

Patients and Doctors: Bridging the Divide



MOUNT SINAI
SCHOOL OF
MEDICINE

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What we'd like to avoid



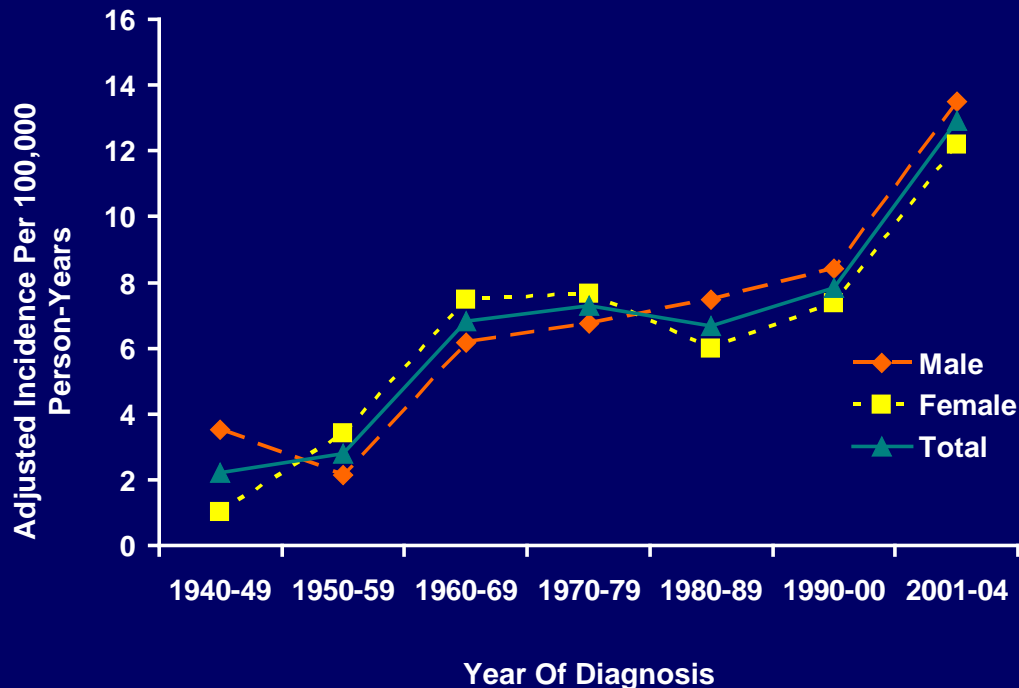
"I'M SORRY DOCTOR, BUT AGAIN I HAVE TO DISAGREE."

Differing Points of View: Overview

- Cause of PSC/IBD
- Prescription Medicines
- Alternative Medicines
- Diet
- Internet and Information about PSC/IBD

