

## Pediatric Crohn's Disease: Finding the Right Path to Care

*An educational program for children with Crohn's Disease, their caregivers, and pediatricians.*

This program is supported by  
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## Pediatric Crohn's Disease: Finding the Right Path to Care

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## Featuring

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## Pediatric Crohn's Disease: Finding the Right Path to Care

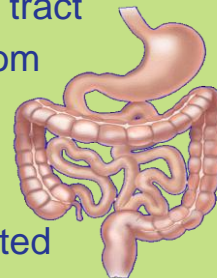
### Goals

- Identify important differences between pediatric and adult Crohn's disease
- Share principles of medical management for children with Crohn's disease
- Address growth and development of the pediatric Crohn's patient
- Discuss the critical role of nutrition
- Offer quality of life and support system insights

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## Crohn's Disease

- An inflammatory bowel disease (IBD)
- Chronic (ongoing) disorder causing inflammation of the digestive or gastrointestinal (GI) tract
- Can involve any area of the GI tract from the mouth to the anus
- Most commonly affects the small intestine and/or colon
- Peak onset in teens, but all ages affected
- 10% of IBD patients are under the age of 18

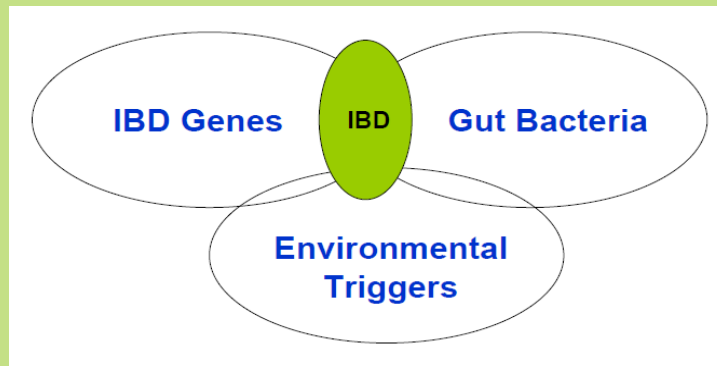


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## Causes of Crohn's Disease

Research suggests three factors work together to cause Crohn's disease



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## Causes of Crohn's Disease

- **Environmental factors** (e.g., infectious agents)
  - May trigger inflammation
  - Immune system “over-responds” to environmental insult
- **Immune cells**
  - Attack normal tissue causing inflammation and tissue injury
  - Inflammatory process can affect other parts of the body (joints, skin, eyes, oral mucosa)
- **Genetic mapping**
  - Has identified associated genes
  - Genes may “turn on” inflammatory pathways
  - Potential new treatments targeting inflammatory pathways signaled by specific genes
  - May predict course of disease and therapy

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## Children With Crohn's: Not Small Adults!



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## Pediatric Crohn's Has Unique Characteristics

- Pediatric and adult disease have similar presentations
  - GI symptoms
  - Extra-intestinal manifestations
- However, presentation is more severe in children
  - Greater progression to surgery
  - More aggressive disease phenotypes
  - Growth and pubertal delay
  - Psychosocial impact of disease

Vernier-Massouille et al. 2008. *Gastroenterology*.  
Van Limbergen et al. 2008. *Gastroenterology*.

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## Treatment Goals

### Overall goals

- Remission, maintenance

### Immediate goals

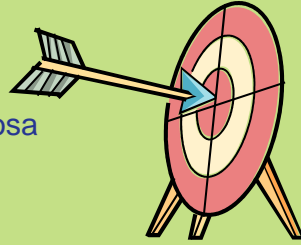
- Suppress inflammation to heal mucosa
- Decrease/alleviate symptoms

### Continued goals

- Prevent disease relapse
- Avoid complications
- Restore normal growth, nutritional status

### Ultimate goals

- Treatment should be reasonable, cost-effective
- Improve quality of life
- Alter the natural history of disease favorably



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## Treatment Challenges and Efficacy

