



Barbara Davis Center for Diabetes  
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



Children's Hospital Colorado

# Screening for T1D and Celiac Disease: The US Perspective

**Edwin Liu, MD**

Colorado Center for Celiac Disease

# Disclosures

- **Takeda:** Advisory board
- UpToDate – celiac disease chapter

\*These activities are not related to any of the data we will be presenting today

# Screening for Celiac Disease

## US Preventive Services Task Force Recommendation Statement

US Preventive Services Task Force

- In 2017, USPSTF found **inadequate evidence** on the harms of screening for or treatment of celiac disease.
- Concluding that the **current evidence is insufficient** to assess the balance of benefits and harms of screening for celiac disease in asymptomatic persons.

# Current recommendations on screening for CD

- No GI group at present recommends screening of the general population
- Screening can be targeted based on:
  - Concerning symptoms
  - Higher risk group

Recommendations fail to recognize that most CD cases are asymptomatic or subclinical, and most do not have a known risk factor.

American College of Gastroenterology 2023  
ESPGHAN 2020, 2022  
AGA 2019

World Gastroenterology Organization 2017  
NASPGHAN 2004, 2016

National Institute for Health and Care Excellence (NICE) 2015

# Why mass screening?

- Fits most of the WHO criteria and most cases remain undiagnosed:
  - Common
  - Testing is simple
  - Culturally acceptable
  - There is a treatment
  - Clinical detection is difficult without screening
  - We lack data on whether nontreatment can lead to severe long-term health complications
  - We lack sufficient data on cost effectiveness

# The data to support mass screening for CD is growing

- Health outcomes:
  - Individuals with screening-identified CD may have a similar disease severity to clinically-identified CD
  - There are overall health benefits in treating screening-identified CD with the GFD
- Quality of life:
  - QOL in screened patients is not different from controls or even lower
- GFD had a positive impact on:
  - Health and psychological well being
  - No decrease in QOL, or improved QOL

US data is sparse but available data consistent with prior findings in Europe with regards to improved health, QoL and adherence – ASK study

Stahl et al. Clin Gastroenterol Hepatol 2024

effective, especially in children (no data yet)

# Mass screening for childhood celiac disease and diabetes

## PI: Marian Rewers

303-724-1ASK | ASKhealth.org  
1 2 7 5

Autoimmunity Screening for Kids



A SIMPLE <sup>FREE</sup> TEST TO DETECT  
**Childhood Diabetes + Celiac**

Approved by the Colorado Multiple IRB #14-0553 Marian J Rewers, MD, PhD



### Sponsors



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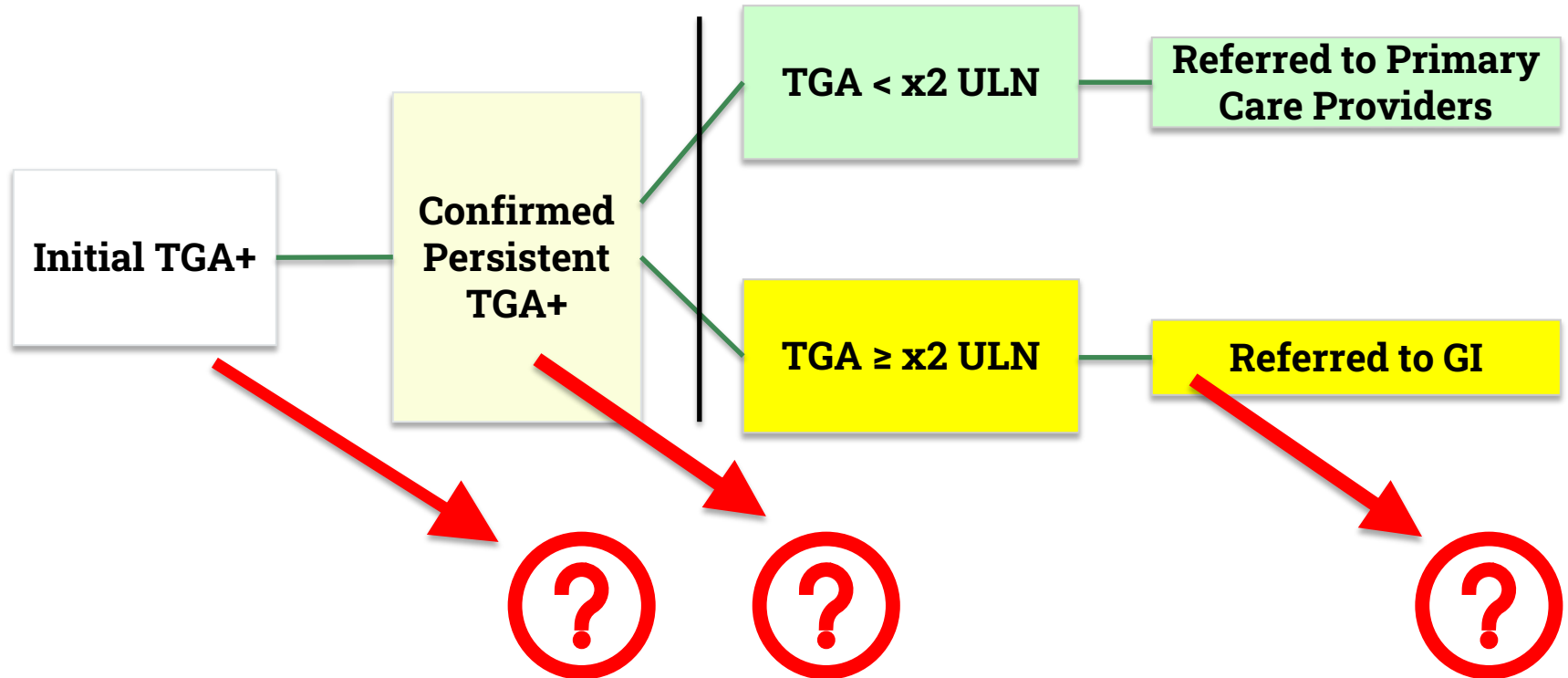
- ▶ ASK is a *free* population screening initiative for early type 1 diabetes and celiac disease
- ▶ Find early signs of diabetes or celiac in children—before they get very sick
- ▶ Assess the feasibility of universal screening
- ▶ Increase public awareness of type 1 diabetes and CD

