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Speakers
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Objectives

- Discuss the financial burden of IBD
- Review resources available to assist in cost of medications and care
- Improve understanding of insurance coverage
- Become familiar with Affordable Care Act (ACA) changes
- Review rights for disability, medical leave, and social security benefits

Inflammatory Bowel Diseases (IBD)

- What is IBD?
  - Chronic, autoimmune inflammatory bowel diseases including ulcerative colitis and Crohn’s disease
  - Caused by genetic, environmental, and immune system abnormalities
  - Primary symptoms include bowel urgency, diarrhea (or constipation), bloody stool, abdominal pain or cramping
  - No known cure but can usually be managed with medications and surgery
Medications

- Aminosalicylates
  - Sulfasalazine
  - Mesalamine
  - Olsalazine
  - Balsalazide
- Corticosteroids
  - Prednisone
  - Prednisolone
  - Budesonide
- Immunomodulators
  - 6-MP/Azathioprine
  - Methotrexate
  - Cyclosporine
  - Tacrolimus
- Biologics
  - Infliximab
  - Adalimumab
  - Certolizumab
  - Natalizumab
  - Golimumab
- Antibiotics
  - Metronidazole
  - Ciprofloxacin
  - Xifaxan
- Additional Medications
  - Anti-diarrheals
  - Bile acid sequestrants
  - Bulking agents
  - Antidepressants
  - Pain medication
  - Antispasmodics

Financial Burden of IBD

- Cost of Care
  - Healthcare costs higher in US than any other country
  - Higher for people <20 years of age
  - Less than one-third of costs due to hospitalization
  - Estimated medical expenses for insured people (costs for insurer)
    - ~$19,000 per year for Crohn’s
    - ~$15,000 per year for ulcerative colitis

Park & Bass, *IBD* 2011
Estimated Cost of Diagnostic Tests

- Blood tests: $1200
- Colonoscopy with biopsies: $8200
- Esophagogastroduodenoscopy: $4900
- CT enterography: $3000
- MR enterography: $6400
- Small bowel follow-through x-ray: $400
- Capsule endoscopy: $4500

Mayo Clinic estimating office

Estimated Surgery Costs

- Laparoscopic-assisted colectomy with ileal pouch-anal anastomosis (IPAA)
  - $43,000 (colectomy with temporary ileostomy)
  - $45,000 (creation of ileoanal pouch)
  - $30,000 (ileostomy closure/reconnection)
- Small bowel resection w/anastomosis: $45,000

Mayo Clinic estimating office
Estimated Hospitalization Costs

- A typical hospitalization stay, with minimal procedures/interventions, would cost approximately $2500 per day
- Amount could vary widely

Mayo Clinic estimating office

Wholesale Prices for Medication

- Medication average cost per month
  - Sulfasalazine: $25/120 tabs
  - Mesalamine (oral)
    - Lialda®: ~$250/120 tabs
    - Asacol® HD: ~$800/180 tabs
    - Delzicol™: ~$270/120 caps
    - Pentasa®: ~$700-800/240 caps
  - Apriso®: ~$160-170/60 caps
  - Canasa®: ~$30/30-day supply
  - Balsalazide
    - Colazal®: ~$135/270 caps
    - Azathioprine: ~$65-70/100 tabs
    - Purinethol or 6-mercaptopurine: ~$40-240/30 tablets
    - Methotrexate: ~$50-60/50 tabs; ~$7.50/10 mL vial

GoodRx.com
Cost of Biologics

- Wholesale prices
  - Infliximab: ~$1900 per 100 mg (5-10 mg/kg dose)
    - Example: 65 kg patient @ 5 mg/kg would get 325 mg
  - Adalimumab: ~$2500 per dose
  - Certolizumab: ~$5100 per dose
  - Natalizumab: ~$300 per dose
  - Golimumab: ~$3100 per dose
- Price does not include infusion (administration)