Epidemiology Of Crohn's Disease

Temporal Trends In Crohn's Disease, Olmsted County, 1940-2004¹



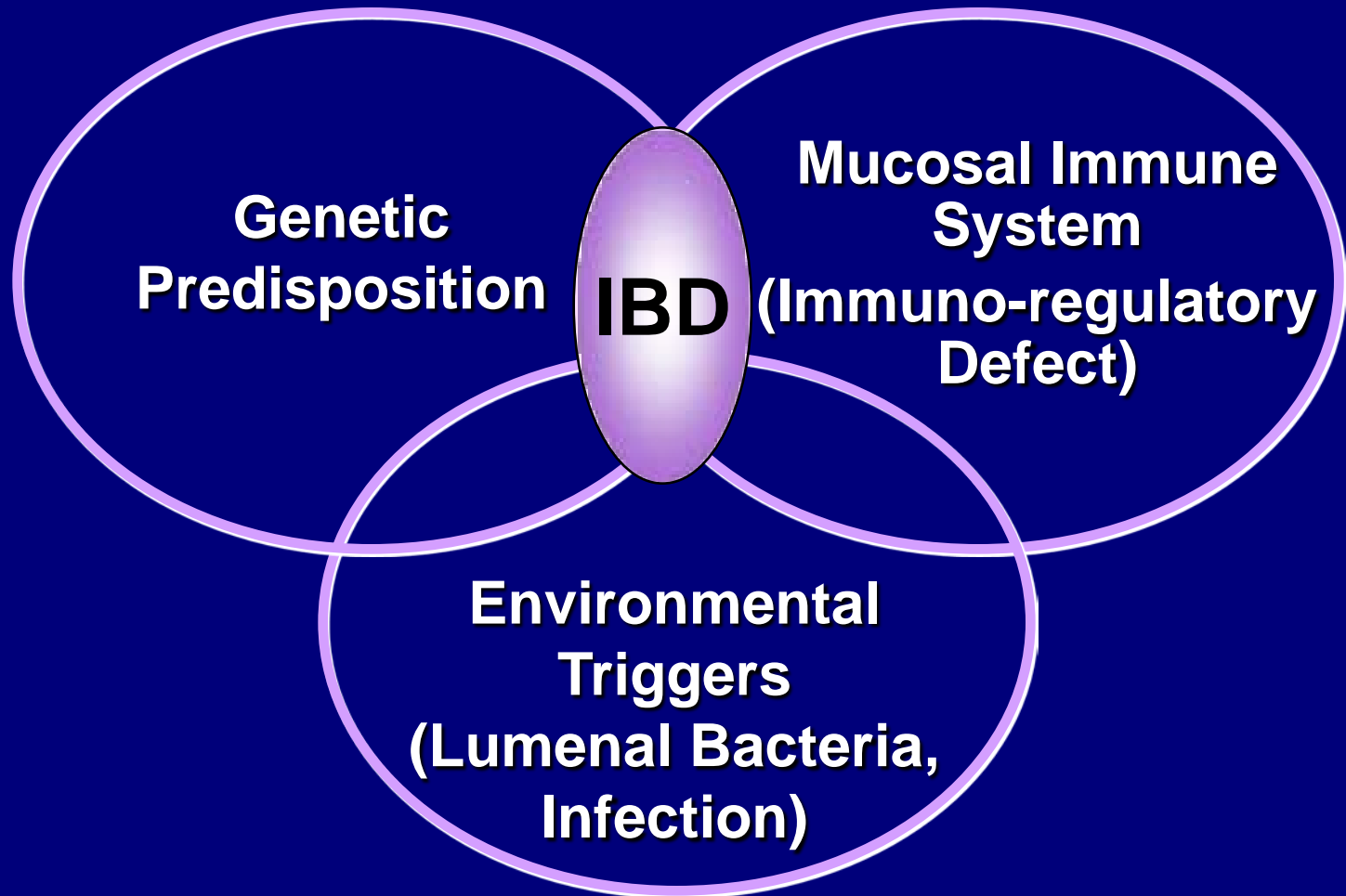
- Prevalence: 100–250 cases per 100,000²⁻³
- ~600–800,000 cases in US³

1. Ingle et al. *Gastroenterology*. 2007;132(4 Suppl 2):A19-20. Presented at Digestive Disease Week; May 19-24, 2007. #104.

