

Diet and Duchenne: Simple Nutrition Advice

Parent JOIN THE FIGHT.
END DUCHENNE.
Project
Muscular
Dystrophy

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Nutrition Risks Early in Life

- Steroid
 - Increased weight
- Behavioral issues
 - “picky eating”
- Vitamin D deficiency
- Calcium



Nutrition Challenges With Age

- Decrease ambulation / energy needs
- Decreased oral Intake
- Swallowing issues
- Impaired gastric function
(Gastroparesis)



Registered Dietician Nutritionist

- *Unsung Heroes*
- RDN evaluation every 6 months
 - Monitor weight/height
 - Caloric intake
 - Mineral/Vitamin intake



Typical Focus of Clinics

- Neurology
- Cardiology
- Pulmonology
- Physical Therapy



Nutrition Impacts Each Area

- Neurology
- Cardiology
- Pulmonology
- Physical Therapy



DMD Care Considerations Working Group

- Experts from a wide range of disciplines
 - U.S. Centers for Disease Control and Prevention
 - TREAT-NMD
 - Patient Advocacy Organizations
- GI/Nutrition Recommendations
 - 6 month
 - 12 month



6 Month Evaluations

- RDN visit
- Screen for Swallowing/Dysphagia
- Screen for Reflux
- Screen for Gastroparesis
- Screen for Constipation



Yearly Evaluation

- Vitamin D levels
- Dietary intake of Calcium



Supplements

- Evidence and guidelines for calcium and vitamin D
- Multivitamin or mineral supplement if below daily recommendations
- No current evidence for or against MVI or herbal supplementation



Special Diets?

- Strong Evidence Based Research Lacking
- Healthy Diet for Entire Family
- Dietician guides individual plans



RED FLAGS

- Choking / Aspiration
- Problems chewing
- Decreased ability to feed self
- Taking long time to eat meal
- Weight loss



G-tube



Benefits (Anecdotal)

- Improves Daily Function
- Improves Ability to Focus
- Improves Endurance / Energy Level
- Access for Fluids/Nutrition



Summary

- Meet regularly with Registered Dietitian
- Closely follow weights and caloric intake
- Consider G-tube



Thank you!