Verbal estimates from Mayo Clinic Specialty Pharmacy

Medication Adherence

- Can be adversely affected when medications are unaffordable
- Nonadherence associated with more frequent flares leading to
  - Increased hospitalizations
  - Worsened quality of life
  - More clinic visits

Greenley et al, IBD 2013
NeedyMeds

www.needymeds.org

• NeedyMeds is a national non-profit organization founded in 1997 by current President, Dr. Richard Sagall

• NeedyMeds’ mission is to provide free access to accurate, comprehensive and up-to-date information about programs that help people afford their medications and healthcare costs

• Information is free, easy to access, updated regularly and anonymous
Patient Assistance Programs

- Patient assistance programs (PAPs) are usually sponsored by pharmaceutical companies and provide free or discounted medications to low or moderate-income, uninsured and under-insured people who meet the guidelines
- No rules for PAPs
  - Eligibility and application requirements vary from program to program
- One requirement is that the healthcare provider usually needs to provide a prescription to the patient, since these programs are for prescription medications
Diagnosis-Based Assistance Programs

- Help with costs associated with specific diseases, types of diseases, or medical conditions
- Programs help people with not just the cost of medications, but other costs of healthcare
- You can look up these programs on the website by condition, program location, or program name

Additional Resources

- Coupons, Rebates & More
  - Offered by various drug companies and may offer a rebate, discount, co-pay assistance, or even free trial size of prescription and over-the-counter medications
- Free/Low-Cost Clinics
  - A database of over 12,000 free or low-cost clinics
- Camps, Retreats, and Scholarships
  - All are available based on a specific diagnosis
- Government Programs
  - Programs that are created, sponsored, and/or funded (all or in part) by state, county, or local governments to assist low-income residents with medical care, prescription assistance, health insurance, etc.
Crohn’s Disease and Ulcerative Colitis Resource Page

- NeedyMeds partnered with CCFA for “one-stop shopping” concept
  - Links to patient assistance programs for IBD medications
  - Links to resources listed in Diagnosis-Based Assistance section
  - Additional information provided by CCFA

http://www.needymeds.org/resourcepages/crohns_colitis.htm

888.694.8872 · www.ccfa.org · info@ccfa.org
NeedyMeds Drug Discount Card

• A FREE drug discount card that can save users up to 80% off the cost of
  – Prescription medications
  – Over-the-counter medications and medical supplies written as a prescription
  – Pet prescriptions purchased at a pharmacy
• No activation or registration needed
• No residency, income, or insurance guidelines
• Accepted at over 63,000 pharmacies including all the major and local chains

Who Can Use the Card?

• The card cannot be combined with insurance
• Those who are uninsured can use the card anytime they are purchasing a medication
• Those that have a public (such as Medicare or Medicaid) or private insurance plan can use the card instead of their insurance if
  – They have a medication not covered under insurance
  – They are in a coverage gap, like the “donut hole”
  – They have a high co-pay or deductible
• Share with your family and friends!
NeedyMeds Checklist

- Did you look for a PAP for your medication? ☑
- Did you try using NeedyMeds Drug Discount Card? ☑
- If there was no PAP, you needed quicker assistance, or help affording an over-the-counter medication, did you check the “Coupons, Rebates & More” section? ☑
- If there was no PAP or you needed assistance for the costs of healthcare for a particular diagnosis, did you check the “Diagnosis-Based Assistance” section? ☑

Contact Information

Elizabeth Messenger
Director of Outreach & Education

info@needymeds.org
NeedyMeds Helpline Number: 1-800-503-6897
## Assistance for Mesalamine Products

- **Asacol HD 800 mg tablets**
  - Co-pay card available; call 1-800-899-2330

- **Lialda 1.2 gram tablets**
  - Co-pay card available
  - Call 1-877-994-0001, visit [www.ActivatePharmacyCard.com](http://www.ActivatePharmacyCard.com), or text “Lialda” to 80404
  - Free medication available
  - To determine eligibility, complete online application (google “Shire Cares”), or call 1-888-227-3755