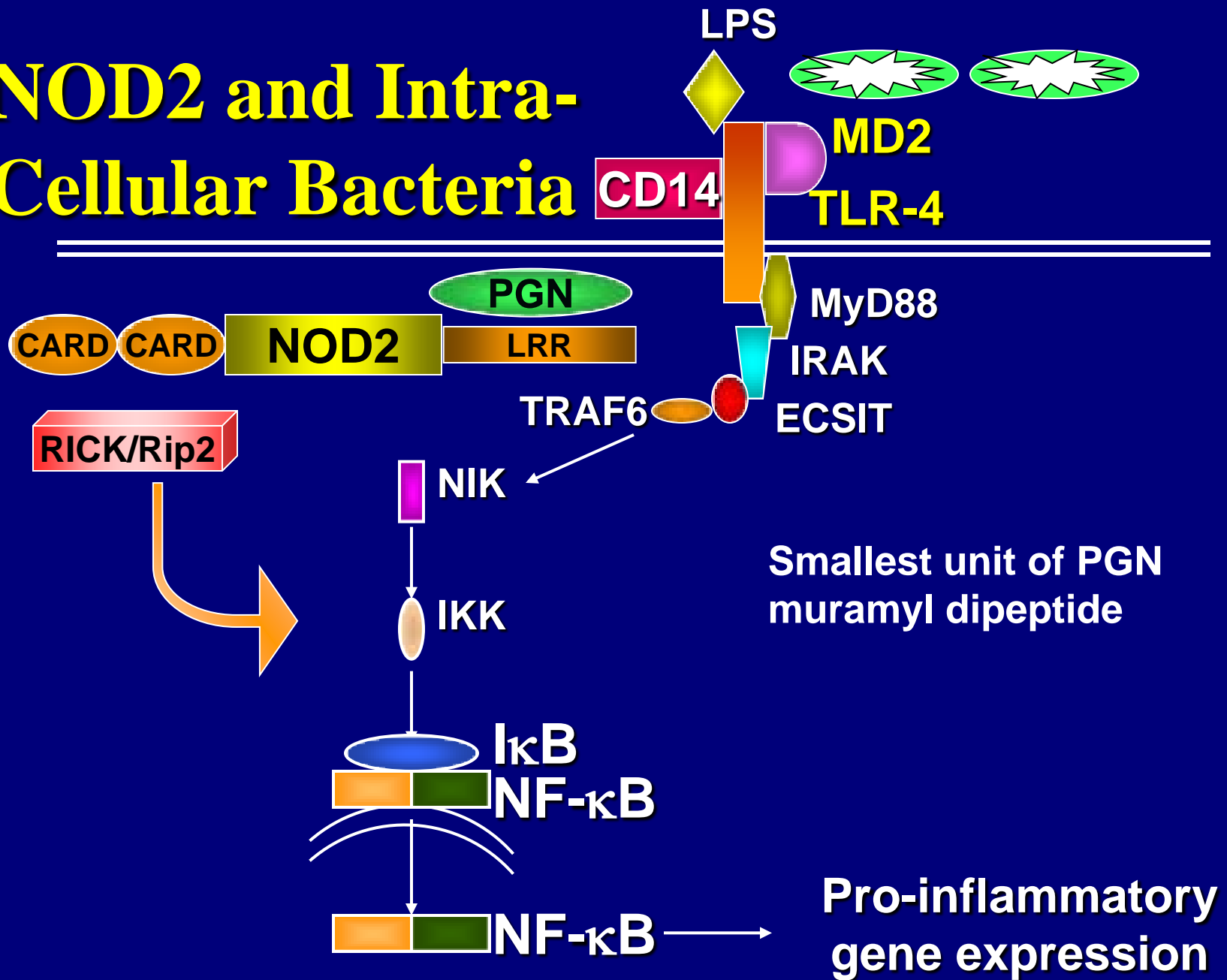
2. Bernstein et al. *Am J Gastroenterol*. 2006;101:1559-1568.

