

Nutrition therapy for children with IBD: making it work!

Stacey Zettle, MS, RD, LDN
UPMC Children's Hospital of Pittsburgh
November 2019

Objectives

- Review nutrition assessment of the pediatric IBD patient
- Identify nutrition therapy approaches to treating IBD
- Describe details of the Crohn's disease exclusion diet

Nutritional assessment of the IBD patient

- IBD patients at risk for malnutrition*
 - Poor intake, malabsorption, increased metabolism
 - Underweight more common in CD vs UC
 - Possible to be overweight and protein or micronutrient malnourished
- Micronutrients of concern**
 - Iron – check at diagnosis and annually
 - Vitamin D – check at diagnosis and annually
 - Zinc – check at diagnosis and annually (CD)
 - B12 – if ileal involvement
 - Folate – def. rare in countries with folic acid fortification, meds?

*Sigall-Boneh et al. *Journal of Crohn's and Colitis*, 1407-1419; 2017.

*Hartman et al. *JPGN*, 63(4): 437-444; 2016

**Fritz et al. *Inflamm Bowel Dis*, 25(3): 445-459; 2019

Nutritional assessment of the IBD patient – calories and macronutrients

- Non-height dependent equation for REE (WHO) — Energy and Protein Requirements, Geneva: WHO; 1985

Age	Male	Female
0-3 yr	60.9(W) - 54	61(W) – 51
3-10 yr	22.7(W) + 495	22.5(W) + 499
10-18 yr	17.5(W) + 651	12.2(W) + 746
18-30 yr	15.3(W) + 679	14.7(W) + 496

	Stress factor
No wasting/stunting	REE x 1.5
Catch up growth needed	REE x 1.7 – 1.8
Overweight	REE x 1.2

- Protein needs
 - DRI 1 g/kg/day
 - Between 1.0-1.5 g/kg
 - 45 kg child: Pediasure provides 0.7 g/kg at 50% to 1.5 g/kg at 100%
- Fluid needs
 - Typical for pediatrics
 - Increase if excessive losses



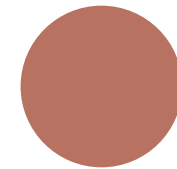
Diet options for IBD

- Exclusive enteral nutrition (EEN, polymeric diet)
- Specific carbohydrate diet (SCD)
- ***Crohn's disease exclusion diet (CDED)***
- IBD-AID
- Mediterranean diet

- Have used EEN?
- Have used CDED?
- Have used SCD?



Audience poll



Exclusive enteral nutrition



Basics

Provides 90 or 100% nutrition needs from formula

Elemental formulas not necessarily better



Barriers

Family/patient buy-in

Difficulty with adherence/social challenges

Taste fatigue

Cost



Tips for success

Ensure family knows all medical benefits/MD and RD enthusiasm

90/10 if medically appropriate – low calorie, high volume foods

- Egg whites, homemade gelatin/gummies (Ensure Clear), air-fried foods, formula popsicles, veggies and homemade veggie chips

Specific carbohydrate diet

- Removes grains, most dairy and sugars
- Promotes non-processed foods with limited additives (see table)
- Legal/illegal list
- Not recommended for:
 - Poor growth
 - Abscess or fistulizing disease
 - Severe disease per PCDAI or PUCAI

Nutrition in Immune Balance (NIMBAL) Therapy (Suskind)

Specific carbohydrate diet

FOOD	LEGAL	ILLEGAL
Fruits	All fresh, unprocessed	Canned or dried
Vegetables	All fresh, unprocessed that are non-starchy	White and sweet potato; parsnips
Protein foods	All fresh/frozen meats with legal ingredients including beef, poultry, pork, wild game, fish, shellfish, eggs	All processed/breaded meats
Fats	Ghee, oils	Vegan margarine, soybean oil
Dairy	SCD yogurt, hard cheese	Commercial yogurt, regular milk, soft cheese
Nuts/seeds	All nuts, coconut, all natural nut butters, most beans	Garbanzo, kidney, pinto beans Soy

Specific carbohydrate diet



Barriers

Introducing different foods
Time needed to cook from scratch
Difficulty with adherence/social challenges
Cost (?)