- **Apriso 0.375 gram capsules**
  - Co-pay card available; call 1-888-535-1976

- **Delzicol 400 mg capsules**
  - No co-pay card or assistance program

- **Pentasa 250/500 mg capsules**
  - No co-pay card
  - Free medication available
  - To determine eligibility, complete online application (google “Shire Cares”), or call 1-888-227-3755

- **Canasa 1000 mg suppository**
  - Co-pay card available
  - Call 1-800-617-8192 or visit [www.canasacare.com](http://www.canasacare.com)

- **Rowasa 4 g/60 mL rectal suspension enema**
  - No co-pay card or assistance program

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Assistance for Budesonide

- Entocort EC 3 mg capsules
  - For Crohn's disease
  - No co-pay card available, now available in generic

- Uceris 9 mg capsules
  - For ulcerative colitis
  - Co-pay card available. Visit www.uceris.com for more information or call 1-877-264-2440.

What is a Specialty Pharmacy and When Should You Use It?
Specialty Pharmacies

Specialty pharmacies fill prescriptions for complex medical conditions

- Medications handled by a specialty pharmacy often include
  - Injectable and infusion drugs
  - Biological medicines
  - High-cost medicines
  - Medicines that have special delivery and storage requirements
    - Example: Drugs that need refrigeration

Specialty Pharmacies

A specialty pharmacy will help with

- Coordinating delivery of your refills
- Communication with your healthcare provider
- Understanding and managing your condition
- Taking your medicine correctly
- Troubleshooting side effects
- Proper medicine storage
Assistance: Biologic Medications

Remicade® (infliximab)
- RemiStart Rebate Program (www.remistart.com)
  - For patients who have commercial insurance that covers medication costs and whose out-of-pocket cost is >$50 per infusion
  - Not available to patients enrolled in federal or state subsidized programs that cover prescription drugs (Medicare, Medicare Part D, Medicaid, or Tricare)
- Janssen Patient Assistance Program (www.jpaf.org)
  - Only for patients with no insurance or who are income eligible
  - Free medication

Simponi® (golimumab)
- SimponiOne Cost Support
  - Patients should call 1-877-697-4676 or visit www.Simponi.com
  - Not valid for individuals enrolled in Medicare, Medicare Part D, or Medicaid
- Janssen Patient Assistance Program (free medication for eligible): www.jpaf.org

Cimzia® (certolizumab pegol)
- www.Cimzia.com/Cimplicity/ or www.cimzia.com
- 1-866-424-6942

Humira® (adalimumab)
1-888-486-4723 or www.MyHumira.com
- AbbVie Patient Assistance Program
  - 1-800-222-6885 or www.abbviepaf.org
  - Only for patients with no insurance or who are income eligible
  - Free medication
Navigating Changes in Insurance Coverage

Loss of Employer Provided Insurance: COBRA Coverage, Conversion Coverage

- Applies to employers with 20+ employees
- Lasts 18-36 months
- Private employer: 1-866-444-3272
- Federal government: 1-877-267-2323, ext 61565
- May be able to convert to an individual policy
  - Contact your State Department of Insurance
  - http://www.naic.org/state_web_map.htm
Affordable Care Act (ACA) 2014

www.healthcare.gov

IBD Patient Protection and ACA

• Insurers can no longer
  – Rescind policies when a member gets sick
  – Deny coverage to children with pre-existing conditions
  – Establish individual lifetime dollar limits on coverage
• Allows young adults to stay on parents policy until age 26
• Establishes external review appeal process for denials of coverage
ACA Timeline

• 2014
  – American Health Benefit Exchange
    ▪ Competitive insurance marketplaces for individuals and small businesses to purchase affordable coverage
    ▪ Open enrollment begins October 1, 2013 and is a 6-month period

