI age 20 - 21.5**

Resources For Information

- Food and Drug Administration
 - www.fda.gov
- American Academy of Pediatrics
 - www.aap.org
- Centers for Disease Control and Prevention
 - www.cdc.gov/vaccines
- The Children's Hospital of Philadelphia Vaccine Education Center
 - www.chop.vaccine.edu

Questions?

