Today’s Program will…

- Help you understand Crohn’s disease and its effects
- Review current treatments, including medications and surgery
- Provide tips for managing your disease
- Share resources to answer your questions and provide support
Poll Question #1

Which best describes you?
A) I am a patient with Crohn’s disease
B) I am a family member of a patient with Crohn’s disease
C) I am a friend of a patient with Crohn’s disease
D) I am unsure if I have Crohn’s disease
E) No connection, just want more information

What is Crohn’s Disease?

- Belongs to a group of conditions known as inflammatory bowel diseases (IBD)
- Chronic inflammatory condition of gastrointestinal (GI) tract
- Patchy, full thickness of intestinal wall
- Mouth to anus, mostly end of small intestine and colon
- Affects estimated 700,000 Americans
- Symptoms and prognosis differ for each person
Symptoms

- Diarrhea
- Bloody stool
- Abdominal pain
- Appetite or weight loss
- Fatigue

Potential Complications

May include:
- Strictures
- Internal fistulas
- Perianal involvement
- Colon cancer
- Malnutrition
- Decreased growth and development
Extra-intestinal manifestations

May include:
• Eyes
• Mouth
• Joints
• Skin
• Bones
• Kidneys
• Liver

What Are the Potential Causes?

Genetic Predisposition
20%–25% of patients have a close relative with IBD

Immune System Abnormalities
An inappropriate reaction by the body's immune system

Environmental Factors
Infections, antibiotics, microbiome, nonsteroidal anti-inflammatory drugs (NSAIDs), diet, smoking, stress
Location, Location, Location

- Ileal involvement 33% of patients
- Colon involvement 20% of patients
- Ileocolonic disease 45% of patients
- Isolated upper tract disease <5%

Patterns of Disease

- Inflammatory Crohn’s disease
  - Inflammatory changes in the lumen
- Stricturing Crohn’s disease
  - Flares and remission
  - Strictures, or narrowing of intestine
- Perforating (fistulizing) Crohn’s disease
  - Fistulas, or tunnel-like formations
  - May include perianal involvement
Treatment Goals

**Induction of Remission**
- Turning “off” the inflammation
- Feeling well, improving quality of life
- Normalization of labs, growth, development and nutrition

**Maintenance of Remission**
- Disease control and optimization of therapy
- NO STEROIDS
- Prevention of relapse over time
- Changing the natural course of the disease

**Disease Monitoring and Prevention**
- Monitoring for early relapse
- Monitoring therapies
- Prevention of infections
- Cancer prevention

Medications

- Over-the-counter
- Antibiotics
- Aminosalicylates
- Corticosteroids
- Immunomodulators
- Biologics
Poll Question #2

My treatment regimen includes:
A) Corticosteroids
B) Aminosalicylates
C) Immunomodulators
D) Biologics
E) Antibiotics
F) Two or more of the above

Over-The-Counter (OTC) Medications

- Address symptoms only
  - Anti-diarrheal agents
  - Laxatives
  - Pain Relievers
- NSAIDs may cause or worsen GI irritation
- Talk with your physician before taking OTC meds
- Complementary and alternative medicine
  - Vitamins
  - Minerals
  - Supplements
Antibiotics

- Effective for
  - pouchitis
  - perianal fistulas
  - abscesses
- Bacterial resistance
- Associated with flares
- Antibiotic-associated diarrhea and *Clostridium difficile*

**Medications:**
- Metronidazole (Flagyl®)
- Ciprofloxacin (Cipro®)
- Rifaximin (Xifaxan®)

Aminosalicylates

- Effective for mild–moderate disease
- Few serious side effects
- Releases medication to specific areas of bowel

**Medications:**
- Sulfasalazine (Azulfadine®) Oral
- Mesalamine (Apriso®, Delzicol®, Lialda®, Pentasa®, Rowasa®) Oral or Rectal
- Olsalazine (Dipentum®) Oral
- Balsalazide (Colazal®, Giazo®) Oral
Corticosteroids

- Initially effective in inducing remission
- Risks include
  - Infection
  - Sleep disturbance and mood swings
  - Neurological changes
  - Changes in physical appearance
  - Growth delays and bone loss

**Medications:**
- Budesonide (Entocort®, Uceris®) Oral
- Hydrocortisone (Cortenema®, Cortifoam®)
  - Enema, oral, intravenous
- Methylprednisolone (Medrol®) Oral or intravenous
- Prednisone, Oral

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Thiopurine Immunomodulators (Azathioprine, 6-MP)

- Steroid-sparing agents, used in maintenance
- Can be taken with other medications to induce remission

**Risks**
- Can be individualized (TPMT genotype)
- Fever
- Pancreatitis
- Low white blood cells
- Elevated liver tests
- Infection (viral)
- Lymphoma (EBV-associated)
**Immunomodulators (cont)**

- Methotrexate
  - Oral and injection
- Recommended if other medications have been ineffective
- May be helpful in improving fistulas
- Need daily folic acid intake
- Common side effects: nausea, headache, and fatigue
- Not to be taken during pregnancy, or by men or women planning conception

