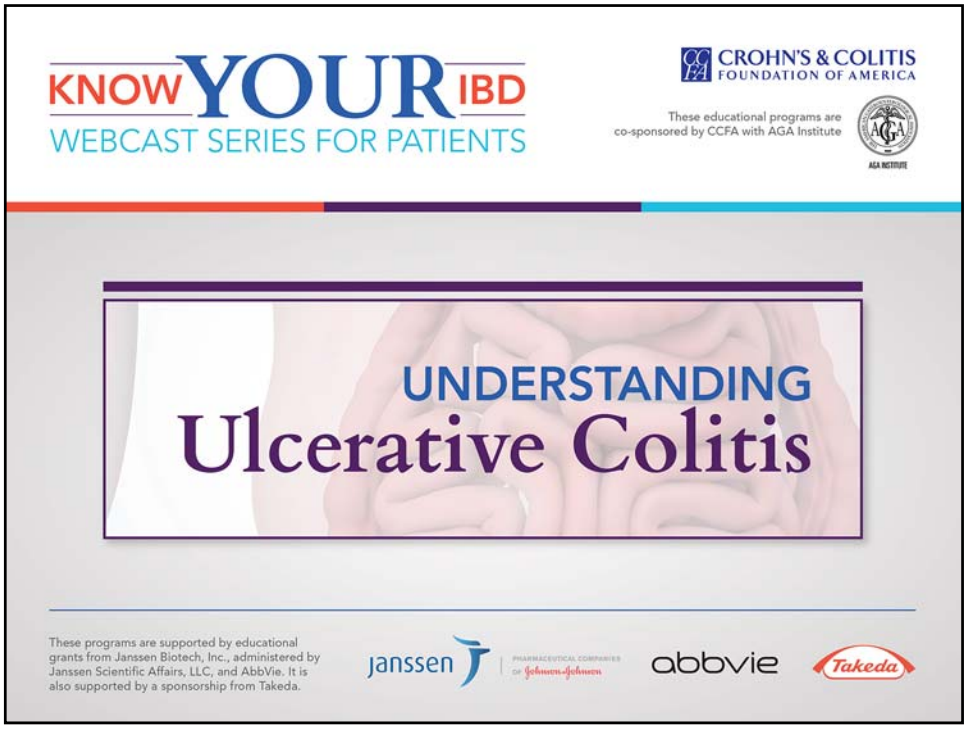


## Program Goals

- Help you understand ulcerative colitis and its effects
- Review current treatments, including medications, and surgery
- Provide tips for managing your disease through diet and complementary and alternative therapies
- Share resources to answer your questions and provide support

## Poll Question #1

Which best describes you?

A) I am a patient with ulcerative colitis
B) I am a family member of a patient with ulcerative colitis
C) I am a friend of a patient with ulcerative colitis
D) I am unsure if I have ulcerative colitis
E) No connection, just want more information



## An Overview of Ulcerative Colitis

- Type of inflammatory bowel disease (IBD)
- Chronic, relapsing disease of large intestine (colon) causing inflammation and ulceration in bowel lining
- About half of the cases are mild
- Flares may be alternating with symptom-free periods
- Usually requires treatment to obtain and maintain remission

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# 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



# Symptoms

- Diarrhea, mixed with blood and mucous
- Abdominal pain and cramping
- Urgency to have a bowel movement
- Appetite loss, fatigue, weight loss
- May be intermittent with flare-ups
- Growth impairment in children
- Non-intestinal complications: joint pain, skin and oral ulceration, eye inflammation, bile duct inflammation, others

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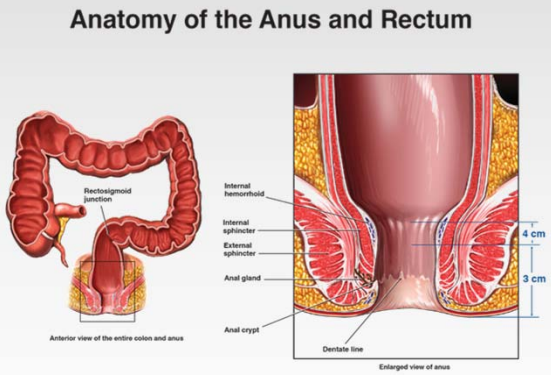
# Disease Pattern

- Rectum (end part of colon) almost always involved
- Classified by extent of area affected
- Patients usually report gradual onset
- Recurrent attacks couple with complete remission of symptoms in the interim





