

CELIAC DISEASE 2020
VISUALIZING A PATH TO
ADVANCE CELIAC RESEARCH
& DEVELOP A CURE

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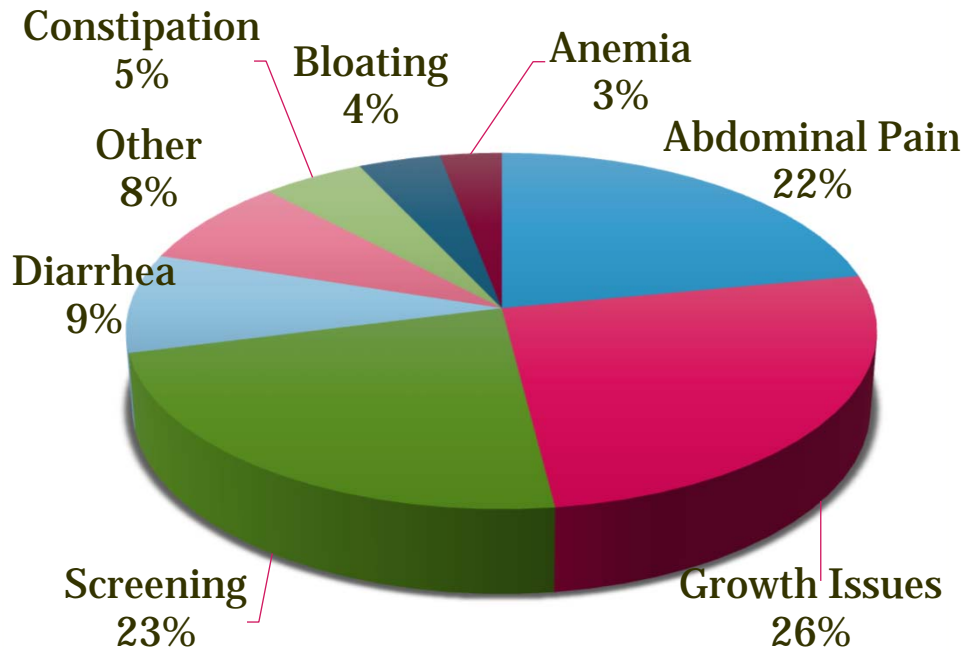
The Magnitude of Celiac Disease

- Celiac disease affects roughly 3 million Americans.
- In the past five years, CHOP cared for 10,126 patients with Celiac Disease & Gluten Related Disorders.
- In 2019, the Center for Celiac Disease followed over 1096 patients with celiac disease in their journey.