- Similar/greater efficacy in inducing remission
- Limited data
  - Treatment extrapolated from adult studies
  - Trials do not often consider pediatric-specific outcomes (growth parameters, markers of bone metabolism)
- FDA recently mandated new drug safety and efficacy for children and adolescents
- Not “one size fits all”
  - Swallowing medications
  - Dosage schedules
- Concerns of drug toxicity
  - Malignancies
  - Infections
  - Impact of lifetime therapy duration



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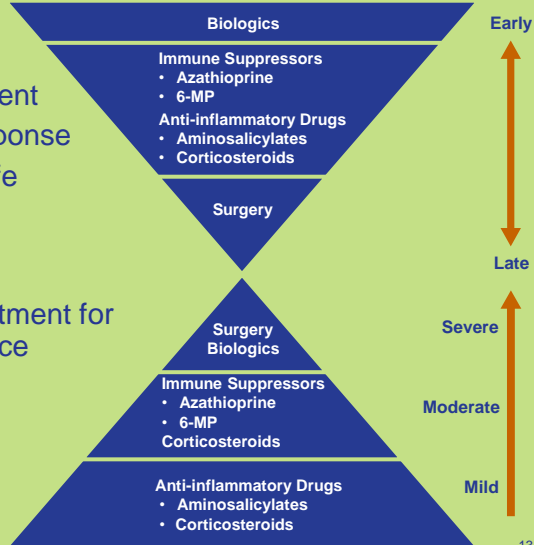
## Treatment Strategies

### "Top-down" Strategy

- Early, aggressive use of infliximab as initial treatment
- Induces rapid clinical response
- May enhance quality of life

### "Bottom-up" Strategy

- Standard, sequential treatment for remission and maintenance
- Cost-effective
- Minimal side effects



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## The Question of Medication

### Considerations

- Medication cannot cure Crohn's disease
- More than one medication may be needed to reduce disease symptoms
- It may take awhile to figure out which one(s) are best
- Each medication presents benefits and risks

Mesalamine  
Azathioprine  
6-MP  
Cyclosporine  
Probiotics  
Adalimumab  
Thalidomide



Natalizumab  
Methotrexate  
Steroids  
Nutrition  
Infliximab  
Certolizumab  
Tacrolimus

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## The Question of Medication (cont)

### How to decide?

- Become informed—you have resources!
  - Your doctors and caregivers
  - CCFA brochures
  - The Internet (with caution!)
- Be open with your doctor—ask questions
- Balance BENEFITS and RISKS



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## Surgery

- Surgery and medicine can combine for best quality of life
- Historically, up to 80% of people with Crohn's eventually undergo surgery<sup>1</sup>

Complications That May Require Surgery Include	Primary Goals of Surgery
<ul style="list-style-type: none"> <li>• Intestinal obstruction or blockage</li> <li>• Excessive bleeding in the intestine</li> <li>• Perforation of the bowel</li> <li>• Formation of a fistula or abscess</li> <li>• Toxic megacolon</li> </ul>	<ul style="list-style-type: none"> <li>• Alleviate complications</li> <li>• Achieve best possible quality of life</li> <li>• Bowel conservation</li> </ul>

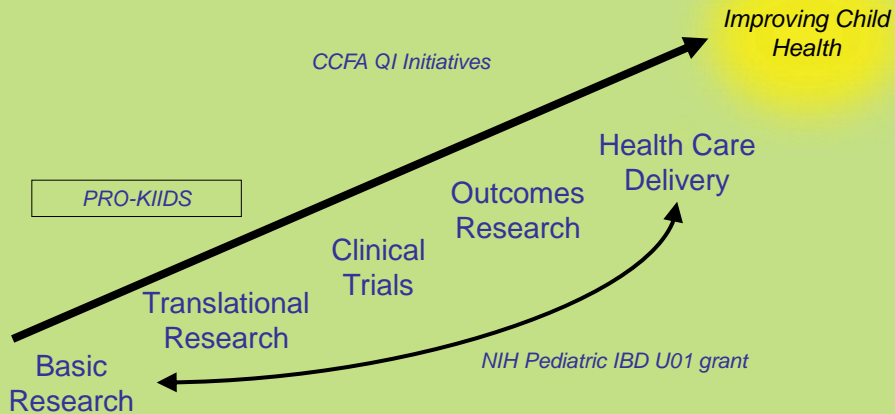
<sup>1</sup> Kane, Sunanda. "When You Need Surgery for IBD." *IBD Self-Management: The AGA Guide to Crohn's Disease and Ulcerative Colitis*. Bethesda, MD: AGA, 2010. Print.