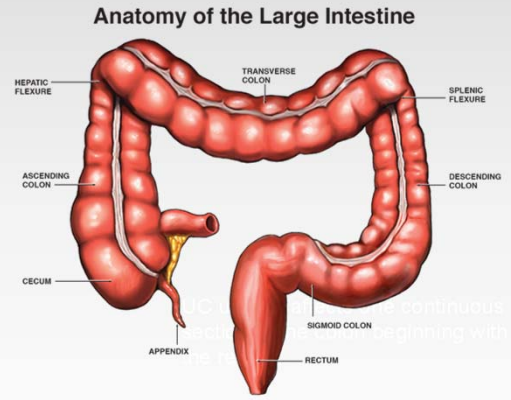



# Disease Pattern

- Triggers include
  - Psychological stress
  - NSAIDs
    - Aspirin, ibuprofen, naproxen
  - Appendectomy
  - Infections (eg, *C. diff*)
- Remission rate declines with disease severity
- Relapse rate higher in younger patients and can decrease with increasing age
- Primarily affects quality of life, not lifespan

# Types of Ulcerative Colitis

- **Proctitis:** involvement limited to rectum
- **Proctosigmoiditis:** involves rectum and sigmoid colon (lower segment)
- **Left-sided colitis:** extends from rectum and entire left colon
- **Pancolitis:** involving the whole colon








# Disease Severity

- **Mild:** up to 4 loose stools daily, may be bloody, mild abdominal pain
- **Moderate:** 4–6 stools daily, moderate abdominal pain, anemia
- **Severe:** over 6 bloody stools daily, fever, anemia
- **Fulminant:** over 10 stools daily, continuous bleeding, abdominal pain, distension; potentially fatal

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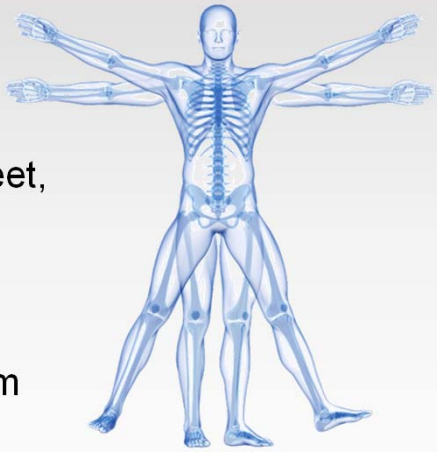
## Extra-Intestinal Features

- Oral ulceration
- Eye inflammation
- Arthritis of hands and feet, lower spine
  - Ankylosing spondilitis
- Skin sores
  - Pyroderma ganrenosm
  - Erythema nodosum





## Risk Factors and Frequency

- Occurs at any age, often in the 30's, with a second peak in 50's or 60's
- Affects all ethnic backgrounds;
  - More common in Caucasians and Ashkenazi Jews
  - More common in women than men
- Higher risk for patients with first-degree relative with UC
- Affects estimated 700,000 in US

# Colorectal Cancer Risk

- UC a risk factor for colorectal cancer
- Increases after 8–10 years from UC onset
- More common as severity of UC increases
- Surveillance colonoscopies recommended for UC patients
  - Recommendations
    - Pan colitis – 10 years after diagnosis
    - Left sided colitis – 15 years after diagnosis
- Inflammation is a risk factor for colorectal cancer; medications treating inflammation reduce risk



# Common Tests to Diagnose and Maintain Ulcerative Colitis

- **Diagnostic testing**
  - Fecal sample (presence of bacteria, parasites)
  - Blood sample (infection, anemia, inflammatory markers)
  - Biopsy of intestinal lining
  - Liver and kidney function tests
- **Endoscopy**
  - Gold standard for UC diagnosis
  - Flexible scope inserted into rectum
  - Sigmoidoscope examines lower third of colon
  - Colonoscope examines entire colon
- **Visual examination**
  - Radiograph
  - Barium enema (radio-opaque)
  - CT scan provides more detail than x-rays

## Managing your Symptoms: Treatment Options

- Over-the-Counter
- Aminosalicylates
- Corticosteroids
- Immunomodulators
- Biologics




## Poll Question #2

My treatment regimen includes:

A) Corticosteroids
B) Aminosalicylates
C) Immunomodulators
D) Biologics
E) Two or more of the above

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## Over-The-Counter (OTC) Medications

**Over-the-Counter**
Aminosalicylates
Corticosteroids
Immunomodulators
Biologics

- Address symptoms only
  - Anti-diarrheal agents
  - Laxatives
  - Pain relievers
- NSAIDs may cause or worsen GI irritation
- Talk with your physician *before* taking OTC meds



