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Cynthia Kapphahn, MD, MPH, Jennifer Derenne, MD and Jennifer Willoughby, RD, CSP have no disclosures to make.
Objectives

- Review current literature on recognition and treatment of ARFID
- Understand the psychological differences between patients with ARFID vs. other eating disorders (ED)s
- Formulate appropriate medical/psychological assessment for teen presenting with food aversion or avoidance
- Identify specific techniques for treating food aversions in inpatient and outpatient settings, to increase variety and amount of foods consumed and improve nutritional status and growth
Case #1- Minimally Eating Miranda

• Miranda is a 14 yo girl coming in for a physical. Per mom and Miranda, she has always been a picky eater, sticking only to PB&J, pasta, + dry cereal. She does not eat any other foods. She has been the same weight for the past year and height has not increased either.

• What else do you need to know? How would you approach diagnosis and management?
Case #2- Super Picky Sammy

- Sammy is a 15 yo male admitted to the hospital from the GI clinic with medical instability (bradycardia) and low weight (<75% mBMI)

- He is a life-long picky eater, who now will only eat cheese pizza, pancakes, and steak. He will eat preferred brands of pizza and pancakes, but does not like what is available in the hospital. He has last eaten fruit about 6 months ago, but states that he is willing to try it. Parents are at wit’s end, and report a high degree of discord in the family related to Sammy’s eating habits.
Case #3- Choking Chelsea

• Chelsea is an 8 year old who comes in for her check up. She has lost 8 lbs in the past year (mom thinks very recently). No family stress, but grades down in the past couple of weeks. Has always been a perfectionist. Now, she is anxious and irritable. She says she wants to gain weight but refuses to eat more than bites at meals. Last week she choked on a Starburst candy and now has been refusing all solid food for several days.
• Weight at 50% (down from 75%), Height at 75%
• What’s going on with Chelsea?
Case #4- Acutely Picky Peter

• Peter is a 12 yo boy who comes in with weight loss. 2 months ago, mom noticed some new behaviors that seemed to start very abruptly, including not letting food touch on the plate, more picky about meals, and other new habits that made homework take longer. What’s going on?
DSM-5: Avoidant/Restrictive Food Intake Disorder (ARFID)

• Eating or feeding disturbance (including but not limited to apparent lack of interest in eating or food; avoidance due to sensory characteristics of food; or concern about aversive consequences of eating) as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one or more of the following:
  – Significant weight loss (or failure to gain weight or faltering growth in children);
  – Significant nutritional deficiency;
  – Dependence on enteral feeding;
  – Marked interference with psychosocial functioning

• No evidence of lack of available food or an associated culturally sanctioned practice
How Do Teens With ARFID Compare To Teens Who Have Anorexia or Bulimia?

- Retrospective case-control study of 8-18 year-olds presenting to 7 adolescent-medicine ED programs across US & Canada (Fisher, 2014)

- N = 712 pts; 98 (13.8%) met ARFID criteria

- Patients with ARFID were demographically and clinically distinct from those with anorexia nervosa (AN) or bulimia nervosa (BN)

How Do Teens With ARFID Compare To Teens Who Have Anorexia or Bulimia?

- **ARFID patients:**
  - Younger than those with AN or BN
  - Longer duration of illness
  - % median BMI between that of patients with AN or BN
  - More likely to be male

<table>
<thead>
<tr>
<th></th>
<th>ARFID</th>
<th>AN</th>
<th>BN</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>12.9</td>
<td>15.6</td>
<td>16.5</td>
<td>p&lt;0.001</td>
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<tr>
<td>Duration of illness (months)</td>
<td>33.3</td>
<td>14.5</td>
<td>23.5</td>
<td>p&lt;0.001</td>
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<tr>
<td>% median BMI</td>
<td>86.5</td>
<td>81</td>
<td>107.5</td>
<td>p&lt;0.001</td>
</tr>
<tr>
<td>% Male</td>
<td>29%</td>
<td>15%</td>
<td>6%</td>
<td>p&lt;0.001</td>
</tr>
</tbody>
</table>

How Do Teens With ARFID Compare To Teens Who Have Anorexia or Bulimia?