Tips for success

Ensure family knows all medical benefits/MD and RD enthusiasm
Plan ahead!
Divide the work (involve the child)



Resources

Breakingtheviciouscycle.info
Pecanbread.com
Nutrition in Immune Balance
(NIMBAL) Therapy – David Suskind,
MD

Crohn's disease exclusion diet (CDED) - basics

Goals:

- Change composition of gut bacteria
- Decrease intestinal permeability
- Restriction of harmful products while allowing to partake in food with family/friends

12 weeks + indefinite maintenance phase

5 mandatory foods in weeks 1-12

Phase 1 (weeks 1-6)

- 50% calories formula, 50% allowed foods

Phase 2 (weeks 7-12)

- 25% calories formula, 75% allowed foods

All foods fresh

CDED aims to eliminate or decrease...

- Animal fats
- Gluten
- Processed meats
- Added sugars
- Maltodextrin
- Polysorbate 80
- Carboxymethylcellulose
- Xanthan gum
- Carrageenan
- Sulfites
- Emulsifiers

Sigall-Boneh et.al. *Journal of Crohn's and Colitis*, 1205-1212; 2017

Sarbagili-Shabat et.al. *Current Opinion in Gastroenterology*, 31(4): 303-8; 2015

INGREDIENTS: DRIED POTATOES, VEGETABLE OIL (CONTAINS ONE OR MORE OF THE FOLLOWING: CORN OIL, COTTONSEED OIL, SOYBEAN OIL, AND/OR SUNFLOWER OIL), RICE FLOUR, WHEAT STARCH, MALTODEXTRIN, MONO- AND DIGLYCERIDES, SALT, DEXTROSE.

INGREDIENTS: CRUST: WHOLE GRAIN OATS, ENRICHED FLOUR (WHEAT FLOUR, NIACIN, REDUCED IRON, VITAMIN B₁ [THIAMIN MONONITRATE], VITAMIN B₂ [RIBOFLAVIN], FOLIC ACID), WHOLE WHEAT FLOUR, SOYBEAN AND/OR CANOLA OIL, SOLUBLE CORN FIBER, SUGAR, DEXTROSE, FRUCTOSE, CALCIUM CARBONATE, WHEY, WHEAT BRAN, SALT, CELLULOSE, POTASSIUM BICARBONATE, NATURAL AND ARTIFICIAL FLAVOR, MONO- AND DIGLYCERIDES, SOY LECITHIN, WHEAT GLUTEN, NIACINAMIDE, VITAMIN A PALMITATE, CARRAGEENAN, ZINC OXIDE, REDUCED IRON, GUAR GUM, VITAMIN B₆ (PYRIDOXINE HYDROCHLORIDE), VITAMIN B₁ (THIAMIN HYDROCHLORIDE), VITAMIN B₂ (RIBOFLAVIN). **FILLING:** INVERT SUGAR, CORN SYRUP, STRAWBERRY PUREE CONCENTRATE, GLYCERIN, SUGAR, MODIFIED CORN STARCH, SODIUM ALGinate, CITRIC ACID, DICALCIUM PHOSPHATE, METHYLCELLULOSE, NATURAL AND ARTIFICIAL FLAVOR, CARAMEL COLOR, MALIC ACID, RED 40.

INGREDIENTS: CUCUMBERS, WATER, DISTILLED VINEGAR, SALT, CALCIUM CHLORIDE, POLYSORBATE 80, NATURAL FLAVOR, YELLOW 5.

INGREDIENTS: ALMONDMILK (FILTERED WATER, ALMONDS), CANE SUGAR, CONTAINS LESS THAN 2% OF: VITAMIN & MINERAL BLEND (CALCIUM CARBONATE, VITAMIN E ACETATE, VITAMIN A PALMITATE, VITAMIN D2), SEA SALT, NATURAL FLAVOR, SUNFLOWER LECITHIN, LOCUST BEAN GUM, GELLAN GUM, ASCORBIC ACID (TO PROTECT FRESHNESS).