**Biological Therapies**

- Block inflammation or stimulate anti-inflammation
- Similar to biologic chemicals in body
- Effective for patients who
  - Do not respond to standard therapy
  - No longer respond to standard therapies
- Risks include
  - Infections
  - Infusion or injection site reactions
  - Lupus, MS, and psoriasis-like reactions
  - Increased risk of melanoma
Biological Therapies (cont)

- **Anti-TNF**
  - Adalimumab (Humira®) Injection
    - Newly approved pediatric indication
  - Certolizumab pegol (Cimzia®) Injection
  - Infliximab (Remicade®) Intravenous

- **Selective adhesion molecule**
  - Natalizumab (Tysabri®) Intravenous

- **Integrin Receptor Antagonist**
  - Vedolizumab (Entyvio™) Intravenous

Medication Considerations in Special Populations

- Each medication presents benefits and risks
- Children require special considerations
  - 10% of people affected by IBD are under the age of 18 and require individualized treatment
  - Few clinical trials have addressed efficacy and dosage in children
  - Treatment approaches for children are largely based on adult experience
- Some medications, including methotrexate, may be contraindicated in pregnant women (but most are OK)
Judging Response to Treatment

• How do I know if my treatment is working?

• If I am in remission, should I stop my treatment?
Judging Response to Treatment

- How do I know if my treatment is working?
- If I am in remission, should I stop my treatment?
- How much time should I allow before trying a new medication?

Surgical Options

- Surgery and medication can combine for better quality of life
- Primary goals of surgery
  - Alleviate complications
  - Alleviate symptoms
  - Achieve best possible quality of life
  - Bowel conservation
Surgical Options

- Stricturoplasty
- Intestinal resection
- Colectomy (partial or complete)
- Proctocolectomy
- Diverting colostomy or ileostomy
- Cannot be cured with surgery

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Elective and Emergency Surgery

**Elective**
- Stricture
- Failure of medication to control disease
- Formation of a fistula or abscess
- Dysplasia

**Emergency**
- Perforation of the bowel
- Intestinal obstruction or blockage
Critical Role of Nutrition

• “Diet” = the food you eat on a daily basis
• “Nutrition” = how your body uses nutrients from your diet
• No known diet alters inflammation
• Certain foods for individual patients may exacerbate symptoms during a flare
• Keep a food diary
  – [www.ccfacommunity.org](http://www.ccfacommunity.org)

Good Nutritional Choices

• Good nutrition is key to:
  – Healing, immunity, and energy levels
  – Preventing or minimizing GI symptoms

<table>
<thead>
<tr>
<th>Recommended Foods</th>
<th>Recommended Supplements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carbohydrates with more soluble fiber (oat brans, legumes, barley)</td>
<td>A daily multivitamin</td>
</tr>
<tr>
<td>Protein (eggs, lean meats, smooth nut butters)</td>
<td>Vitamin B12 (monthly injection may be given to patients with ileitis)</td>
</tr>
<tr>
<td>Well-cooked fruits and vegetables</td>
<td>Calcium, Vitamin D</td>
</tr>
<tr>
<td>Healthy fats (canola or olive oil)</td>
<td>Folic acid</td>
</tr>
</tbody>
</table>
CAM

- National Center for Complementary and Alternative Medicine categories
  - Natural products (e.g., supplements and probiotics)
  - Mind and body medicine (e.g., meditation and acupuncture)
  - Manipulation and body-based practices (e.g., massage and spinal manipulation)
- Of interest to Crohn’s patients because
  - Medications do not perfectly control disease
  - Difficult symptoms
  - Side effects of medications
- Can be used as adjunctive therapy to conventional therapy; rarely will it be a sole treatment

Probiotics

- “Good” bacteria claims to “restore” balance in gut
- Limited studies on effectiveness
- Do NOT treat active Crohn’s disease
- Strains
  - VSL#3®
  - Escherichia coli Nissle 1917 (Mutaflor®)
  - Lactobacillus acidophilus (Flora-Q®)
- Discuss with physician before initiating treatment
Poll Question #3

Have you used complementary and alternative medicine for Crohn’s in addition to medications
   A) Yes
   B) No

Monitoring Crohn’s Disease

• There is no one test to diagnose Crohn’s disease
• You may have one or more tests and procedures:
   – Blood and stool tests
   – Endoscopy
   – External imaging
Blood and Stool Tests

• Check medication levels
• Test function of body systems and response to treatment
• Monitor risk of infection
• Look for abnormalities
• Include:
  – Complete blood count
  – Comprehensive metabolic panel (CMP)
  – C-reactive protein (CRP)
  – Erythrocyte sedimentation rate (ESR)
  – Fecal calprotectin (FCP)