3. Loftus. *Gastroenterology*. 2004;126:1504-1517.

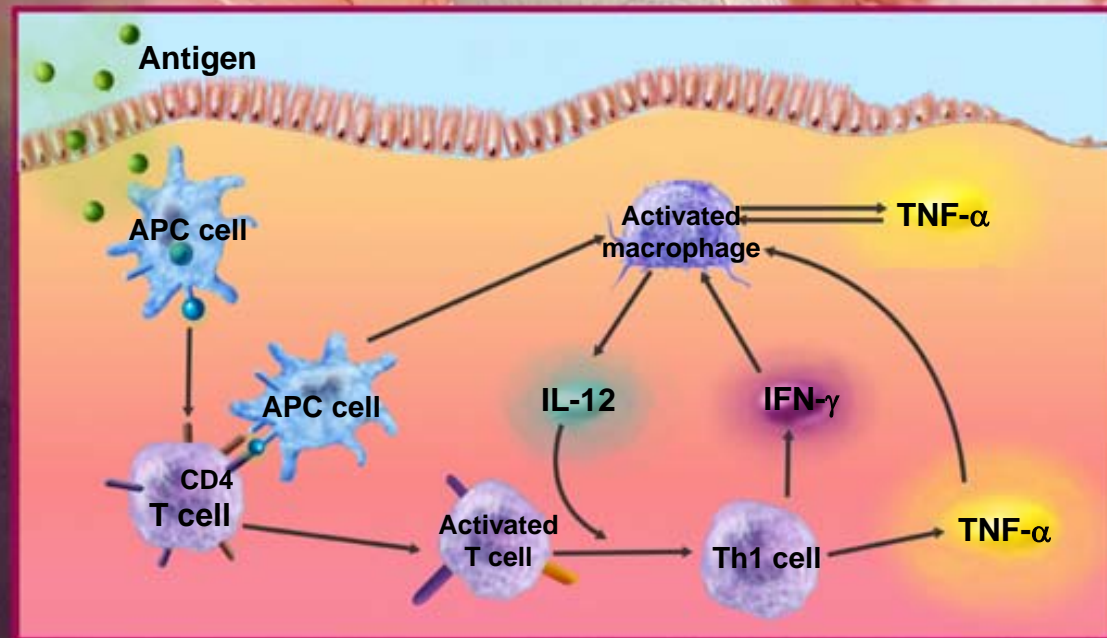
Etiologic Theories in Inflammatory Bowel Disease