Made with stuff you can pronounce and ingredients you recognize Water, potato extract, tapioca starch, rice flour, high oleic canola/sunflower oil*, inulin, rice starch, psyllium husk, egg white, yeast, sea salt, caraway seeds, xanthan gum, ground caraway seeds, vinegar, sodium bicarbonate, natural enzymes.

CDED aims to increase...

- Fruits and vegetables (soluble fiber, resistant starches)
- Lower fat animal proteins
- Healthy oils
- Complex carbohydrates



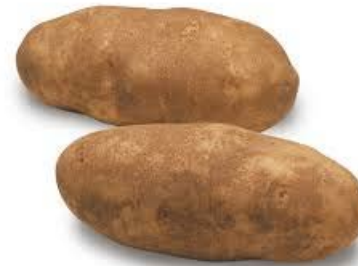
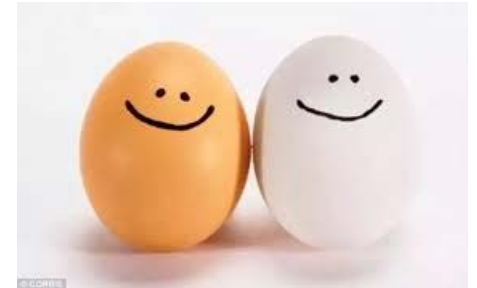
Sigall-Boneh et.al. *Journal of Crohn's and Colitis*, 1205-1212; 2017

CDED - formulas

Standard	Pediasure Boost Kids Essentials
Semi- elemental	Pediasure Peptide Peptamen Junior
Elemental	Neocate Junior Elecare Junior Neocate Splash
High calorie	Pediasure 1.5 Boost Kids Essentials 1.5 Ensure Plus Boost Plus Pediasure Peptide 1.5 Peptamen Junior 1.5
New	Orgain Healthy Kids Kate Farms Pediatric Standard 1.2

CDED – Phase 1 (weeks 1-6)

- 50% calories from formula
- 50% calories from foods
 - Mandatory:
 - 5 oz chicken breast
 - 2 eggs
 - 2 fresh potatoes, peeled
 - 1 apple, peeled
 - 2 bananas



Sigall-Boneh et.al. *Inflammatory Bowel Disease*, 20: 1353-1360; 2014
Modulife training module (mymodulife.com/experts), 2019

Estimated formula intake – weeks 1-6

- WHO equation with stress factor 1.5 - 1.9

Age (years)	Boys (bottles Pediasure/day)	Girls (bottles Pediasure/day)
3-4	3	3
5-8	3.5	3.5
9-10	4	4
11-12	5	4.5
13-14	5.5	4.5
15+	6.5	4.5

CDED Phase 1 - Eat

Eat daily:

Protein foods	Carbohydrate foods	Fruits	
Fresh chicken breast (at least 5 oz) Eggs (2/day)	White potatoes, peeled (2/day)	Bananas (2/day) Apple, peeled (1/day)	

OK to eat daily:

Protein foods	Carbohydrate foods	Fruits	Vegetables
Fresh fish (1x/wk)	White rice White rice noodles (1x/day) Rice wraps White rice flour	Avocado (1/day) Strawberries (1 c/day) Melon (1/4 c/day)	Tomatoes (2/day) Cucumbers, peeled (2/day) Carrot (1/day) Fresh spinach (1 c/day) Lettuce (1 c/day)

CDED Phase 1 - Eat

Condiments OK to eat daily:

Fats	Herbs/spices	Sweeteners	Other
Olive oil Canola oil	Salt Pepper Fresh/single ingredient herbs/spices	Honey (3 Tbsp/day) Sugar (2 Tbsp/day)	Onion Garlic Ginger Lemon/lime juice

