HEALTH AND NUTRITION
FOR JM KIDS AND THEIR FAMILIES

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CureJM
FOUNDATION
www.curejm.com
Tessa's Juvenile Dermatomyositis (JDM) Story
What can we cover in just one hour?

• Basic nutrition and health guidelines
• Special considerations for JM
• Popular diets
• The feeding environment
• Ready, set, go!
5 FRUITS & VEGGIES
2 HOURS OR LESS OF RECREATIONAL SCREEN TIME
1 HOUR OR MORE OF PHYSICAL ACTIVITY
0 SWEETENED DRINKS
Special Nutrient Needs for JM Children

- **Calcium**: 800-1200mg/day for children (1200-1500mg/day for adolescents)
  - 400-800mg supplementation (depending on calcium intake from food)
- **Vitamin D**: 400-800IU/day
  - Most children’s multi-vitamins and Vit D supplements contain 400IU
- Complete multi-vitamin with minerals
- **Probiotics**
  - Previous recommendation did not recommend probiotics for the immuno-compromised population
  - This recommendation may be becoming outdated (?)
  - As with all supplements, do so moderately and speak with your doctor
Special Nutrient Needs for JM Children

• PLEASE REMEMBER, THESE ARE GENERAL NUTRITIONAL GUIDELINES. YOU SHOULD ALWAYS SPEAK WITH THE TREATING PHYSICIAN BEFORE STARTING, CHANGING OR DISCONTINUING ANY SUPPLEMENTS, VITAMINS OR PROBIOTICS. PLEASE ALSO REPORT ALL SUPPLEMENTS THAT YOUR CHILD IS TAKING TO YOUR PHYSICIAN AT EACH VISIT SO THAT THE PHYSICIAN CAN ADVISE ANY CHANGES IN DOSAGE.
Side Effects of Medications That Affect Eating

• Nausea/vomiting
• Taste alterations/metallic taste
• Constipation
• Increased (or decreased) appetite
• Strong cravings/Desire for sweet/salty foods
• Increased fluid needs/decreased thirst
Steroids

• Weight gain (from adrenal changes and increased appetite)
  • Have low calorie snacks available (handout)
• Bloating, discomfort, and high blood pressure
  • Low sodium foods (handouts)
Reading labels

• Look for foods with <250mg sodium per serving
Special Diets of Consideration

- Food sensitivities
- Gluten-free
- Anti-inflammatory
- FODMAP
- Autoimmune Paleo
- Plant-based/vegetarian
- Needs are INDIVIDUAL
WHY IS NUTRITION SO CONFUSING?
• Eat REAL food
• Avoid eating highly-processed foods as a norm
• Look for unbalance in the diet and make adjustments (excessive dairy, grain, meats?)
Nutrition is more than just food we serve our children.

Nutrition is feeding. Feeding is parenting.

It can be positive or negative.
If there was a fly on your wall during mealtime...

What would he see?
Long term effects of NEGATIVE food environment

• Food insecurity → over eating
• Pressure to eat → less consumption of fruits and vegetables, food aversions
• Stressful mealtime → meal aversion
• Restrictive feeding practices → poor self regulation
• Overly permissive → obesity
Benefits of POSITIVE food environments

- Higher self esteem
- Better nutrition choices longterm
- More positive family relationships
- Better social skills, grades, less risky behavior (family meals)
- Fewer emotional and behavioral problems, greater emotional well-being, more trusting and helpful behaviors towards others, and higher life satisfaction (frequent family meals)
What does a positive meal time look like?

• Offering healthy choices at meals and snacks. ‘Snacks’ don’t have to be ‘snack foods’ – they can be healthy too!
• Offering new foods along side familiar foods.
• Setting expectations for trying new foods while avoiding negative pressure.
• Never giving up on introducing a new food. It may take 10+ times of offering a food before a child will accept it.
• Allowing children to practice serving their own portion sizes. They will improve with practice.
• Keeping the conversation NOT about the food.
• Having FUN! Playing mealtime family games, sharing stories about the day, etc.
Make mealtime about FAMILY time NOT THE FOOD!
Play games, talk, be silly – NO pressure!
RESOURCES
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<tr>
<td>Hair appt</td>
<td>Visit - afternoon</td>
<td>Breakfast</td>
<td>Dinner</td>
<td>water grass</td>
<td>Dinner</td>
<td>mow grass</td>
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<tr>
<td>Dinner</td>
<td>Information</td>
<td>Dinner</td>
<td>Dinner: Burgers &amp; Fries</td>
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<tr>
<td>Meal: lasagna</td>
<td>Care for children</td>
<td>Care for children</td>
<td>Care for children</td>
<td>Holiday</td>
<td>Meal</td>
<td>Meal: Fried Chicken</td>
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<td>Meal: Trail Mixes</td>
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<tr>
<td>Meal</td>
<td>Care for children</td>
<td>Ride to Dr Appt</td>
<td>Meal</td>
<td>Ride to Dr Appt</td>
<td>Something else</td>
<td>Happy Birthday Suzy</td>
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<tr>
<td>Meal: Turkey and dressing</td>
<td>Care for children</td>
<td>Care for children</td>
<td>Supper: frog legs</td>
<td>meal test</td>
<td>Care for children</td>
<td>Ride to Dr Appt</td>
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Online Grocery Delivery
### Daytime Jobs

<table>
<thead>
<tr>
<th>POINTS</th>
<th>MY JOB</th>
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<tr>
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<td>Stretching</td>
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<td>3 physical therapy activities</td>
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<td>Try a new food</td>
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<td>Eat 3 different colors</td>
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<td>5</td>
<td>Help with dinner</td>
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<td>15</td>
<td>Eat 5 fruits and vegetables</td>
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<td>10</td>
<td>Random Act of Kindness</td>
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**TOTAL POINTS**

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In Summary

• Remember basic health messages for the entire family
• Have proper vitamin/mineral supplementation
• Low sodium foods (steroids)
• Seek advice of a Registered Dietitian if considering diet restrictions/special diet
• Eat REAL food and balance the diet
• Observe your mealtime environment
• Invest in your child’s long term relationship with food
Thank you!

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