INFLAMMATORY BOWEL DISEASE 101:
Understanding Your Child’s Diagnosis

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Objectives

- **What is IBD**
  - Crohn’s disease vs. ulcerative colitis
  - Treatment options
- **Living with IBD**
  - Diets, school, travel
  - Mental health
  - Adherence
  - Research, outreach
I may have IBD, but IBD doesn’t stop me from my career plans...

Kathleen Baker
Silver Medal
2016 Rio Olympics

Mike McCready
Pearl Jam

Anastacia
Pop Star-UK

David Garrard
NFL QB
Who does IBD affect?

- 1.6 million people with IBD in US
  - ~80,000 <18 years old
- 70-90 children diagnosed each year with IBD at Cincinnati Children’s
  - >750 IBD patients at Cincinnati Children’s
- Genetics
  - 1\textsuperscript{st} degree relative (3-20x than general pop. to develop IBD)
  - Identical twin
    - Crohn’s - 1 in 2-3 lifetime risk
    - UC – 1 in 5 lifetime risk
- Both parents with IBD
  - Child has 1 in 3 lifetime risk
What is IBD?

Inflammatory bowel disease (IBD)

Ulcerative Colitis 25%

70%

~5%

Indeterminate colitis
When are children diagnosed?

Very early onset
UC=CD

Cause of IBD

>200 Genes

Loss of:
1. Barrier function
2. Bacterial killing
3. Immune regulation

Immune system “attacks” healthy cells of the gut, causing inflammation

Environment (Microbiome)

Improper Immune response

1. Increase in Aggressive bacteria
2. Decrease in Protective bacteria
3. Infections – viral or bacterial, smoking, antibiotics
IBD Analogy
IBD Myth’s

- Stress. Wrong
- It’s IBS (irritable bowel syndrome). Wrong
- My diet caused it. Wrong
- Sick forever. Wrong
- Everyone has diarrhea or blood in stool. Wrong
- Vaccine for IBD. Wrong
## Common Symptoms

<table>
<thead>
<tr>
<th>Symptoms/Signs</th>
<th>Crohn’s disease</th>
<th>Ulcerative colitis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rectal bleeding</td>
<td>++</td>
<td>++++</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>++++</td>
<td>+++</td>
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<tr>
<td>Diarrhea</td>
<td>++</td>
<td>++++</td>
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<tr>
<td>Weight loss</td>
<td>++++</td>
<td>++</td>
</tr>
<tr>
<td>Growth failure</td>
<td>+++</td>
<td>+</td>
</tr>
<tr>
<td>Perianal disease</td>
<td>++</td>
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</tr>
<tr>
<td>Mouth ulcer</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Skin rashes</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Fevers</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Low red blood cells</td>
<td>+++</td>
<td>++++</td>
</tr>
<tr>
<td>Joint pains/swelling</td>
<td>+</td>
<td>+</td>
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</tbody>
</table>
Basic Anatomy

- Inflammation in colon: more diarrhea and bloody stools
- Inflammation in rectum: more urgency, mucus, bloody stools
- Inflammation in small intestine: nausea/vomiting, constipation, weight loss, nutrient deficiencies (iron, Vitamin B12, folate, Vitamin D)
Goals of Therapy

• Main goals in treating IBD:
  – Induce remission
  – Maintain remission
  – Improve quality of life (go to school, work, practice, out with friends)
  – Minimize side effects of medications
Treatment options

• Diet
• Medications
  – Oral
  – Topical (enema, suppository)
  – IV (infusions)
  – IM (injections)
• Surgery
• Complementary (acupuncture, diet combo)
• Probiotics
Selection of Medications

Severity is dependent on:

1. Endoscopy findings
2. Extent of disease
3. Complications
   - Growth failure
   - Abscess
   - Fistula
   - Stricture

- **Severe:** Infusions, injections, surgery
- **Moderate:** oral, topical, infusions, injections
- **Mild:** oral and topical
Types of Medications & Delivery