CDED Phase 1 - Avoid

Protein foods	Carbohydrate foods	Fruits	Vegetables
Processed meat and fish (chix nuggets, fish sticks, lunch meat, etc) Red meat/beef Soy products Dairy/milk products Non-dairy commercial milks Nuts	Wheat products (cereal, bread, wheat pasta, baked goods) GF commercial products Corn Oat Other flours Legumes	Dried fruit All other fruit	Canned vegetables All other vegetables

CDED Phase 1 - Avoid

Condiments	Beverages	Other
Margarine Commercial salad dressings Syrups (maple, corn) Artificial sweeteners Mixed seasoning packets Others oils and oil sprays	Soda Boxed/bottled juice Other sweetened drinks Gatorade Coffee	Canned products Packaged snacks (potato chips, pretzels, cookies, cakes, etc.) Candy Chocolate

Phase 1 example meal plan

BREAKFAST



Scrambled Eggs



Peeled Apple (1), 1 serving



Banana (1), 1 serving

MORNING SNACK



500 mL prepared ModulenTM
(1), 1 serving

LUNCH



Strawberry Banana Smoothie

AFTERNOON SNACK



Microwave Potato Chips

DINNER



Baked Chicken & Potatoes









Apple Ginger Smoothie

Phase: 1, 2, 3
















Super Green Smoothie

Phase: 1, 2, 3
















Banana Peach Smoothie

Phase: 2, 3















Banana Orange Avocado Smoothie

Phase: 1, 2, 3









Honey Pear Smoothie

Phase: 2, 3









Tropical Smoothie

Phase: 2, 3
















Blueberry Banana Smoothie

Phase: 2, 3










Banana Smoothie

Meal: **Breakfast**
Phase: 1, 2, 3






Apple & Banana Smoothie

Meal: **Breakfast, Lunch**
Phase: 1, 2, 3










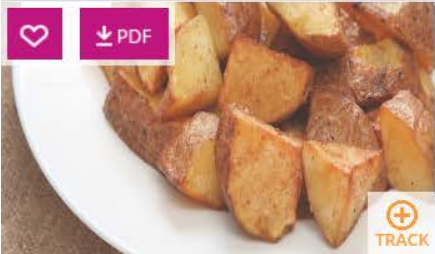





Fried Eggs

Meal: **Breakfast, Lunch**
Phase: 1, 2, 3














Breakfast Potatoes

Meal: **Breakfast**
Phase: 1, 2, 3














Scrambled Eggs

Meal: **Breakfast, Lunch**
Phase: 1, 2, 3














Baked Avocado Eggs

Meal: **Breakfast, Lunch**
Phase: 1, 2, 3












VIEWED



Veggie Hash Browns

Meal: **Breakfast, Dinner, Lunch**
Phase: 1, 2, 3









2 Ingredient Banana Pancakes

Meal: **Breakfast**
Phase: 1, 2, 3











Rice Granola

Meal: **Breakfast**
Phase: 1, 2, 3







Rice Gnocchi

Meal: **Dinner, Lunch**

Phase: 1, 2, 3








Pita Bread

Meal: **Dinner, Lunch**

Phase: 1, 2, 3












Potato and Carrot Fans

Meal: **Dinner, Lunch**

Phase: 1, 2, 3











Potato Salad

Meal: **Dinner, Lunch**

Phase: 1, 2, 3





Potato and Onion Omelet

Meal: **Breakfast, Dinner, Lunch**

Phase: 1, 2, 3






Paprika Baked Potatoes

Meal: **Dinner, Lunch**

Phase: 1, 2, 3














Stir-Fried Chicken and Noodles

Meal: **Dinner, Lunch**

Phase: 1, 2, 3