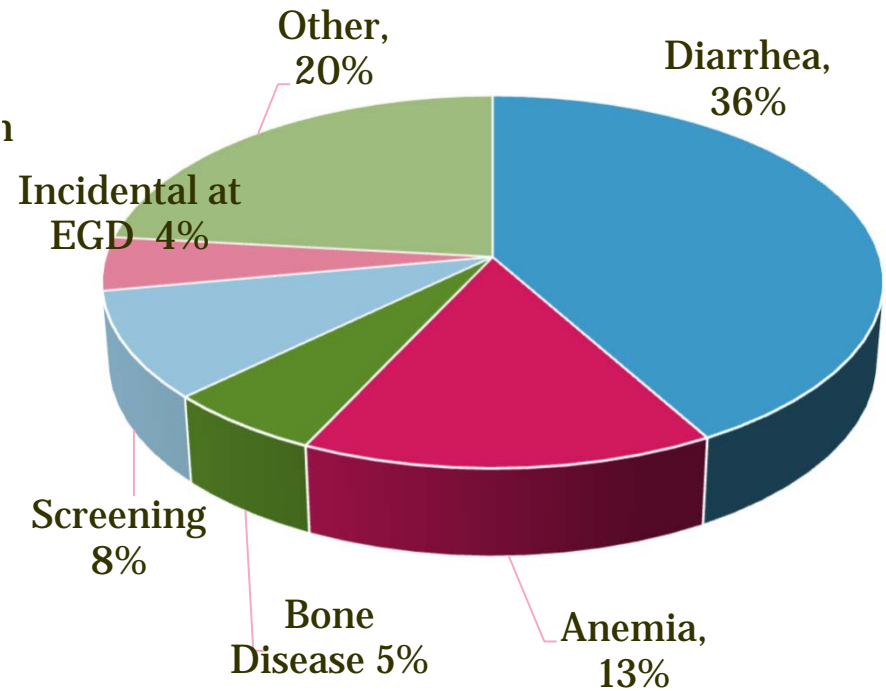


Findings from the Pediatric and Adult Endoscopy Study

**Pediatrics, %
(n=244)**



**Adults, %
(n=1499)**



Singh A, Green PH et al 2019

MAJORITY REMAIN UNDIAGNOSED

- Delays or missed diagnosis of celiac disease may lead to comorbidities, cancer and higher mortality rates (4x the risk of death)
- Reversing the intestinal damage and villous atrophy that occur can take exponentially longer
- Early detection and treatment of celiac disease lowers medical costs and result in health care costs savings.

THE BURDEN OF CELIAC DISEASE

- Psychological vulnerability & increased anxiety/depression rates in celiac disease
- Gluten-free diet can cause social isolation, economic burden and poor quality of life
- 1 in 5 children don't heal on the gluten-free diet

SOCIAL ANXIETY & ISOLATION^{3,4}

49% of children with celiac disease exhibit anxiety, including social and separation anxiety, physical symptoms, excessive worry and pessimism.

37% of women with celiac disease have symptoms of depression.



SACRIFICING MAJOR LIFE EXPERIENCES^{1,2}

49% have sacrificed life experiences because of their gluten-free diet and/or celiac disease.

60% of gluten-free college students report becoming sick from dining on campus, and 42% report missing class as a result of gluten exposure.

ACCIDENTAL EXPOSURE⁵

70% remain exposed to gluten while on the gluten-free diet, putting their long-term health at risk.



REPRODUCTIVE HEALTH^{7,8}

Women with celiac disease are significantly more likely to miscarry or give birth prematurely than other women.

Women with unexplained infertility are **SIX TIMES MORE LIKELY** to have celiac disease.

DAILY BURDEN^{9,10}

80% of people with celiac disease report having difficulty staying strictly gluten-free. Additionally, people with celiac disease report a higher negative impact on their quality of life (also called burden of disease) than do people with Type 2 diabetes, congestive heart failure, hypertension, and inflammatory bowel disease.