- Compared to youth with AN or BN, ARFID patients:
  - More likely to have a comorbid medical condition
  - More likely to have an anxiety disorder
  - Less likely to have a mood disorder

<table>
<thead>
<tr>
<th></th>
<th>ARFID</th>
<th>AN</th>
<th>BN</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>% with comorbid medical condition</td>
<td>51%</td>
<td>10%</td>
<td>11%</td>
<td>&lt;0.001</td>
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<tr>
<td>% with anxiety disorder</td>
<td>58%</td>
<td>36%</td>
<td>33%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>% with mood disorder</td>
<td>19%</td>
<td>31%</td>
<td>58%</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

ARFID: A Distinct Entity

- Picky eaters (28.7%)
- Generalized anxiety (21.4%)
- GI sx (19.4%)
- Hx vomiting/choking (13.2%)
- Food allergies (4.1%)

<table>
<thead>
<tr>
<th>Characteristics at Initial Outpatient Presentation</th>
<th>ARFID (n = 29)</th>
<th>AN (n = 40)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, median (range), y</strong></td>
<td>16 (8-20)</td>
<td>16 (9-25)</td>
<td>0.21</td>
</tr>
<tr>
<td><strong>Female, % (No.)</strong></td>
<td>83 (24)</td>
<td>93 (37)</td>
<td>0.27</td>
</tr>
<tr>
<td><strong>Eating disorder behaviors, % (No.)</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Binge-eating</td>
<td>11 (3)</td>
<td>50 (20)</td>
<td>0.0008</td>
</tr>
<tr>
<td>Self-induced vomiting</td>
<td>3 (1)</td>
<td>37 (15)</td>
<td>0.001</td>
</tr>
<tr>
<td>Excessive exercise</td>
<td>32 (9)</td>
<td>60 (24)</td>
<td>0.02</td>
</tr>
<tr>
<td>Other psychiatric diagnosis, % (No.)</td>
<td>71 (20)</td>
<td>29 (8)</td>
<td>0.03</td>
</tr>
</tbody>
</table>
The Many Expressions of ARFID

Limits food intake for reasons other than weight loss

Chronic

ARFID: Classic “picky eater”, no underlying medical issues

ARFID: With underlying medical issues

Acute

ARFID: With phobia

OCD symptoms

ARFID: With OCD

Food avoidance associated with PANDAS or PANS
Assessment
Assessment: Key Questions

• Developmental concerns- initiation of feeding, food sensitivities, transition to solids or cup, rate of introduction of new foods

• Documented developmental delay or failure to thrive, medical conditions necessitating feeding tube or parenteral nutrition

• Previous evaluation by nutrition, GI, allergy, etc.
Assessment: Key Questions

• History of sensory sensitivity (clothing, food texture, food taste, smell, color)
• Need for nutritional supplements (Boost, Ensure, Carnation Instant Breakfast)
• 24 hour recall and similarity to “usual” pattern of eating. What is frequency of meals and snacks? Are they “glut” eaters? Does eating look different on weekends, holidays, at school vs home?
Assessment: Key Questions

- Eating behaviors in family members (e.g. dieting or medically restrictive eating)
- Is there tension at meals? How do family members handle child’s eating? Are family members consistent in their response? Is there high expressed emotion within the home?
Assessment: Key Questions

• Full assessment of mood and anxiety symptoms and their effect on eating and appetite

• Temperamental factors (obsessive, difficult to regulate, slow to warm up, ability to tolerate transition)

• Previous treatment and outcome
Helpful Questions in Diagnosis

- Do you feel like your current weight is too high, too low, or just right?
- If you’re wanting to gain weight, what do you feel is getting in the way of that?
- Any foods that you avoid eating and if so, why?
- How often do you weigh yourself?
- Do you feel guilty after eating certain foods?
- How do you feel if you miss a workout?
Is it a “typical” eating disorder or is it ARFID?