Tuscan Chicken with Sage

Meal: **Dinner, Lunch**

Phase: 1, 2, 3









Lemon & Garlic Chicken

Meal: Dinner, Lunch
Phase: 1, 2, 3





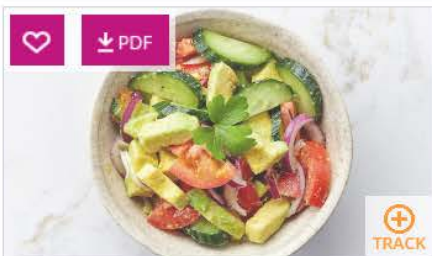








Baked Potato

Meal: Dinner, Lunch
Phase: 1, 2, 3













Summer Salad

Meal: Dinner, Lunch
Phase: 1, 2, 3












Honey Glazed Carrots

Meal: Dinner, Lunch
Phase: 1, 2, 3






Carrot Fries

Meal: Dinner, Lunch
Phase: 1, 2, 3











Pesto Chicken Kebabs

Meal: Dinner, Lunch
Phase: 1, 2, 3














Baked Chicken Breast

Meal: Dinner, Lunch
Phase: 1, 2, 3








Potato Pancakes

Meal: Dinner, Lunch
Phase: 1, 2, 3



Quick Orange Squares

Phase: 1, 2, 3



Pastry Cream

Phase: 1, 2, 3



Sweet Cream Puffs

Phase: 1, 2, 3



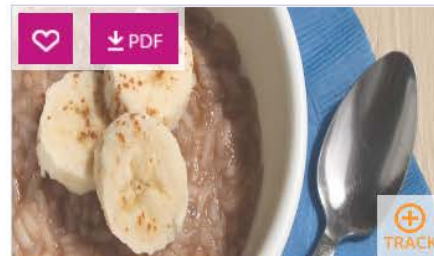
Strawberry Banana Sorbet

Phase: 1, 2, 3



Orange Juice Cake

Phase: 1, 2, 3



Rice Pudding

Phase: 1, 2, 3



Meringues

Phase: 1, 2, 3



Crunchy Cookie

Phase: 1, 2, 3

CDED – Phase 2 (weeks 7-12)

- 25% calories from formula
- 75% calories from foods
 - All fruits and vegetables
 - Red meat, tuna, nuts, beans
 - Bread, quinoa, oatmeal



Sigall-Boneh, et.al. Inflammatory Bowel Disease, 2014
Modulife training module (mymodulife.com/experts), 2019

Estimated formula intake – weeks 7-12

Age (years)	Boys (bottles Pediasure/day)	Girls (bottles Pediasure/day)
3-4	1.5	1.5
5-8	2	2
9-10	2	2
11-12	2.5	2.5
13-14	3	2.5
15+	3	2.5

CDED Phase 2 - Eat

Eat daily:

Protein foods	Carbohydrate foods	Fruits	
Fresh chicken breast (at least 5 oz) Eggs (2/day)	White potatoes (2/day)	Bananas (2/day) Apple (1/day)	

OK to eat daily:

Protein foods	Carbohydrate foods	Fruits	Vegetables
Fresh fish (1x/wk) Lean red meat (1x/wk) Tuna (1 can/wk) Almonds, walnuts, cashews (1/4 c/day) Lentils, peas, chickpeas, beans (1/2 cup dry/day)	White rice White rice noodles (1x/day) Rice wraps White rice flour Sweet potato (1/day) Whole grain bread (1 sl/day) Quinoa Oatmeal (1/2 c/day)	All*	All**

CDED Phase 2 - Eat

Condiments OK to eat daily:

Fats	Herbs/spices	Sweeteners	Other
Olive oil Canola oil	Salt Pepper Fresh/single ingredient herbs/spices	Honey (3 Tbsp/day) Sugar (2 Tbsp/day)	Onion Garlic Ginger Lemon/lime juice Baking soda/powder Raw tahini (2 Tbsp/day)

CDED Phase 2 - Avoid

Protein foods	Carbohydrate foods	Fruits	Vegetables
Processed meat and fish (chix nuggets, fish sticks, lunch meat, etc) Soy products Dairy/milk products Non-dairy commercial milks	Wheat products (cereal, wheat pasta, baked goods) GF commercial products Other flours	Dried fruit	Canned vegetables