- Remicade: infusion at hospital or home (4-8 weeks)
- Humira: at home injection (1-2 weeks)
- Cimzia: at home injection (monthly)
- Simponi: at home injection (monthly)
- Entyvio: infusion at hospital (4-8 weeks)
- Methotrexate: injection or oral
- Prednisone: oral or infusion (in hospital)
- 6-MP, azathioprine: oral (daily)
- Lialda, Pentasa, canasa: oral or per rectum (daily)
- Entocort, Uceris: oral or per rectum (daily)
Common side effects

- Prednisone: weight gain, increased appetite, poor sleep, irritability, moon facies, acne
- Remicade/Humira: pain by IV or injection site, allergic reactions (low risk)
- 6MP/Methotrexate: monitor liver and white blood cell numbers
- Enteral therapy: stigma of not eating, feeding tube in place
Other Common IBD “medicines”

• Vitamins/minerals
  – Vitamin B12
  – Vitamin D
  – Folate
  – Iron
  – Multivitamins

• Nutritional Supplements
  – Boost, Pediasure, Ensure

• Probiotics
  – “healthy” bacteria
A little more on Enteral Therapy

- Liquid formula (shakes) to treat Crohn’s disease
  - 50-75% effective in children/adults
- Exclusive enteral nutrition (EEN)
  - Similar remission rates as steroids
  - Intestinal healing
  - Induction
    - 4-12 weeks to induce remission
  - Maintenance
    - Sole source of all nutrition (100% vs. 80%)
    - Repeat 4 week cycle every 3-4 months
    - Addition of Crohn’s medication (5-ASA, 6MP, Methotrexate)
Is EEN (aka “shake diet”) for me?

- Predictors of poor response to diet therapy
  - Fistula (opening to skin surface or other organ)
  - Strictures (narrowing of the intestine)
  - Severe growth failure (malnourished)
  - Inflammation along colon only
  - Foodies
  - Intolerance to volume of formula, NG placement
Specific Carbohydrate Diet (SCD)

- Alternative “treatment” for Crohn’s or ulcerative colitis
- Elimination of most carbs to reduce inflammation in the gut
  - Sugars (lactose, sucrose, HFCS)
  - Grains (corn, wheat, oats, rice)
  - Starches (potatoes)
  - Dairy

Clinical and Mucosal Improvement With Specific Carbohydrate Diet in Pediatric Crohn Disease

*Stanley A. Cohen, ‡Benjamin D. Gold, †Salvatore Oliva, ‡Jeffery Lewis, †Angela Stallworth, ‡Bailey Koch, †Laura Eshee, and §David Mason
SCD foods to eat or avoid

Foods that may be eaten
- Fresh/frozen vegetables and legumes
- Fresh/raw/dried fruits, unsweetened juices (not from concentrate)
- Navy beans, lentils, peas, split peas, most nuts (unroasted preferably; nuts coming directly from shells so that nothing is added), natural peanut butter (with no sugar), lima beans, string beans
- Fresh/frozen meats, poultry, fish, eggs
- Some (natural/hard) cheeses (cheddar, Colby, Swiss, Havarti), homemade yogurt fermented >24 hours (no sugar added), dry curd cottage cheese
- Honey
- Tea, coffee, mustard, vinegar, most oils

Foods to avoid
- Canned vegetables
- Canned fruits, unless packed in own juices
- All grains, including flours
- Potatoes, yams, parsnips
- Chickpeas, bean sprouts, soybeans, mung beans, fava beans, and garbanzo beans
- Seaweed and byproducts, including agar and carageenan
- Processed, canned, breaded, smoked meats/fish
- All milk, buttermilk, commercially prepared yogurt and sour cream, heavy cream, soy/rice/potato/oat/hemp milk
- Instant tea or coffee, coffee substitutes, beer
- Canola oil, mayonnaise (due to additives), cornstarch, chocolate or carob, bouillon cubes or instant soup bases, all products made with refined sugar, sugar substitutes, Stevia, pectin, ketchup, ice cream, molasses, corn or maple syrup, baking powder, medication containing sugar, all seeds, balsamic vinegar, fructo-oligo saccharides
Indications for Surgery

- Failure of medical therapy
- Obstruction (vomiting, belly distention, fevers)
- Intestinal perforation
- Fistula or abscess (infection)
- Bleeding requiring blood transfusions
Risk of Surgery

25-60% lifetime risk (1990-early 2000’s)