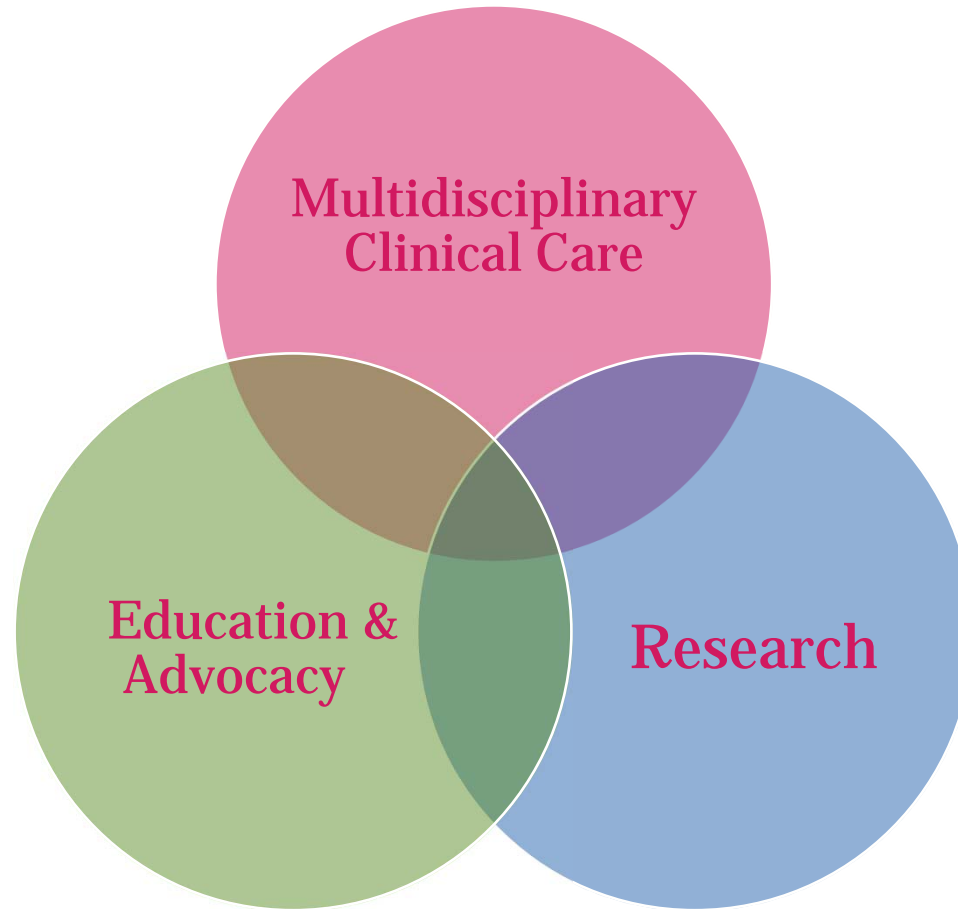


BRAIN FOG⁴

89% of patients experience this symptom after gluten exposure. Some describe it as difficulty concentrating, forgetfulness and grogginess.

Infographic images cited from *Beyond Celiac*

3 Pillars to Success Against Celiac Disease



WHAT ARE THE HURDLES TO A CURE?

- **Funding is Essential**
 - Federal funding in celiac disease has been poor
 - Build a biorepository and infrastructure for translational research
 - Sequencing (metabolomics, stem cell organoid research) = \$\$\$
- **Commitment to Scientific Research**
 - Dedicated Celiac Disease clinicians, research staff & leadership
 - Expertise in effective human intestinal models
 - Collaborative research & a robust national registry
- **Patient Participation**
 - Volunteers of all age groups - pre & post gluten-free diet changes
 - Specimen collection

SECURE FUNDING FOR CELIAC DISEASE RESEARCH WITH AN EMPHASIS IN PEDIATRICS

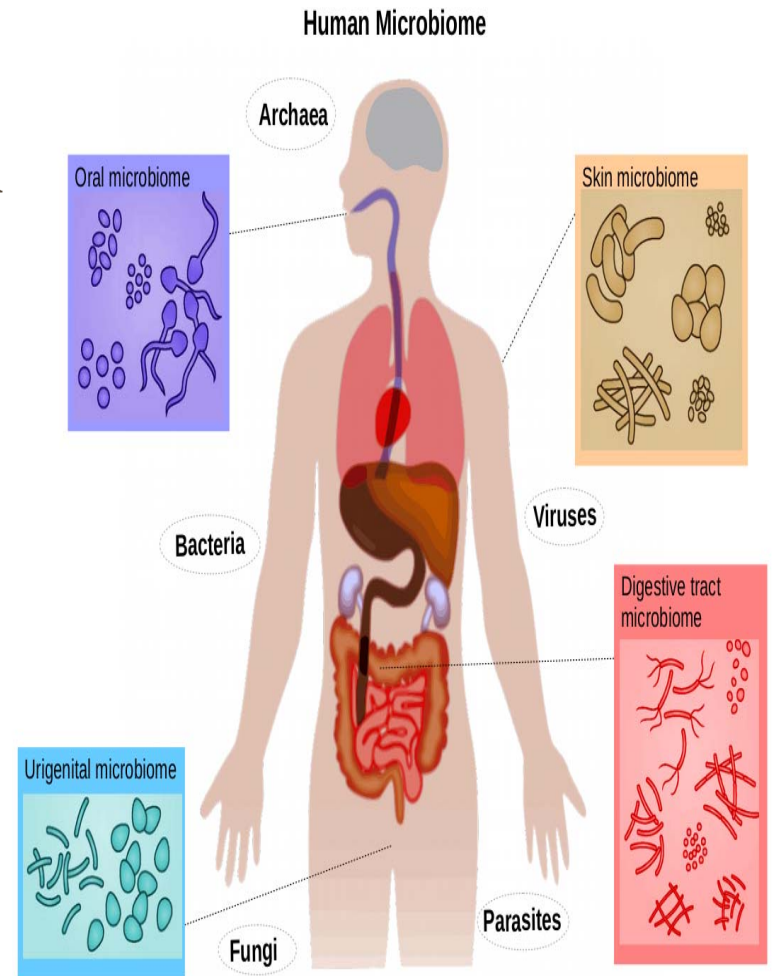
From developing groundbreaking treatments for chronic diseases, to saving babies who are born prematurely, pediatric research has increased the ability to live healthier lives and grow into productive adults.