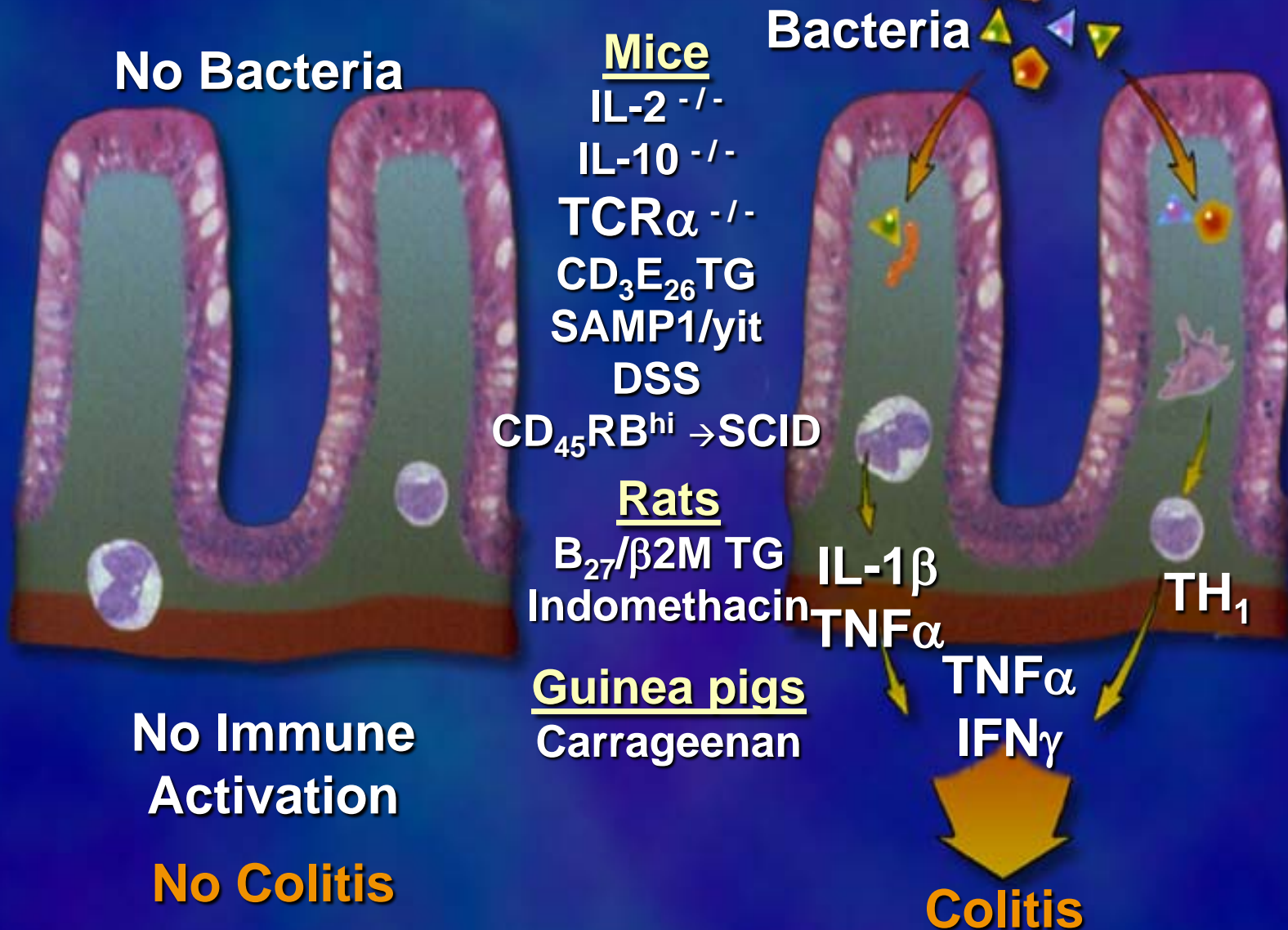
NOD2 and Intra-Cellular Bacteria



Key Inflammatory Mediators in Crohn's Disease



Luminal Bacteria Stimulate Immune-Mediated Colitis



Cause of PSC and IBD: Patient Perspective

- Bad genes (my parents; will I give it to my children?)
- Environment (bad food)
- Environment (medicine, tobacco)
- Don't Much Care