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## Hope for the Future

### Integrating Research With Health Care Delivery



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## PRO-KIIDS CCFA Pediatric IBD Clinical Research Network

### Ultimate goals

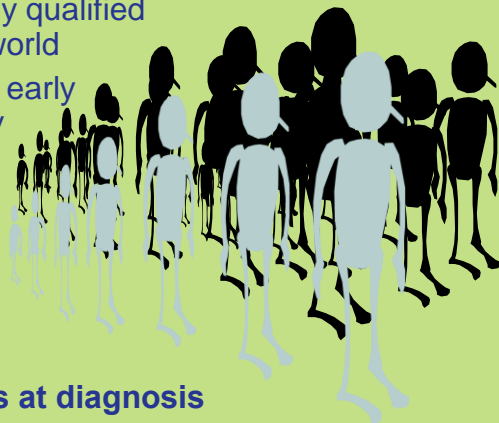
- Resources available to any qualified investigators around the world
- Clinical studies to prevent early complications and surgery

### Database collects

- Genetic makeup
- Environmental exposures
- Bacteria in bowel
- Immune reactivity

### 1100 children with Crohn's at diagnosis

- 3 years → 160–200 patients with complication/surgery



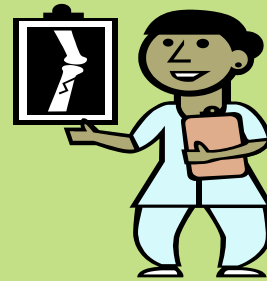
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## Bone Health

### Decreased bone mineral density common in children and adolescents with Crohn's disease

- Poor calcium absorption/intake; vitamin D deficiency
- Decreased physical activity
- Inflammation
- Maximum accumulation of calcium in your bones occurs in mid-teen years
- Steroid use increases short- and long-term risk

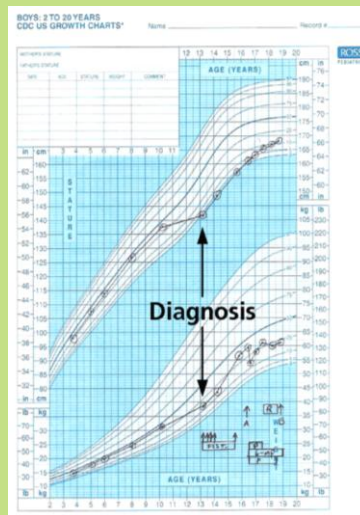


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## Growth Failure

### Growth failure more common in Crohn's vs. ulcerative colitis

- Issues are noted both pre- and post-diagnosis
- Decreased rate of growth and height percentiles
  - Adult height compromised
  - Crohn's disease: 32%–88%
  - UC: 9%–34%
- Growth good marker for disease activity
- "Growth window" crucial



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## Factors Impacting Growth

- Disease severity/degree of inflammation
  - Inflammatory cytokines (IL-6, TNF)
  - Corticosteroid therapy
  - Inadequate oral intake
  - Diarrhea
- Time from onset of symptoms to diagnosis and treatment (medical, surgical,<sup>1</sup> and nutritional) is crucial
- Disease location—small intestinal/jejuna
- Significant increase in height velocity post-operation regardless of location



<sup>1</sup>Davies et al. 1990. *Br J Surgery*.

## Impact on Puberty

- Medical and psychological impact
- Similar factors affect growth and onset of puberty
  - Poor nutrition
  - Pro-inflammatory cytokines
  - May or may not be made up later in life
- Delayed age of peak height velocity (middle of puberty)<sup>1</sup>
  - ~25% children with Crohn's
  - Delay usually 6–12 months

<sup>1</sup>Hildebrand et al. 1994. *JPGN*.