Primary and secondary celiac disease prevention is an essential public health goal.

Novel therapeutics will be better evaluated in native intestinal cell models and those with few other comorbidities and drug interactions.

ED FWHUID O#DIQ NV#D Q G #IIHFWR I# P LFUR EIR P H#R Q #F HOLD F #G LVHD VH

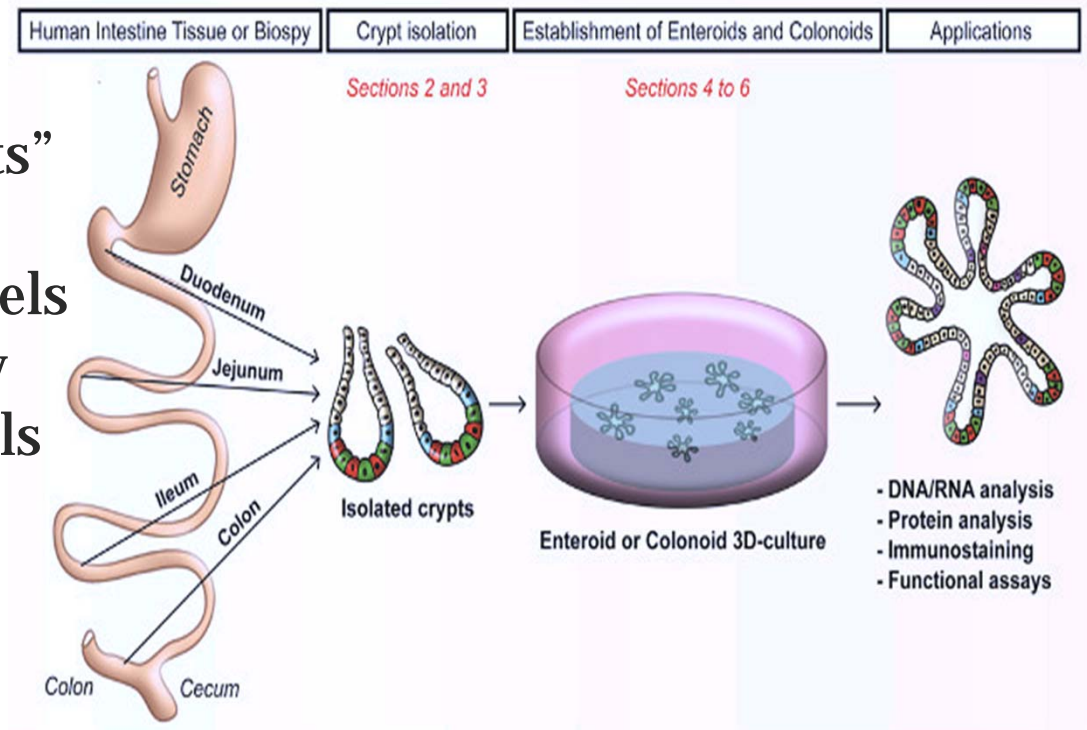
- The microbiota of infants genetically predisposed (HLA-DQ-2/8) to celiac disease differs from that of non-predisposed children
- Antibiotics early in life and certain infections (e.g. reovirus) increase the risk for developing celiac disease
- Celiac patients have distinct gut bacteria at diagnosis (\uparrow *Bacteroides*, \uparrow *Escherichia coli*), that normalizes after starting gluten-free diet