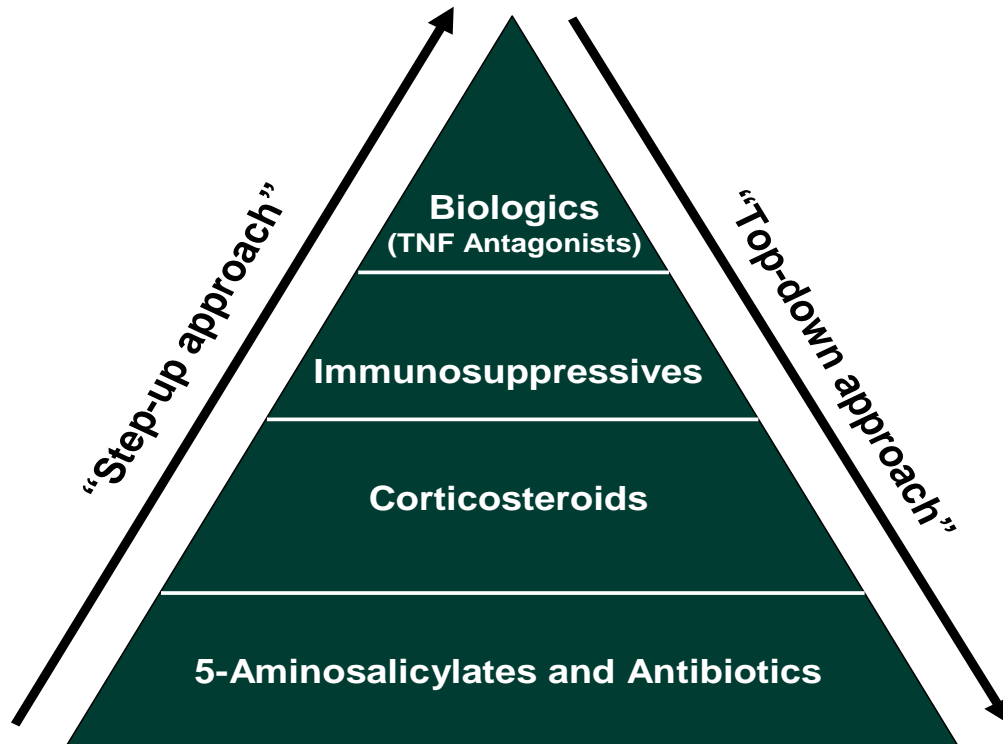
Common Ground

- Don't really know
- We're both here to get patients better

Differing Points of View: Overview

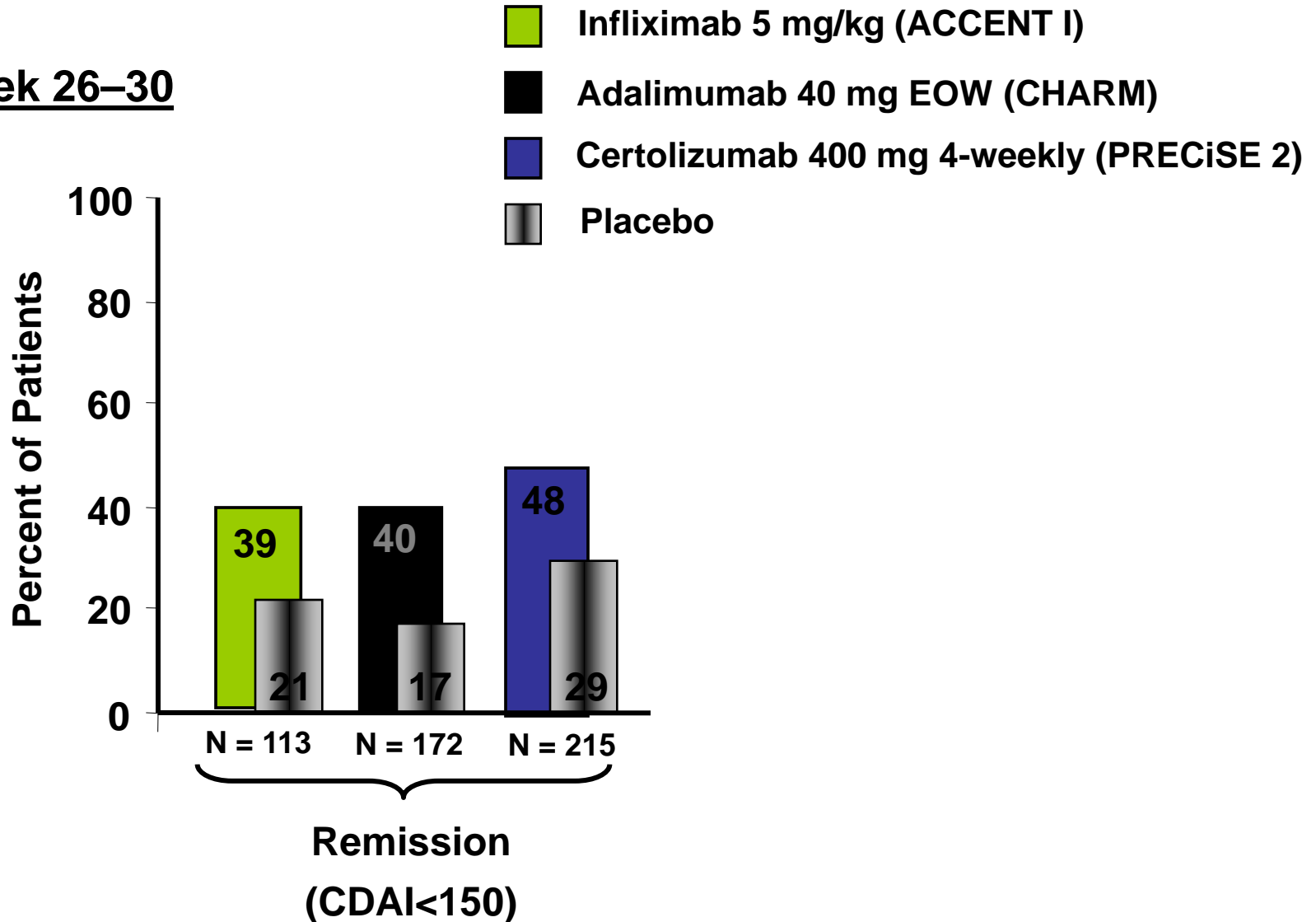
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Step-up vs Top-down Approach