Crohn’s disease

10-15% lifetime risk

Ulcerative colitis
Types of Surgery

• Crohn’s disease
  – Limited intestinal removal (no ostomy bag)
  – Ileostomy or colostomy
  – Strictureplasty

• Ulcerative colitis
  – Remove colon
  – Ileostomy (temp)
  – Pouch
Living with IBD
School & IBD

• 504 Plan
  – Rehabilitation Act of 1973 that prohibits discrimination based upon disability

• Talk to admissions counselors (college-age)
  – Meal plan
  – Dorm options (single room, close to bathroom)
  – Scholarships
504 Plan Highlights

• Go to the bathroom whenever you need to
• Private bathroom, i.e. nurse’s office
• A place to keep your emergency supplies
• Permission to take regularly scheduled and emergency medication at the nurse’s office
• Permission to eat snacks and drink liquids throughout the day
• Get help with classwork that you missed and have quizzes, tests, and projects rescheduled
• “Stop the clock” during tests so you can use the bathroom and not lose any test-taking time
• Excused absences due to illness, medical appointments, and treatments

• Even if you are doing well and do not feel like you need a 504 Plan, it is always good to have it in place—just in case
Vaccines

• Live vaccines (avoid when on 6MP, azathioprine, methotrexate, Remicade, Humira, Cimzia, Entyvio, high dose prednisone)
  – Intra-nasal influenza
  – MMR, varicella (chicken pox), oral polio

• Safe vaccines in IBD
  – Influenza shot
  – Pneumococcal
  – Hepatitis B
  – Meningococcal
  – HPV (men & women)
Travel with IBD

• Carry emergency kit
• Know where you can find clean bathrooms
  – (Starbucks-Yes, Truck stop, Ummmmm…)
• Tell your doctor if traveling outside of US
  – When to call, see local physician
  – Antibiotics
  – Flying with medications
• [Link](http://blog.cincinnatichildrens.org/rare-and-complex-conditions/handy-checklist-traveling-crohns-ulcerative-colitis/)
Quality of Life in IBD

- 25-30% of children with IBD have symptoms of depression and/or anxiety
- 10-30% meet criteria for clinical depression or an anxiety disorder
  - Stressful life events (school, competitions, friends)
  - Family dysfunction (doctors appointments, hospitalized, surgery, infusions)
  - Steroid treatments (mood changes)

- These rates are similar to children with other chronic illnesses

Mackner, et al. Inflamm Bowel Dis 2006
Coping with IBD

• Guided imagery
• Cognitive therapy
  – Discussions about coping mechanisms
  – Role playing
  – Breathing and relaxation methods
  – Positive reinforcement
  – Journal writing
• Alternative therapy
  – Massage therapy
  – Acupuncture
Transitioning to Adult GI

Transition Readiness
Start at age 14
Final Transition at 18-22

Tasks
Know your medications
Call in refills
Schedule appointments
Is there a risk of cancer with IBD?

- Risk of lymphoma:
  - 2/10,000 general population
  - 4-6/10,000 with certain IBD medications
- Colon cancer
  - Screening colonoscopy 8 yrs. after diagnosis
  - Continue colonoscopy every 1-2 years
Diet Tips - during flares

• Eat smaller meals more often
• Reduce the amount of greasy or fried foods you eat
• Avoid trigger foods, especially during flares
• Limit certain high-fiber foods such as seeds, nuts, popcorn, beans, green leafy vegetables, wheat bran, and raw fruits and vegetables
• Limit drinking milk or milk products if you are lactose intolerant
• Active diarrhea, avoid…
  – Avoid caffeine in coffee, tea, soda
  – Avoid dehydration by drinking extra fluids
Speed bumps

- Flares, hospitalization, surgery
- Self-management

Active Engagement

• Research
  – Observational studies
    • Stool, blood, tissue from biopsies
    • Quality of life assessment
    • Adherence
  – Clinical Trial
    • COMBINE
      – Anti-TNF alone vs. Anti-TNF with methotrexate (currently enrolling)
      – PROTECT (completed)

• Social Activism
  – Facebook
  – Crohn’s & Colitis Foundation
    • Kick for Crohn’s
    • Walk for a cure
    • Run for a cure
  – Local fundraising for CCHMC
Questions?