



MANAGING THE Costs OF YOUR IBD CARE



Wednesday, December 18th, 2013

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Speakers

Karen Hanson, RN, CNP

Nurse Practitioner, Division of Gastroenterology and Hepatology
Mayo Clinic, Rochester, MN

Susanne Benouna

Medical Secretary, Division of Gastroenterology and Hepatology
Mayo Clinic, Rochester, MN

Elizabeth Messenger

Director of Outreach & Education
NeedyMeds, Gloucester, MA

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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

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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

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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

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Financial Burden of IBD

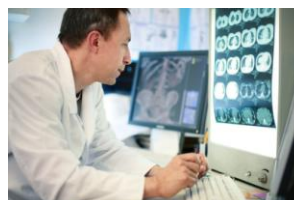
- Cost of Care
 - Healthcare costs higher in US than any other country
 - Higher for people <20 years of age
 - Less than one-third of costs due to hospitalization
 - Estimated medical expenses for insured people (costs for insurer)
 - ~\$19,000 per year for Crohn's
 - ~\$15,000 per year for ulcerative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

Park & Bass, *IBD* 2011

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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

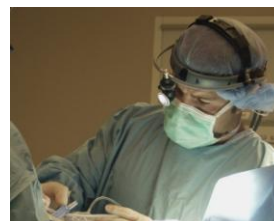


Mayo Clinic estimating office

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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



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Estimated Hospitalization Costs

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



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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

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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

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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

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Affording Your Medications

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NeedyMeds

www.needy meds.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

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www.needymeds.org
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Español
Patient Assistance Programs

- ◆ Brand Name Drugs
- ◆ Generic Name Drugs
- ◆ Program List
- ◆ Company List
- ◆ PAP Applications
- ◆ Coupons, Rebates & More
- ◆ Application Assistance

Additional Resources

- ◆ Diagnosis-Based Assistance
- ◆ Free/Low Cost Clinics
- ◆ NeedyMeds Drug Discount Card
- ◆ Discount Drug Cards

Over \$37,101,309.74 Saved with the NeedyMeds Drug Discount Card
Save on Your Prescriptions


The NeedyMeds Drug Discount Card saves you up to 80% or more off the cost of:

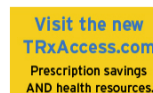
- ◆ Prescription Medicines
- ◆ Over-the-Counter Drugs
- ◆ Pet Prescription Drugs

Click on the card to learn more and get your own card.



Learn how to use our extensive resources at the **Next Monthly Webinar:** July 17 at 2:00PM Eastern Time

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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

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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

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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 13,000 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.

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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

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Crohn's Disease and Ulcerative Colitis Resource Page

The Crohn's Disease and Ulcerative Colitis Resource page is a collaborative project of NeedyMeds and the National Eczema Association. It is created to provide information on criteria and to streamline and simplify the way those with economic need find assistance paying for their medications.

Crohn's disease and ulcerative colitis are chronic, and often times painful, illnesses that attack the digestive system. Collectively known as inflammatory bowel disease (IBD), over 1.4 million Americans suffer from Crohn's and colitis, for which there is no cure. The mission of the Crohn's & Colitis Foundation of America (CCFA) is to cure Crohn's disease and ulcerative colitis, and to improve the quality of life of children and adults affected by these diseases.

Click HERE to learn more about NeedyMeds and how to use the information on the website and click HERE for more details on pharmaceutical patient assistance programs.

Medications used in the treatment of Crohn's Disease and Ulcerative Colitis:
 Blue names means the drug is available through a Patient Assistance Program; an asterisk indicates the drug is not currently available through a patient assistance program.

<ul style="list-style-type: none"> adalimumab Azathioprine (azathioprine)* Azoxycoban Azulfidine (sulfasalazine) budesonide (budesonide) butyrate Canasa (mesalamine) certolizumab pegol Cipro (ciprofloxacin) clonidine Citalopram (citalopram)* cyclosporine Dalacin (clindamycin) Dexamet (dexamethasone)* Diphen (diphenhydramine)* Entocort EC (budesonide)* Ergo (ergometrin)* Gefix (hydroxyzine) Genotropin (somatropin) hydrocodone/paracetamol Hytrin (terazosin) Shedir (sulfasalazine) infliximab 	<ul style="list-style-type: none"> Lacta (mesalamine) Mezlin (methylnaloxonium) mesalazine mesalamine metformin methylnaloxonium metoprolol Neoral (cyclosporin pegol) niacin Podipin (prednisolone) Porac (prednisolone) prednisolone progesterone Propin (propylthiouracil)* Rutivectol (metoprolol) Rumocol (prednisolone) Sulfasalazine (sulfasalazine)* Roxane (mesalamine)* Sulfasalazine (sulfasalazine) sulfasalazine sulfasalazine Tegretol (carbamazepine) Ultrax (budesonide)* Ultrax (budesonide)* Ultrax (budesonide)*
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Other Sources of Assistance:

- Care4U: Online Access Program
- March of Dimes Foundation
- The Drey Foundation
- Children's Special Health Care Services - Indiana State Department of Health

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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

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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!

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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?

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Contact Information

Elizabeth Messenger

Director of Outreach & Education

info@needymeds.org

NeedyMeds Helpline Number: 1-800-503-6897

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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, 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

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Assistance for Mesalamine Products

- 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
- 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.

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

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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



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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
- Refills on time



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Assistance: Biologic Medications

Remicade® (infliximab)

Access One : 1-888-ACCESS-1 (1-888-222-3771) or www.JanssenAccessOne.com

- 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.jipaf.org)
 - Only for patients with no insurance or who are income eligible
 - Free medication

Simponi® (golimumab)

Access One: 1-888-ACCESS-1 or www.JanssenAccessOne.com

- 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.jipaf.org

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Assistance: Biologic Medications

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

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Navigating Changes in Insurance Coverage

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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

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Affordable Care Act (ACA) 2014

www.healthcare.gov

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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

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ACA Health Insurance Enrollment

- 2014
 - American Health Benefit Exchange
 - Competitive insurance marketplaces for individuals and small businesses to purchase affordable coverage
 - 2013 open enrollment ends December 23rd for coverage beginning January 1st.
 - Enrollment ends by March 31st, 2014
 - CCFA webinar on January 29th, 2014 *Health Insurance Marketplace 101*

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IBD & Employment

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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

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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

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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



www.dol.gov/whd/fmla

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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)

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FMLA Employee Responsibilities

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

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Disability

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

Sewell & Velayos, *IBD* 2013

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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)

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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

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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



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Private Organization Co-pay Assistance (currently available)

HealthWell Foundation

1-800-675-8416

www.healthwellfoundation.org

info@healthwellfoundation.org

Modest Needs Foundation

One-time emergency grants to financially needy families or individuals

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
- help@patientadvocate.org
- Phone: 1-800-532-5274
- Fax: 757-873-8999

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CCFA Educational & Support Resources

- Irwin M. and Suzanne R. Rosenthal IBD Resource Center (IBD Help Center)
 - Provides disease management information, and information on financial assistance
 - Phone: 1-888-694-8872
 - Email: info@ccfa.org
 - Answer chat: www.ccfa.org
- Educational webcasts: www.ccfa.org/resouces/webcasts
- Connect with other patients
 - CCFA Community website: www.ccfacommunity.org
 - Support groups and Power of Two (peer mentors): www.ccfa.org/chapters



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Next Webcast in 2014: Health Insurance Marketplace 101



Register today!

www.ccfa.org/resources/health-insurance-marketplace.html

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QUESTIONS?

We Want Your Feedback!

www.surveymonkey.com/s/managing-ibd-costs

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