Long-term Maintenance of Remission in CD

Week 26–30



But is it safe?



Paths Meet

- Keeping one another informed of latest progress
- Open-mindedness of weighing benefits and risks
- Hippocratic Oath to 'do no harm' vs. giving something a shot because it might work
- Individualize
- Clinical trials

Differing Points of View: Overview

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CAM: Physician's Perspective

- “If it hasn't been subjected to a double-blind, placebo-controlled, double-dummy randomized trial with concealed allotment, then I'm not interested.”
- It's too soon to tell

But is it safe?



CAM's: Patients' Perspective

“Natural” and “safe”

- Probiotics
- Prebiotics
- Herbal medications
- Vitamins
- Acupuncture
- Supplements
- Yoga
- Other

Paths Meet

- Keeping one another informed of latest progress
- Open-mindedness
- Hippocratic oath to do no harm vs. giving something a shot because it might work
- Clinical trials

Overview

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- **Diet**
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Diet in IBD: Physician's Perspective

- It's about the plumbing
 - Avoidance of uncooked fruits and vegetables in patients with stricturing disease
 - Liquid diet with partial obstruction
- General principles of micronutrient absorption
- “I dunno”
- Impossibility of dietary trials
- It's too soon to tell

Diet: Patient Perspective

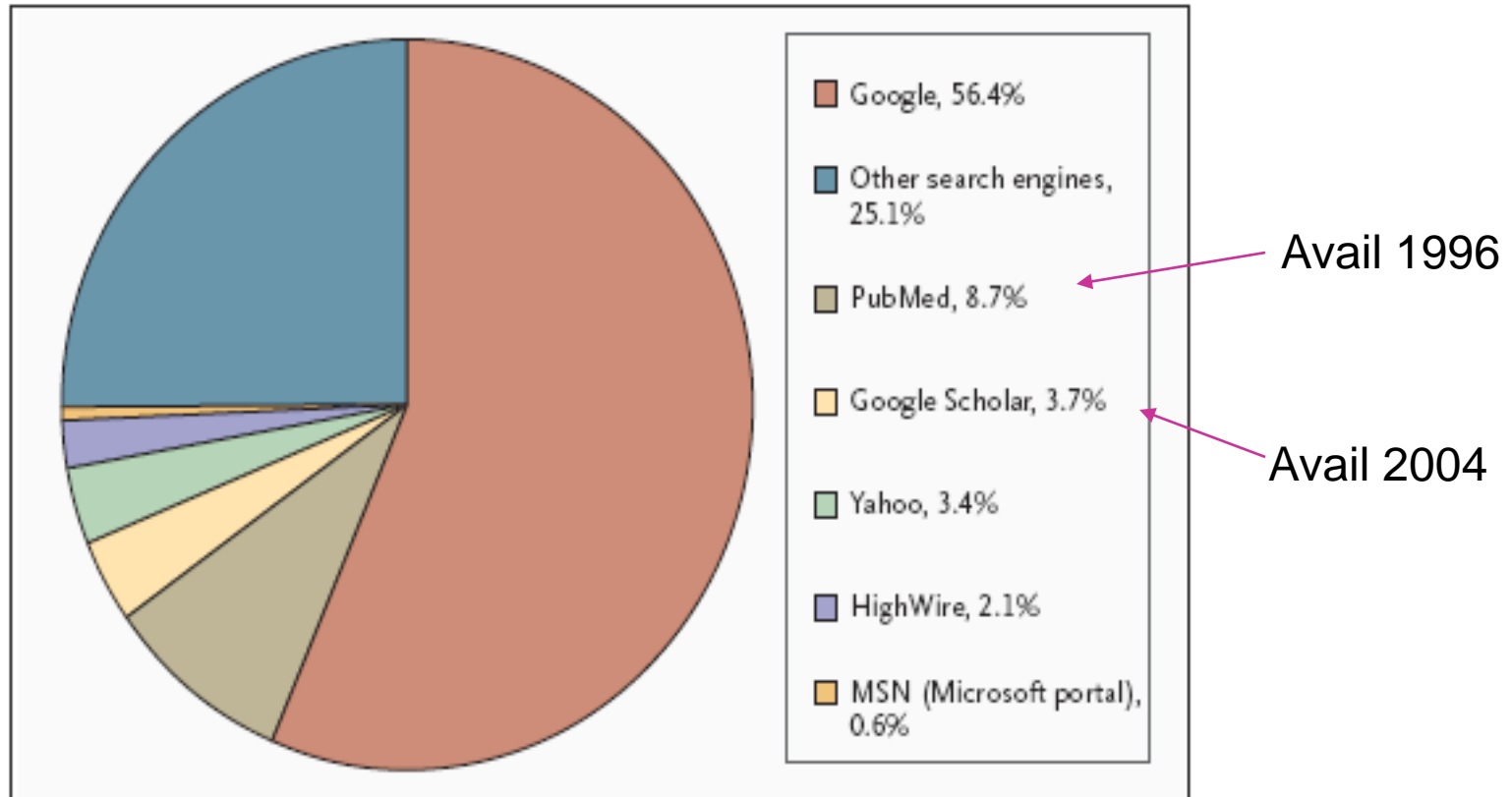
- Near primary or primary importance
- Something to take control of
- Success with manipulation
- Specific Carbohydrate Diet (SCD)