## Aminosalicylates

Over-the-Counter
**Aminosalicylates**
Corticosteroids
Immunomodulators
Biologics

- Effective for mild-moderate active disease
- Few serious side effects
- Useful in maintaining remission
- **Medications:**
  - Sulfasalazine (Azulfadine®) Oral
  - Olsalazine (Dipentum®) Oral
  - Balsalazide (Colazal®, Giazo®) Oral
  - Mesalamine (Apriso ™, Asacol®, Asacol HD®, Canasa®, Delzicol®, Lialda®, Pentasa®, Rowasa®) Oral or Rectal

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# Corticosteroids

- Over-the-Counter
- Aminosalicylates
- **Corticosteroids**
- Immunomodulators
- Biologics

- Moderate-to-severe disease
- Short-term control of flares
- Risks include
  - Infection
  - Sleep disturbance and mood swings
  - Neurological changes
  - Changes in physical appearance
  - Growth delays
  - Bone loss and fracture
- **Medications:**
  - Budesonide (Entocort®, Uceris®) Oral
  - Hydrocortisone (Cortenema®, Cortifoam®)
    - Enema, oral, intravenous
  - Methylprednisolone (Medrol®) Oral or intravenous
  - Prednisone, Oral



# Immunomodulators

- Over-the-Counter
- Aminosalicylates
- Corticosteroids
- **Immunomodulators**
- Biologics

- Steroid-sparing agents, used in maintenance
- Also used if no response to aminosalicylates
- May take up to 3 months to work
- **Medications (oral):**
  - Azathioprine (Imuran®, Azasan®)
  - 6-mercaptopurine (Purinethol®)

# Biological Therapies

- Over-the-Counter
- Aminosalicylates
- Corticosteroids
- Immunomodulators
- **Biologics**

- 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
  - Maintaining remission
  - Tapering off of steroids
- **Medications (intravenous):**
  - Infliximab (Remicade®) intravenous
  - Adalimumab (Humira®) injection
  - Vedolimumab (Entyvio™) intravenous
  - Golimumab (Simponi®) injection



# Risks of Anti-TNFs and Immunomodulators

If 10,000 patients were treated for 1 year

| Event | Estimated Frequency |
|---|---|
| NHL (baseline) | 2/10,000 |
| NHL (on IMs) | 4-9/10,000 |
| NHL (on anti-TNF with prior IMs) | 4-9/10,000 |
| Hepatosplenic T-cell lymphoma | Unknown |
| Death from sepsis (lower for younger patients) | 4/1,000 |
| Tuberculosis | 5/10,000 |

Anti-TNF, anti-tumor necrosis factor; IMs, immunomodulators; NHL, non-Hodgkin lymphoma.
Table adapted from Siegel CA. In *Inflammatory Bowel Disease: Translating Basic Science Into Clinical Practice*. Wiley, 2010.

# Location, Location, Location

**Rectum often responsible for most nagging symptoms**

- Frequency
- Urgency
- Night-time bowel movements
- "Tenesmus"

**Rectal therapy can minimize these symptoms**

- Enema
- Suppository
- Foam



# Surgery

- Option for patients not responding to medication
  - (25–40% of cases)
- Considered a "cure" for UC, but symptoms can continue after surgery
- Possible approaches:
  - Proctocolectomy
    - Removal of entire colon
    - Small intestine brought to abdominal wall (ostomy)
    - Patient wears an appliance to "catch" waste
  - Ileoanal anastomosis
    - Preserves normal bowel function
    - Creates internal pouch from small intestine; requires stages of surgery for completion

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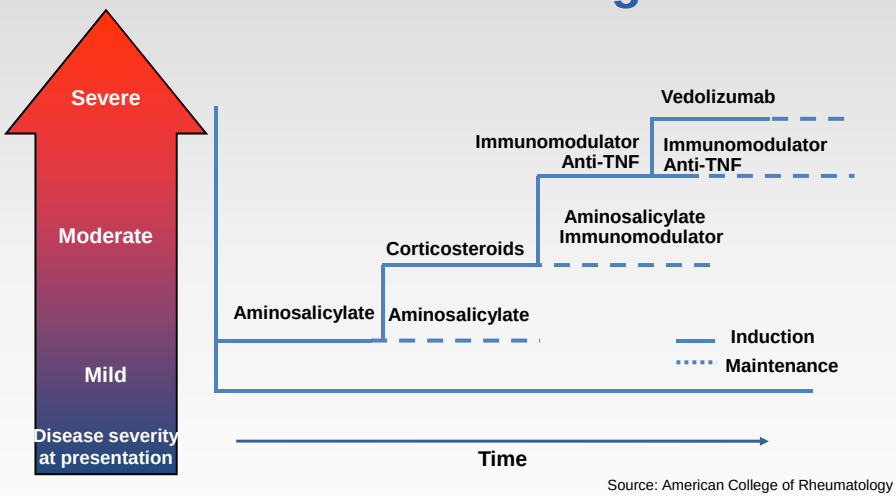
# Treatment Strategies