IBD & Employment
Impact of IBD on Employment

- Lost wages
- Time away from work
  - Symptomatic IBD patients are twice as likely to miss work than nonsymptomatic IBD patients
  - CD patients with fistulas, depression, use of immunosuppressants had greater risk of sick leave
  - UC patients who are older with longer disease duration more likely to be disabled

Siebert et al, IBD 2013

Americans with Disabilities Act (1990)

- Employment
  - Reasonable accommodations, prohibits discrimination
- Public Services
  - Access to public services and activities
- Public Accommodations
  - Access to restaurants, hotels, stores, etc
- Telecommunications
  - Telecommunication devices for the deaf
- Miscellaneous
  - Prohibits coercing, threatening, or retaliating against individuals with disabilities and their advocates

www.ada.gov or 1-800-514-0301
Family Medical Leave Act (FMLA)

- Covered employers must grant an eligible employee up to 12 work weeks of unpaid leave during any 12-month period for one or more of the following reasons
  - Birth and care of the newborn child of the employee
  - Placement with the employee of a son or daughter for adoption or foster care
  - Care for an immediate family member (spouse, child, or parent) with a serious health condition
  - Medical leave when the employee is unable to work because of a serious health condition

FMLA Benefits

- Can be used for intermittent leave of absence
- Maintains job security and restoration, and all other benefits (health insurance, etc.)
- Use of FMLA cannot result in loss of benefits accrued
- In some cases, may use paid leave as FMLA leave (must be determined prior to leave)

www.dol.gov/whd/fmla
FMLA Employee Responsibilities

- 30-day advance notice when practical
- Documentation from GI provider
- Re-certification annually
- Updates when requested
- Formal paperwork from HR department

Disability

- IBD patients have higher rates of unemployment than general population
  - Patients with active disease have higher rates than those with inactive disease
- Higher rates of disability

Sewell & Velayos, IBD 2013
Applying for Disability

www.ssa.gov
www.ccfa.org/resources/social-security.html

- SSI-Supplemental Security Income
- SSDI-Social Security Disability Insurance
- Social Security Childhood Disability Benefit (children under 18 years)

Additional Resources for Uninsured

- Applying for Medicaid or state high-risk pool insurance
  - www.healthcare.gov
  - www.familiesusa.org
  - Some high-risk pools are closed to new enrollees
- Community health centers
  - www.hrsa.gov
- NeedyMeds
  - www.needymeds.org
Other Financial Resources

- Food stamps
- Aide to Families with Dependent Children
- Energy Assistance Programs
- Rental Assistance Programs
- United Way (311 or 211) Resources
- Check your state agencies

Private Organization Co-pay Assistance (currently available)

**HealthWell Foundation**
Medicare patients only
1-800-675-8416
[www.healthwellfoundation.org](http://www.healthwellfoundation.org)
[info@healthwellfoundation.org](mailto:info@healthwellfoundation.org)

**Modest Needs Foundation**
One-time emergency grants to financially needy families or individuals
[www.modestneeds.org](http://www.modestneeds.org)

**Patient Advocate Foundation**
- Provides patients with arbitration, mediation, and negotiation
- Settles issues with access to care, medical debt, and job retention related to their disease
  - [www.patientadvocate.org](http://www.patientadvocate.org)
  - [help@patientadvocate.org](mailto:help@patientadvocate.org)
  - Phone: 1-800-532-5274
  - Fax: 757-873-8999
CCFA Educational & Support Resources

- Information Resource Center
  - Provides disease management information, and information on financial assistance
  - Phone: 1-888-694-8872
  - Email: info@ccfa.org
  - Answer chat: www.ccfa.org

- Bathroom access card

- Connect with other patients
  - CCFA Community site: www.ccfacommunity.org
  - Support groups and Power of Two (peer mentors): www.ccfa.org/chapters

We Want Your Feedback!

www.surveymonkey.com/s/finances-webcast