## Overall Principles: Growth Failure and Bone Health

- Timing is key—intervene before puberty starts
- Optimize nutrition
  - Caloric and vitamin/mineral deficiencies
- Re-assess disease activity
- Consult with an endocrinologist
- Minimize corticosteroids!
  - Utilize enteral nutrition
  - Maintenance medications (Biologics/IM)
  - Surgery when timed/used judiciously



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## The Critical Role of Nutrition

Including good nutrition in your diet is essential to quality of life and improved long-term outcomes

- “*Diet*” = the food you eat on a daily basis
- “*Nutrition*” = how your body uses nutrients from your diet

Careful food choices may

- Lessen symptoms
- Prevent disease exacerbation

Crohn's patients are prone to becoming malnourished

- Loss of appetite (caused by nausea, pain)
- Increased caloric needs caused by chronic disease
- Poor digestion and absorption of nutrients

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## Principles of Good Nutrition

Good nutrition is key to

- Medications being more effective
- Healing, immunity, and energy levels
- Preventing or minimizing GI symptoms
- Normal bowel function



Poor nutrition or malnutrition contributes to

- Negative growth effects in children and teens
- Negative impact on hormone levels (especially girls)

Several diets advertised as specifically for managing IBD

- Most have not been proven scientifically
- Claims are supported by small numbers
- Talk with your doctor about your questions

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## Good Nutritional Choices

- Choose foods wisely and with careful consideration
- Strive for a well-balanced, healthy diet that includes hydration and continual adequate nutrient intake
- Discuss specific intake and dosage with your pediatric gastroenterologist

Foods	Supplements
Carbohydrates with more soluble fiber (oat brans, legumes, barley)	A daily multivitamin
Protein (eggs, lean meats, smooth nut butters)	Vitamin B12 (monthly injection may be given to patients with ileitis)
Deeply colored fruits and vegetables	Calcium
Foods high in vitamins and minerals	Vitamin D
Healthy fats (canola or olive oil)	Folic acid

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## During a Flare

- Low-residue diet will relieve pain and diarrhea
- Avoid foods that increase stool output
- Eat smaller, more frequent meals
- Add nutrition supplements if appetite is poor

### Low-Residue Foods

#### Grains

Plain cereals  
White rice  
Refined pasta  
AVOID whole grains

#### Fruits

Fruit juices (except prune)  
Apple sauce  
Bananas

#### Vegetables

Potatoes (no skin)  
Well cooked

#### Meat and protein

Well cooked  
AVOID beans, nuts, seeds

#### Dairy

As tolerated or additional sources

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## Nutrition Support Therapy

- Additional support may be necessary during the disease course due to weight loss, severe inflammation, oral intake issues, surgery, or obstruction

Liquid Nutritional Supplements	Enteral Nutrition	Parenteral Nutrition
<ul style="list-style-type: none"> <li>• Pediatric nutrition shake</li> <li>• Adult nutrition shake</li> <li>• Nutritional energy drink</li> <li>• Specific carbohydrate drink</li> </ul>	<p>Nutrient-rich liquid formula administered through</p> <ul style="list-style-type: none"> <li>• Nasogastric (NG) tube from nose to stomach</li> <li>• Gastrostomy tube (G-tube) directly from abdominal wall to stomach</li> </ul>	<ul style="list-style-type: none"> <li>• Delivered through a catheter placed into a large blood vessel</li> <li>• More complications than enteral nutrition</li> <li>• Requires specialized training to administer</li> <li>• Now rarely necessary</li> </ul>

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## “It’s Tough Being Different...”

- Specific issues facing children/teens with Crohn's disease
  - Defining what it means to have a chronic illness
  - Coping with procedures, clinic visits, hospitalizations
  - Adhering to complicated medical and dietary regimens
  - Quality of life and social interactions impacted
  - Body image and disordered eating patterns
  - The need for support systems at home and at school
- Children and teens with chronic disease are at greater risk of psychological stressors
  - Low self-esteem
  - Poor social functioning
  - Depression
- Quality of life and support resources are key

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## Psychosocial Screening: What Do We Want to Assess?