CDED Phase 2 - Avoid

Condiments	Beverages	Other
Margarine Commercial salad dressings Syrups (maple, corn) Artificial sweeteners Mixed seasoning packets Others oils and oil sprays	Soda Boxed/bottled juice Other sweetened drinks Gatorade Coffee	Canned products Packaged snacks (potato chips, pretzels, cookies, cakes, etc.) Candy Chocolate

Phase 2 example meal plan

BREAKFAST



Spinach & Tomato Scramble



Home Fries



MORNING SNACK



Apple Ginger Smoothie



LUNCH



Honey Pear Smoothie



DINNER



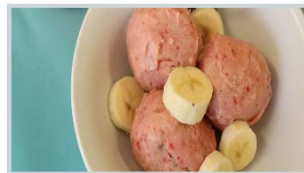
One Pan Garlic Herb Chicken & Potatoes



Sautéed Zucchini



EVENING SNACK



Strawberry Banana Sorbet





Spinach Side Salad

Meal: **Dinner, Lunch**

Phase: 1, 2, 3



Banana Mint Salad

Meal: **Dinner, Lunch**

Phase: 1, 2, 3



Quinoa Salad

Meal: **Dinner, Lunch**

Phase: 2, 3



Summer Salad

Meal: **Dinner, Lunch**

Phase: 1, 2, 3



Chopped Salad

Meal: **Dinner, Lunch**

Phase: 2, 3



Chickpea Tuna Salad

Meal: **Dinner, Lunch**

Phase: 2, 3



Quinoa Oatmeal

Meal: **Breakfast**

Phase: 2, 3



Lentil and Rice Patties

Meal: **Dinner, Lunch**

Phase: 2, 3



Loaded Sweet Potatoes

Meal: **Dinner, Lunch**

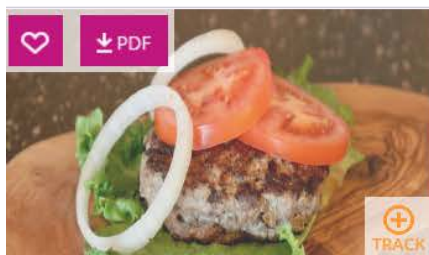
Phase: 2, 3



Honey Almond Granola

Meal: **Breakfast**

Phase: 2, 3



Hamburger

Meal: **Dinner, Lunch**

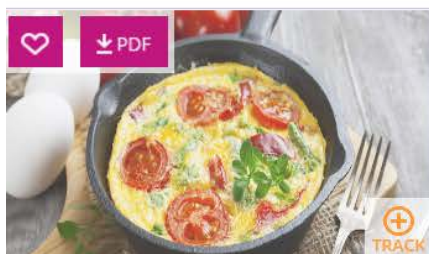
Phase: 2, 3



Chili

Meal: **Dinner, Lunch**

Phase: 2, 3



Summer Vegetable Frittata

Meal: **Breakfast, Dinner, Lunch**

Phase: 2, 3



Pesto Chicken Kebabs

Meal: **Dinner, Lunch**

Phase: 1, 2, 3





Banana Bread

Phase: 2, 3



Almond Butter

Phase: 2, 3



Salad Skewers

Phase: 2, 3



Hummus

Phase: 2, 3



Apple & Honey

Phase: 1, 2, 3



Apple Cinnamon Chips

Phase: 1, 2, 3



Rosemary Garlic Rice Crackers

Phase: 1, 2, 3



Rice Granola

Meal: **Breakfast**

Phase: 1, 2, 3



CDED Phase 3 - maintenance

- 25% calories from formula 7 days per week
- No mandatory foods
- Eat “on plan” 5 days per week
- Eat “free” meals as desired 2 days per week
 - Homemade preferred
 - Avoid binging
- One restaurant meal = one less day to eat “free” foods
- Always avoid soda, fast food, processed meats