- **Primary goals of medical treatment:**
  - Remission
  - Prevention of recurrence
  - Control impact of complications



# Treatment Strategies




Source: American College of Rheumatology

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# Treatment Strategies

- Monotherapy
  - Single medication treatment
- Combination therapy
  - Multiple medication treatment
- Choice of strategy dependent on
  - Disease severity
  - Patient's considerations



# UC Impact on Quality of Life

- **Practical Consequences of UC Flare-up**
  - Unpredictable episodes of diarrhea, bleeding, cramping
  - Sudden urgency to use restroom
  - Temptation to avoid travel or activity
- **Medication Adherence**
  - Decreased chance to flare
  - Increased chance of obtaining remission
  - Prospective study in patients with UC in remission and taking mesalamine found chance of remission was
    - 89% in adherent patients
    - 39% in non-adherent patients
  - Colorectal cancer prevention (possibly 5-ASAs)

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# UC Impact on Quality of Life: Long-Term Medication

| Prescription Medications | Potential Side Effects |
|---|---|
| Methotrexate | Liver cirrhosis, low white blood cell counts, inflammation of the lungs |
| Aminosalicylates | Pancreatitis, pericarditis |
| Biologics | Redness, itching, bruising, pain, or swelling on the injection site; may experience rash, nausea, and upper respiratory infection (cough and sore throat). |
| Antibiotics | Stomach pain, indigestion, nausea, Increased risk of tendonitis |
| Steroid (Not for maintenance treatment; 3–4 months usual limit) | Weight gain, "moon face," increased blood pressure, suppressed immune system, increased infection risk |
| **Over-the-Counter Medications** | **Potential Side Effects** |
| Anti-diarrheals | Increased risk of toxic megacolon |
| NSAIDs – aspirin, ibuprofen (Advil, Motrin, others) or naproxen (Aleve) | Can make symptoms worse (even short-term) |



# UC Impact on Quality of Life

**Managing a Chronic Illness**

- Advance planning
  - Medications
  - Personal supplies
  - Bathroom locations
- Overcoming fear of being in public
  - Ileostomy patients
- Maintaining social interaction to enhance self image

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# UC Impact on Quality of Life

**Exercising With UC**

- Helps maintain weight and well-being, reduce stress
- Things to emphasize
  - Consider low-impact activities
    - Yoga
    - Swimming
    - Golf
    - Bowling
  - Walk instead of run
  - Plan bathroom breaks
  - Listen to your body (ie, don't needlessly overdo)
  - Consult your physician
  - Exercise between flare-ups



# UC Impact on Quality of Life

Role of Diet in Managing UC

- Link between diet and flare-ups not established
- Avoid foods that aggravate symptoms
  - Limit dairy products if lactose-intolerant
- Experiment with fiber
- Eat several smaller meals instead of 3 large ones
- Drink ample fluids
- Consider nutritional supplements
- Consider probiotics

## 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?


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## Poll Question #3

How comfortable do you feel discussing concerns about managing ulcerative colitis with your doctor?

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

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## CCFA Partners


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

**www.ccfapartners.org**



## Key Points on Ulcerative Colitis

- Chronic, relapsing disease of large intestine (colon) causing inflammation and ulceration in bowel lining
- 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-ulcerative-colitis.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
- Kane S. *IBD Self-Management: The AGA Guide to Crohn's Disease and Ulcerative Colitis.* Bethesda, MD: AGA; 2010.

**Additional Resources**

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



# Questions?

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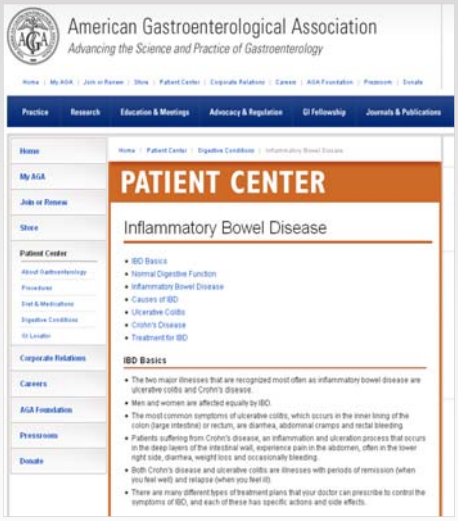
# AGA Resources

- Education: http://www.gastro.org/patient-center/digestive-conditions/inflammatory-bowel-disease
- 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

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# 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.ccfacommunity.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

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TAKE STEPS FOR CROHN'S & COLITIS

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