PennCHOP
MICROBIOME PROGRAM

INTESTINAL 3-D MODELING IN CELIAC DISEASE & IMMUNOTHERAPY

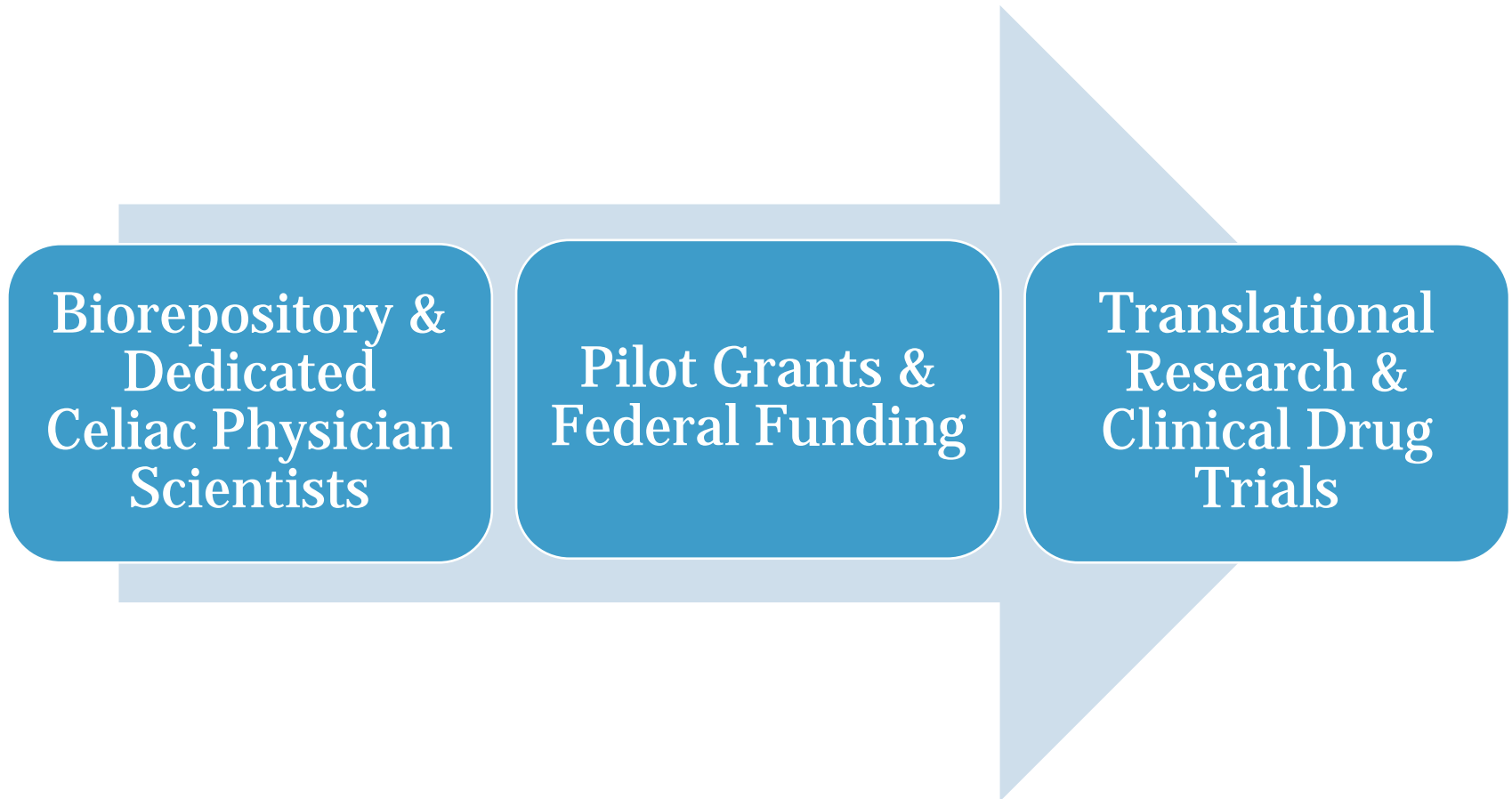
- CHOP scientists can study genomics and immunology changes in the intestinal cell environment using “mini guts”
- These human intestinal models have potential to identify key signals and alter immune cells with gluten exposure.
- This may identify novel cell therapies and patients for immunotherapy



SAVING CHILDREN'S LIVES

- Children's Hospital of Philadelphia is one of the nation's largest recipients of NIH funding in children's hospitals.
 - In 2019, our Research Institute spent over \$360 million on research
 - \$147 million (40%) of funding was in form of federal research dollars
- With this support, CHOP has made breakthroughs in treatment and innovation that changed lives in so many pediatric cancers and chronic diseases which would not be possible. Its time we do this in celiac disease too.

FROM SCIENTIFIC DISCOVERY TO CURE



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THANK YOU FOR YOUR SUPPORT!!

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<https://www.chop.edu/centers-programs/center-celiac-disease>