“Typical” ED
- Body image disturbance and/or overvaluation of shape and weight
- Limits or avoids foods to control weight

ARFID
- No body image disturbance, often recognize they are underweight
- Foods avoided for a specific reason that causes very high anxiety - pain, nausea, fear of choking or vomiting, strong taste or texture
Food Preferences

“Typical ED”
- “Good” vs. “bad” foods, “healthy” vs. “unhealthy
- Vegan, vegetarian, gluten free
- Prefers: Fruits and vegetables
- Avoids: Fats, carbohydrates, high caloric density foods

ARFID
- May prefer:
  - More processed, higher fat foods (e.g. chips, ice cream, chicken nuggets)
  - Specific brand
  - “Beige” diet
- May avoid:
  - Certain foods based on sensory characteristics, e.g. texture, odor
  - Fruits and vegetables
“Typical Eating Disorders” vs. ARFID

• Kids with ARFID may worry about gaining too much weight or getting fat - as it is culturally and societally normal to be aware of weight/shape even if don’t have an ED

HOWEVER

• Weight loss itself can trigger an eating disorder

• ARFID may → more typical AN or BN
Medical Assessment

• If AFRID only, without underlying medical condition:
  – Review of symptoms, physical examination, and labwork: Findings all similar to that expected with malnutrition
Recommended Labwork

• To assess for organic etiology and medical complications of malnutrition:
  – CBC with ESR
  – Comprehensive metabolic panel, phosphorus, magnesium
  – Thyroid function tests (TSH, free T4, total T3)
  – LH, FSH, estradiol or testosterone
  – Urinalysis
  – 25-OH vitamin D

• If short stature or GI symptoms, assess for celiac disease
  – Tissue transglutaminase (TTG)
  – Total IgA
Treatment
Goals of Treatment in ARFID

- Get the kid eating! Basic goals first with stepwise approach
- Weight and growth restoration
- Adequate intake from all food groups
- Increase variety of foods and range of foods kids eat
- Eating well in varying social situations
- Eating without fear
- Eating without eventual pain or managing the pain without sacrificing intake
Multidisciplinary Team Members

• Pediatrician or adolescent medicine physician - monitor medical stability, growth
• Therapist - master’s or doctoral level clinician with experience treating anxiety and eating disorders
• +/- Psychiatrist - if medications are being used
• Occupational therapist - may be useful for assessing swallowing, and making recommendations re: position and posture while eating, acupressure, biofeedback
• Nutritionist - RD may be useful consultant to parents if they are having trouble figuring out appropriate ways to meet nutritional needs.
• Typically do NOT recommend structured meal plans
Role of the Medical Provider

• Provide comprehensive medical assessment
• Monitor physical health including vital signs and laboratory tests
• Determine whether safe to treat as outpatients or require medical hospitalization

ARFID kids may be as sick as those with other eating disorders!

– Interpret results in the context of physiological adaptation to malnutrition
– Lab test results can be normal even with life-threatening ARFID
– Lack of appropriate growth for age may be equally concerning
Hospitalization may be indicated for any of the following:

- Physiological instability
  - Severe bradycardia (pulse < 50 beats/min in day; <45 beats/min @ night)
  - Hypotension (<90/45 mm Hg)
  - Hypothermia (body temperature < 96°F, 35.6°C)
- Orthostasis:
  - Increase in pulse (>20 beats/min)
  - Decrease in blood pressure (>20 mm Hg systolic or >10 mm Hg diastolic)
- Low weight: ≤ 75% Median body mass index for age and sex
- EKG abnormalities (e.g., prolonged QTc)
- Dehydration
- Electrolyte disturbance (e.g. low potassium, sodium, phosphorus)
- Acute medical complications (syncope, seizures, cardiac failure, etc.)
Family-based Treatment (FBT)  
(LeGrange & Lock)

• **Premise**: Patients with an eating disorder are unable, by the nature of their illness, to select meals that will best meet their nutritional requirements.

• Patients temporarily require that their parents take control in planning, preparing, and plating all meals and snacks. Control of meal planning is gradually returned to the patient as he or she is able to demonstrate healthy behaviors and decision-making.