- Psychosocial assessment + assessment of disease activity at each pediatric GI visit
  - General well-being: energy level, GI symptoms, diet
  - Emotional functioning: anxieties, self/body image
  - Activities of daily living: school, hobbies
  - Challenges: medication regimen, “normal” activities
  - Relationships: family, friends



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## Partnering to Manage Crohn's Disease

- Screening
  - Is there a support network of family members/friends?
  - Is a counselor or psychologist needed?
  - Are school accommodations needed and/or in place?
  - Does child/adolescent need help with stress reduction?
- Self-management
  - Disease education and knowledge
    - Encourage use of resources available on the web
    - Review educational materials together
  - Learn necessary skills
  - Prepare for independence



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## Help Your School to Help You

"All qualified persons with disabilities within the jurisdiction of a school district are entitled to a free appropriate public education. The ED Section 504 regulation defines a person with a disability as any person who (i) has a physical or mental impairment which substantially limits one or more major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment."

SECTION 504 OF THE REHABILITATION ACT OF 1973

### Initial Diagnosis

#### Contact List:

- School nurse
- Guidance counselor
- Adjustment counselor/  
school social worker
- Teachers
- Administrators

#### Student File Letter:

- Definition of Crohn's
- Associated symptoms
- Cyclical nature
- Home tutoring option
- Gym considerations
- Mind-gut connection

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## Requesting a 504 Plan

- Make the request in writing
- Include supporting medical documentation
- Parents, patient (if age-appropriate), school nurse, administrator, and guidance counselor should meet to develop a workable plan

### Sample 504 Plan Accommodations

- |  |  |
|--|--|
| • Bathroom pass                                  | • Extra set of books                                       |
| • Nurse's office pass                            | • Increased time between classes                           |
| • Nurse's training for medication administration | • Copies of syllabi, lesson plans                          |
| • Food/drink in class                            | • Permission to Xerox class notes                          |
| • Stop-the-clock testing                         | • In-home/after school tutoring prior to prolonged absence |
| • Postponement of cumulative term grades         | • Field trip/extracurricular transportation                |
| • Revised seating chart                          |  |



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## Take Home Tips

- Prioritize
- Advocate
- Communicate
- Collaborate
- Ask others for help
- Maintain relationships with key staff
- Document, Document, Document
- Educate yourself
- **EDUCATE OTHERS...**schools want to help



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## Family Medical Leave Act of 1993 (FMLA)—Synopsis of Law

Covered employers must grant an eligible employee up to a total of 12 workweeks of unpaid leave during any 12-month period for one or more of the following reasons:

- For the birth and care of the newborn child of the employee
- For placement with the employee of a son or daughter for adoption or foster care
- To care for an immediate family member (spouse, child, or parent) with a serious health condition
- To take medical leave when the employee is unable to work because of a serious health condition



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## Transition and Transfer of Care

- Transition = process
  - Message of empowerment and initiative
  - Sends message of optimism to young adults
  - Imparts confidence the patient is capable of access care in the adult healthcare system
- Transfer of care = single act



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## Pediatric and Adult Provider Differences

- Differences between pediatric and adult health care providers and systems
- Transition and transfer of care steps benefit patient care

Pediatric	Adult
Multi-disciplinary	Often single MD
Family focused	Patient focused
Protective	Collaborative
Parental responsibility	Expectation of autonomy
Generalist, social focus	Specialized, disease focus

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## Goals of Transition

*"The goal of a transition program is to achieve for each chronically ill patient a continuum of care that includes normalization of social and emotional development and the acquisition of independent living skills."*

*NASPGHAN Medical Position Statement, 2002*

- Graduated increase in patient responsibility for managing his/her disease
- Successful transition
  - Uninterrupted care
  - Coordinated care
  - No sense of abandonment for patient

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## Developmental Framework for Transition Plans

- Roughly mirrors stages of development
- Commonly accepted stages = chronological age
- Skill development
  - Communication
  - Resource gathering and decision making
  - Self-care and self-advocacy
  - Assertiveness and self-determination
- Additional considerations
  - Maturity
  - Medical status
  - Emotional readiness of parent/caregiver