Endoscopic Procedures

<table>
<thead>
<tr>
<th>Endoscopic Procedure</th>
<th>Observation</th>
</tr>
</thead>
</table>
| Colonoscopy                  | • Insert through anus  
                              | • Observe rectum, colon and lower small intestine 
                              | • Fasting                                              |
| Flexible sigmoidoscopy       | • Shorter scope  
                              | • Lower colon  
                              | • Enema before procedure                                |
| Capsule endoscopy            | • Swallow camera capsule  
                              | • Difficult areas to reach                              |
| Upper endoscopy (EGD)        | • Upper abdominal pain  
                              | • Nausea  
                              | • Vomiting  
                              | • Difficultly swallowing                                |
| Endoscopic ultrasound (EUS)  | • Ultrasound images below surface of gut  
                              | • Fistulas in rectal area                                |
# External Imaging Procedures

<table>
<thead>
<tr>
<th>Imaging procedure</th>
<th>Observation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Computed tomography (CT, CTE)</td>
<td>X-ray images at various angles</td>
</tr>
<tr>
<td></td>
<td>May include contrast</td>
</tr>
<tr>
<td>Magnetic resonance imaging (MRI)</td>
<td>• Soft tissue images with magnetic waves</td>
</tr>
<tr>
<td></td>
<td>• Small intestine and other areas</td>
</tr>
<tr>
<td>Small bowel imaging (SBFT, SBS)</td>
<td>Swallowing barium</td>
</tr>
<tr>
<td></td>
<td>Evaluates small intestine</td>
</tr>
<tr>
<td>Barium enema</td>
<td>Barium placed directly in colon</td>
</tr>
<tr>
<td></td>
<td>Colon distended with air</td>
</tr>
<tr>
<td>White blood cell scans</td>
<td>Detect WBC in intestinal tissue</td>
</tr>
<tr>
<td></td>
<td>Cause of inflammation</td>
</tr>
<tr>
<td>Ultrasound</td>
<td>High-frequency sound waves</td>
</tr>
<tr>
<td>X-rays</td>
<td>Detect blockages in small or large intestine</td>
</tr>
</tbody>
</table>

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## Tips to Prepare for Your Doctor’s Visit

- Know any preparatory instructions prior to visit
- Make prioritized list of questions
- Write down symptoms and side effects
- Bring someone you trust with you
- Carry a timeline list of
  - Medications and dosage (present and past)
  - Include vitamins/supplements
  - Prescribing physician and contact info
  - Hospitalizations and surgeries
  - Life event changes
- Use tools to help keep track
- Bring item to keep you relaxed during your wait
Poll Question #4

How comfortable do you feel discussing concerns about managing Crohn’s disease with your doctor?

A) Very comfortable  
B) Comfortable  
C) Somewhat comfortable  
D) Not comfortable at all

Strengthen Communication with Your Doctor

Questions to Ask Your Doctor

- What parts of my bowel are affected?
- What treatment plan is suitable for me?
- Would you recommend probiotics?
- What side effects from medication may occur?
- How soon do symptoms subside?
- Should I change my diet or take supplements?
- Are there any restrictions on my activities?
- How often do I need a follow-up colonoscopy?
Key Points on Crohn’s Disease

• Inflammatory condition of GI tract with patchy, full thickness of intestinal wall
• Symptoms and prognosis differ for each person
• Know the goals of your treatment strategies
• Talk to your doctor about monitoring your disease
• Prepare for your visits – create checklists for your care
• Have open communication with your healthcare team

References

References
• CCFA website: www.ccfa.org/resources/living-with-crohns-disease.html
• CCFA website: www.ccfa.org/resources/types-of-medications.html
• Rubin, DT. Treatment Options in IBD webcast: www.ccfa.org/resources/IBD-treatments-webcast.html
• National Center for Complementary and Alternative Medicine: http://nccam.nih.gov

Additional Resources
• Treatment and Self-Management: http://www.ibdetermined.org/
• Community Site: http://www.ccfacomunity.org/
• Irwin M. and Suzanne R. Rosenthal IBD Resource Center (IBD Help Center): 888.694.8872 or info@ccfa.org
QUESTIONS?

AGA Resources


• Patient guide to GI procedures: http://www.gastro.org/patient-center/procedures

• Patient guide to diets and medications: http://www.gastro.org/patient-center/diet-medications
CCFA Resources

• Irwin M. and Suzanne R. Rosenthal IBD Help Center
  M-F, 9:00 AM-5:00 PM ET
  – Phone: 1-888-694-8872
  – Email: info@ccfa.org

• Educational webcasts: www.ccfa.org/resources/webcasts.html

• Connect with other patients
  – CCFA Community website: www.ccfacompany.org
  – Support groups and Power of Two (peer mentors):
    – www.ccfa.org/chapters

• GI Buddy: online tracking tool and mobile app www.ccfa.org/gibuddy

• Local educational events, visit: www.ccfa.org

CCFA Partners

• Registry of patient-reported outcomes
• Available for pediatric and adult patients

www.ccfapartners.org
Get Involved!

Team Challenge
CROHN’S & COLITIS

Take Steps
FOR CROHN’S & COLITIS

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