• This is an outpatient treatment that may begin in the hospital (or hospitalization may be necessary at points along the way).
Family-based Treatment (FBT)

- **Phase 1:** Weight restoration- family selects meals and encourages/demands completion. Patient is too brain starved to make rational decisions.
- **Phase 2:** Returning control over eating back to the adolescent
- **Phase 3:** Establishing healthy adolescent identity and managing normal developmental tasks
Treatment Approach: Family based treatment, chaining and shaping for ARFID

– 15-30 outpatient sessions
– Length of treatment will depend on nature of issue, severity, parent/child motivation, and developmental age of child
– Both parents and any additional caregivers responsible for feeding should be present if possible (extended family members, nanny, etc)
Treatment: Phase One (weekly)

- **Psychoeducation** re: anxiety and avoidance, nutritional need for expanded food repertoire
  - Help parents understand their child’s eating behaviors and how to best respond to them (set firm and consistent expectations, but be warm and empathic with the process).
  - Introduce incentive strategies to reward effort if developmentally appropriate.
  - Enforce regular mealtimes, observe amount eaten.
  - Help kids understand why eating is difficult for them (trauma, anxiety, “supertaster” status, etc) - validate their concerns
- **Coping and relaxation strategies** (breathing, visualization, progressive muscle relaxation, anti-nausea bands, essential oils, candles)
Treatment: Phase One (weekly)

Practice exposure and response prevention techniques

- **Shaping**: rotate preferred foods, repeatedly introduce non-preferred foods in small amounts. It may take 50-100 presentations before a food is no longer considered novel. Food preferences may change over time with age and experience.

- **Chaining**: introduce new foods that are relatively close to a preferred food and switch back and forth (e.g., pancakes and waffles, cheese pizza vs pepperoni pizza)

Work through the exposure hierarchy, building confidence as progressively scarier foods are added.
Phase II (biweekly)- focus on return to independent eating

–Chaining and shaping may still be occurring, but there is more success with previously challenging foods

–Families practice normal social eating (with modifications)- eating with friends, at restaurants, being more flexible

–Families are encouraged to practice ERP on their own, in creative ways

–Kids are given more freedom to choose their own foods, with the expectation that they will not fall back into old patterns. Parental oversight remains, but is gradually reduced as the child consistently demonstrates good choices
Phase III (monthly)- focus on return to healthy living

- Families introduce more challenging (vegetables), complex and “mixed” foods
- Child continues to practice tasting and eating new foods
- Ongoing focus on refining coping strategies, phasing out incentive programs
Always, Sometimes, Never

Ask parents and child work together to list:

1. Foods the child will always (or almost always) eat when offered. These are “preferred” foods

2. Foods the child will sometimes eat, even if not “preferred”

3. Foods the child will not eat (not an exhaustive list), but it would be easier or beneficial to the family if they could
Exposure Hierarchy

- Ask parent and child to work together to rank the foods listed in “sometimes” and “never” columns in order of perceived difficulty.
- Relatively easy foods will be at the bottom of the list.
- Difficult foods are at the top of the list.
- Use a thermometer to help parent and child assess the amount of fear/discomfort/anxiety associated with each food.
- 0 is no fear, 10 is extremely high fear or discomfort.
Fear thermometer

- Full Panic
- High Anxiety
- Anxious / Aggitated
- Minor fears / Worry
- Calm
- Total Relaxation
Exposure Hierarchy

Describe, in broad terms, what makes you anxious:

- Eating new foods that are hard to crunch

Describe specific situations related to your anxiety that make you feel varying levels of discomfort. On a scale of 0 to 10 (10 being not at all anxious, and 10 being extremely anxious), rate how much each situation affects you:

<table>
<thead>
<tr>
<th>Anxiety Producing Situation</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carrot sticks</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td>10</td>
</tr>
<tr>
<td>Crunchy peanut butter</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
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<td>Toast</td>
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<td></td>
<td>7</td>
</tr>
<tr>
<td>Potato chips</td>
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<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5</td>
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</table>
Resources for Parents

• Food Chaining: The Proven 6-Step Plan to Stop Picky Eating, Solve Feeding Problems, and Expand Your Child’s by Cheri Fraker