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## Fundamental Principles of Transitioning

- Flexible process
- Responsible
  - Designated, proactive healthcare provider takes responsibility and encourages an open, interactive relationship
- Written
  - Request a written transition plan from the healthcare provider
- Timely
  - Begin initial discussions during adolescence; set goals that can be reached and are age-appropriate
- Planned
  - Develop a plan for what will happen at age 18
  - Involve patient, parents, and healthcare provider
  - Complete transfer during or after college, or after employment is stabilized



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## Transfer of Care Timeline

	Age 11–13	Age 14–16	Age 17–19	Age 20–23
Suggest independent visits	X	Direct questions and explanations to patient		
Parents remain in waiting room	For a small portion of the visit	Patient decides when parents remain; explain what must legally be shared with parents; address parental concerns	Remind of legal rights and responsibilities at age 18	
Review medications, doses, side effects, strategies	X	Also include names and purposes of common procedures; keep medical information in wallet or backpack		Secure medical summary and checklist
Guidance on overall health, fitness, risk taking behaviors	X	Learn to access medical records, keep files, and call to schedule appointments		
Discuss support networks		X	Identify future adult providers and encourage interviews	Transfer medical records to adult provider
Discuss future plans		Begin to talk about transfer of care	Potential barriers to transfer of care; insurance status	Final visit with pediatric GI after initial visit with adult GI

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## Milestones In Transition Readiness

- **Knowledge** of type of illness: Crohn's disease vs. ulcerative colitis
- **Understanding** of medications (what they are, what they do, side effects, etc.)
- **Adherence** to treatment plan
- **Awareness** of appropriate nutrition and its contribution to overall health
- **Prepared** with self-management skills
- **Informed** about reproductive health issues, transition to college/work place, insurance details
- **Network** of ongoing adult support
- **Plan** for finding an adult healthcare provider

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## Support and Resources

### Education

- National Dissemination Center for Children with Disabilities: [www.nichcy.org](http://www.nichcy.org)
- United States Department of Education: [www.ed.gov](http://www.ed.gov)
- Parent Advocacy Coalition for Educational Rights: [www.pacer.org](http://www.pacer.org)
- Advocacy for Patients with Chronic Illness, Inc. – 504 Template for Students with IBD: [www.advocacyforpatients.org](http://www.advocacyforpatients.org)



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## Support and Resources (cont)

### Peer and Family

- [www.ucandcrohns.org](http://www.ucandcrohns.org): A CCFA website for older children and teens with IBD; website link to a chat room for children with chronic diseases
- Camp Oasis: A CCFA-sponsored camp for children and teens with IBD
- CCFA support groups: Contact your local CCFA chapter for groups in the area ([www.ccfa.org](http://www.ccfa.org))
- [www.ibdu.org](http://www.ibdu.org): A website for young adults



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## Support and Resources (cont)

### Financial, Legal, and Medical

- Adolescent Health Transition Project: Univ. of Washington: [depts.washington.edu/healthtr](http://depts.washington.edu/healthtr)
- Healthy and Ready to Work: [web.syntiro.org/hrtw/?n=hrtw/](http://web.syntiro.org/hrtw/?n=hrtw/)
- Institute for Child Health Policy Health Care Transition Site: [www.ichp.ufl.edu/about\\_ichp](http://www.ichp.ufl.edu/about_ichp)
- New Freedom Initiative: [www.hhs.gov/newfreedom](http://www.hhs.gov/newfreedom)
- U.S. Dept. of Health and Human Services, Healthy People 2010: [www.health.gov/healthypeople](http://www.health.gov/healthypeople)



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## Question-and-Answer Session

## CCFA Information Resource Center

If you have additional questions, please contact the CCFA Information Resource Center:

- **Toll-free:** 888.MY.GUT.PAIN (888.694.8872)  
Monday through Friday 9:00 AM – 5:00 PM ET
- **Website:** [www.ccfa.org](http://www.ccfa.org)
- **Email:** [info@ccfa.org](mailto:info@ccfa.org)





## Thank you for your participation

*Help us develop programs that will benefit you in the future.*

*Please complete the program evaluation.*