CDED Phase 3 - Eat

OK to eat

Protein foods	Carbohydrate foods	Fruits	Vegetables
Fresh chicken breast Eggs Fresh fish Lean red meat (1x/wk) Tuna Almonds, walnuts, cashews Lentils, peas, chickpeas, beans Yogurt (unflavored Greek pref., 1/day) *Hard cheese (cheddar, swiss, Colby, 1 oz/day)	White potatoes (2/day) White rice White rice noodles (1x/day) Rice wraps White rice flour Sweet potato Whole grain bread (2 sl/day) Pasta (1 cup/day, in place of bread) Quinoa Oatmeal	All	All

CDED Phase 3 - Eat

Condiments OK to eat:

Fats	Herbs/spices	Sweeteners	Other
Olive oil Canola oil Butter (grass fed)* Ghee*	Salt Pepper Fresh/single ingredient herbs/spices	Honey (3 Tbsp/day) Sugar (2 Tbsp/day)	Onion Garlic Ginger Lemon/lime juice Baking soda/powder Raw tahini (2 Tbsp/day) Coffee (1 c/day, brewed)

CDED Phase 3 - Avoid

Protein foods	Carbohydrate foods	Fruits	Vegetables
Processed meat and fish (chix nuggets, fish sticks, lunch meat, etc) Soy products Non-dairy commercial milks	GF commercial products	Dried fruit	Canned vegetables
Condiments	Beverages	Other	
Margarine Commercial salad dressings Syrups (maple, corn) Artificial sweeteners Mixed seasoning packets Others oils and oil sprays	Soda Boxed/bottled juice Other sweetened drinks Gatorade	Canned products Packaged snacks (potato chips, pretzels, cookies, cakes, etc.) Candy Chocolate	

CDED Phase 3 – example meal plan

- Breakfast – cereal with formula as “milk”; homemade pancakes or waffles; fruit
- Lunch – Grilled cheese sandwich with side salad or veggies; yogurt
- Dinner – homemade pizza with veggie toppings

ModuLife website and app

- mymodulife.com/experts
 - mymodulife.com
 - **Modulife app (Apple and Android)**
-
- Cooking demos (cook chicken, make French fries, smoothies)
 - Meal planner
 - Recipes
 - Message an Expert
 - Videos explaining the diet/phases/mandatory foods



Patient feedback – Modulife platform

- Recipes are good
- App start date did not line up with actual start date (no option to adjust)

How to educate

- Removes foods that may be worsening disease
- Can decrease inflammation and cause healing
 - May change bacteria and prevent them sticking to intestines
- Increased fruits/vegs and fewer processed foods will help you be healthy
 - NOT “no more processed foods for you ever again!”
 - This is a balanced diet
- Diet is like a drug – works well for most, may not work for all
- Diet changes every 6 weeks
- “If it is not on the list, it does not exist.”



Pediatric Patient and Parent Experiences With Crohn's Disease Exclusion Diet: Barriers and Facilitators to Implementation



Angela Sandell, MD, Debra Bogen, MD, David Keljo, MD, PhD, Stacey Zettle, RD, Judy Chang, MD, Sandra Kim, MD

- Pediatric patient and family barriers and facilitators to CDED implementation
- Subject characteristics
 - 18 dyads
 - 78% new onset disease
 - Average patient age: 14.7 yr
 - Average weeks attempted: 9
 - ~90% parents had completed some college and working full time
 - Average household income
 - 33% = \$50-75k
 - 27% = \$75-100k
 - 27% = >\$100k
 - Pittsburgh, PA = \$58k

NASPGHAN, October 2019, Chicago, IL



Pediatric Patient and Parent Experiences With Crohn's Disease Exclusion Diet: Barriers and Facilitators to Implementation



Angela Sandell, MD, Debra Bogen, MD, David Keljo, MD, PhD, Stacey Zettle, RD, Judy Chang, MD, Sandra Kim, MD

Barriers

- Financial
- Difficulty conceptualizing diet
- Poor cooking skills
- Social isolation
- Patient/parent frustration
- Time consuming

Facilitators

- Resilience to challenge
- Empowerment in disease tx
- Motivation based on improvement
- Cooking/organizational creativity
- Food literacy



Thank you!