• Suffering Succotash: A Picky Eater’s Quest to Understand Why We Hate the Foods We Hate by Stephanie VW Lucianovic

• Child of Mine: Feeding with Love and Good Sense by Ellyn Satter
Psychopharmacology in ARFID

• No psychotropic medications approved for children or adolescents with eating disorders

• Medications to stimulate appetite are rarely useful (cyproheptadine, megestrol, paroxetine, mirtazapine)

• Treatment of underlying anxiety is often most appropriate indication
Psychopharmacology in ARFID

- Food is best medicine, medicine will work better with food
- SSRIs are gold standard
- Alpha agonists (watch out when VS unstable) and benzodiazepines can be helpful rescue medications, especially with severe anxiety and panic that is interfering with getting fork to mouth
- Anecdotally, low doses of atypical antipsychotics can help in some resistant cases, but need to be thoughtful and careful given cost and potential long term consequences
Goals for a Healthy Relationship with Food

- Variety of foods
- Food consumption patterns – establish a consistent pattern of eating
- Hunger – ability to recognize cues
- Caloric intake (if appropriate)
- Food fears
- Restored GI function – absence of diarrhea, constipation and bloating
- Social eating
- Enjoying meals!
Nutrition Intervention

• Adequate caloric intake for weight restoration
  – Via use of oral supplements (CIB, Pediasure/Ensure, Boost)
  – Via use of calorie boosters/modulars (fat modulars, dry milk powder)
  – High calorie smoothie/pudding/milkshake recipes
• Work on variety of food groups
• Provide substitutions
  – Use of checklist/food journals (age and anxiety dependent)
• Meal Planning with parents + patient if appropriate
• Recommend vitamin/mineral supplements- Ca++ and Vit D

• Weight gain of 0.5 - 1.0 kg per week is appropriate as an outpatient.
Oral Supplementation

• Age dependent
  – 12 years and younger, pediatric product
  – 13 years and older, adult product
Calorie Boosters

• Calorie boosting with fat sources (butter, olive/canola oil, nut butters, cheese, dips – ranch, cream cheese, etc)

• Protein boost: dry-non fat milk powder
  – *Do not routinely recommend protein powder

• Prescription modulars
  – Duocal
  – Benecalorie
Role of Occupational Therapist

• Evaluation of swallowing difficulties
• Treatment:
  – Assistance with behavior modification plans
  – Relaxation
  – Biofeedback
  – Techniques to manage anxiety, fear of physical patterns/sensations:
    • Diaphragmatic breathing
    • Body positioning: upright, shoulders relaxed, feet on floor
    • Acupressure points to decrease “over fullness”, pain, nausea
Outcomes
Avoidant/Restrictive Food Intake Disorder and Anorexia Nervosa Subtypes: How do they compare?
Sieke E, Strandjord S, Richmond M, Khadilkar A, Rome E.

Length of Stay (days)

<table>
<thead>
<tr>
<th></th>
<th>ARFID</th>
<th>AN-R</th>
<th>AN-BP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Length of Stay (days)</td>
<td>9.4</td>
<td>6</td>
<td>5.8</td>
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</table>
Avoidant/Restrictive Food Intake Disorder and Anorexia Nervosa Subtypes: How do they compare?

Sieke E, Strandjord S, Richmond M, Khadilkar A, Rome E

Recovery at 1 Year

<table>
<thead>
<tr>
<th>Subtype</th>
<th>Recovery at 1 Year</th>
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<tbody>
<tr>
<td>ARFID</td>
<td>61.9%</td>
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<tr>
<td>AN-R</td>
<td>56.7%</td>
</tr>
<tr>
<td>AN-BP</td>
<td>19.5%</td>
</tr>
</tbody>
</table>
And now, back to our cases!
Case #1- Back to Miranda…

• She acknowledges she is underweight but can't seem to gain. She is open to it, but feels she never has an appetite; eats small portions at meals.