Overview

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- Diet
- **Internet and Information about PSC/IBD**

Searching for the Right Search — Reaching the Medical Literature

Robert Steinbrook, M.D.



Referrals from Search Engines to Web Sites of 844 Journals Hosted by HighWire Press.

Data are for June 2005 and are from HighWire Press.

“On the fly data....”

- Unpublished Italian study found that taking lithium seemed to slow progression of ALS.
- 34 patients from the website solicited lithium Rx from their doctors and started taking it. Up to 109 members now. And now track their progress with the data tools on the website.
- Is this good for people for whom the pace of traditional science is too slow to help them?
“Even it’s half true, it’s still groundbreaking. I don’t want to wait for something else. I don’t have time to wait.”

Physician Advocacy of the Internet?

NOPE

- Only 4% of patients were ever advised by a physician to get medical information from the Web (JAMA Conner Oct 18, 2000)
- Only 39% of physicians see the internet as a valuable health information resource for consumers (Reents et al. 1998. www.cyberdialogue.com)
- Neither the growth in patient use of the Web as an information resource nor a significant volume of web content is being driven by physicians

One Physician's Practical Approach

- pscpartners.org
- ccfa.org site has spot on information
- crohnsandme.com web site also
- Discuss findings on the web with physician before changing approach to therapy
- Grain of salt for everything on the web (especially chat rooms)

Thank you