• Dislikes many meats; averse to vegetables due to the textures; “carb queen”

• Food allergies: peanut, soy, banana, melons

• No body image concerns or fear of weight gain
Miranda’s Growth Chart
Case #2- Super Picky Sammy

During evaluation with OT, no swallowing or chewing abnormalities were observed. However, he shut down and had significant difficulty eating the scrambled eggs that were presented to him. On further questioning, he admitted to being certain that he would not like the foods that he was not used to, and that caused him to freeze and “not even want to try”.

What is your working diagnosis and treatment approach?
Case #2- Super Picky Sammy

• When evaluated by the psychiatry team, he denies anxiety or concerns about vomiting or choking. He “doesn’t know” why he cannot eat, but states that he wants to get better so that he doesn’t need to be in the hospital or go to appointments all the time.

• Parents note some longstanding social issues and sensory integration difficulty when he was younger; the evaluating clinician noted that Sammy appeared somewhat detached and pedantic during the interview.
Sammy’s Growth Chart
Case #3- Choking Chelsea...

- If Chelsea presents acutely after choking...
  - Consider ARFID, anxiety, phobia
  - Screen for abuse, sexual assault, PANS (Pediatric Acute-onset Neuropsychiatric Syndrome)

- If Chelsea presents chronically...
  - ASD/Asperger syndrome driving food or texture aversions
  - Former premies with initial feeding disorders
  - Underlying GI or other illness
  - Delayed diagnosis of ARFID
Chelsea’s Growth Chart

2 to 20 years: Girls
Stature-for-age and Weight-for-age percentiles

NAME: Chelsea Choker

2 to 20 years: Girls
Body mass index-for-age percentiles

NAME: Chelsea Choker
Medical Evaluation of Choking/Dysphagia

• Most cases can be diagnosed by history and clinical presentation alone

• If etiology for swallowing difficulties unclear, consider:
  – OT assessment for swallowing dysfunction
  – Barium swallow
  – Endoscopy

• If unintentional vomiting and low weight, consider:
  – Upper GI with small bowel follow through, to r/o superior mesenteric artery syndrome
Case #4- Acutely Picky Peter

• During history portion of the assessment, Peter fidgets, taps his fingers, walks in small circles in corner, at times appears to be arching or stretching his back and neck, leaves to use restroom
Peter’s Growth Chart

2 to 20 years: Boys
Stature-for-age and Weight-for-age percentiles

NAME Peter Picky

Record #

Father’s Stature
Mother’s Stature

Date Age Weight Stature BMI

To calculate BMI: Weight (kg) = Stature (in) x Stature (in) x 10,000

2 to 20 years: Boys
Body mass index-for-age percentiles

NAME Peter Picky

Record #

Date Age Weight Stature BMI Comments

*To calculate BMI: Weight (kg) = Stature (in) x Stature (in) x 10,000


SOURCE: Developed by the National Center for Health Statistics in collaboration with
the National Center for Chronic Disease Prevention and Health Promotion.

http://www.cdc.gov/growthcharts
Pediatric Acute-onset Neuropsychiatric Syndrome (PANS)

- Characterized by abrupt, dramatic onset of obsessive-compulsive disorder or severely restricted food intake

PLUS

- Additional neuropsychiatric symptoms, of severe and acute onset

- Etiology: Infectious trigger, environmental factors, or other possible factors trigger “molecular mimicry” autoimmune response → brain inflammation

PANS vs. ARFID/OCD

• Consider PANS if food avoidance/refusal based on:
  – Contamination fears
  – Fear of choking, vomiting, or swallowing
  – Altered sensory sensitivity (taste, texture, odor)

• And note other unusual features, such as:
  – Unfounded irrational fears and/or phobias
  – Personality changes, separation anxiety
  – Decline in math, reading or handwriting abilities
  – Motor/vocal tics, “piano playing” finger movements
Resources on PANS

For more info on diagnosis and treatment of PANS:

• National Institute of Mental Health website

• Stanford Medicine: PANS website
  https://med.stanford.edu/pans.html
Take Home Messages

• ARFID is common
• It may be confused with other eating disorders and medical conditions
• It requires a multidisciplinary team approach
• Family Based Treatment is gold standard if available
Thank you!
Questions?

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willouj3@ccf.org