# Pathway Based on TGA testing

Initial Screen

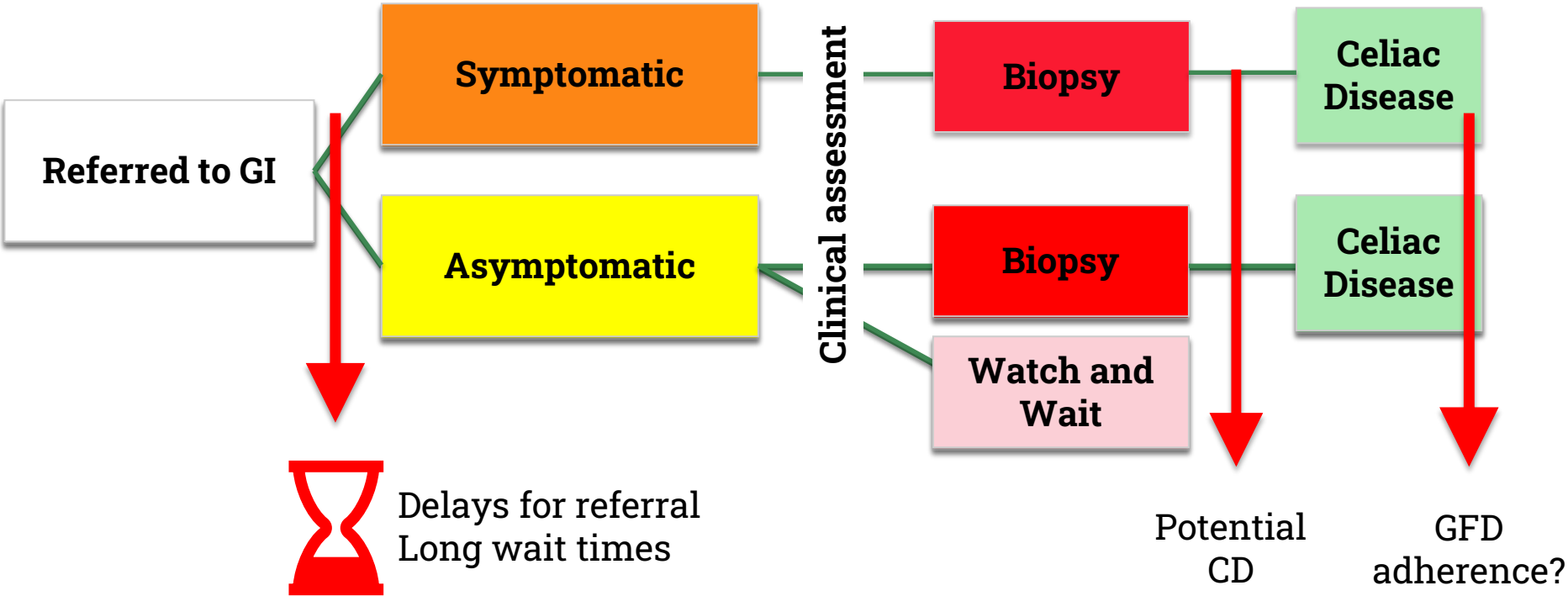
Confirmation

Follow-up





# Celiac Center Follow Up



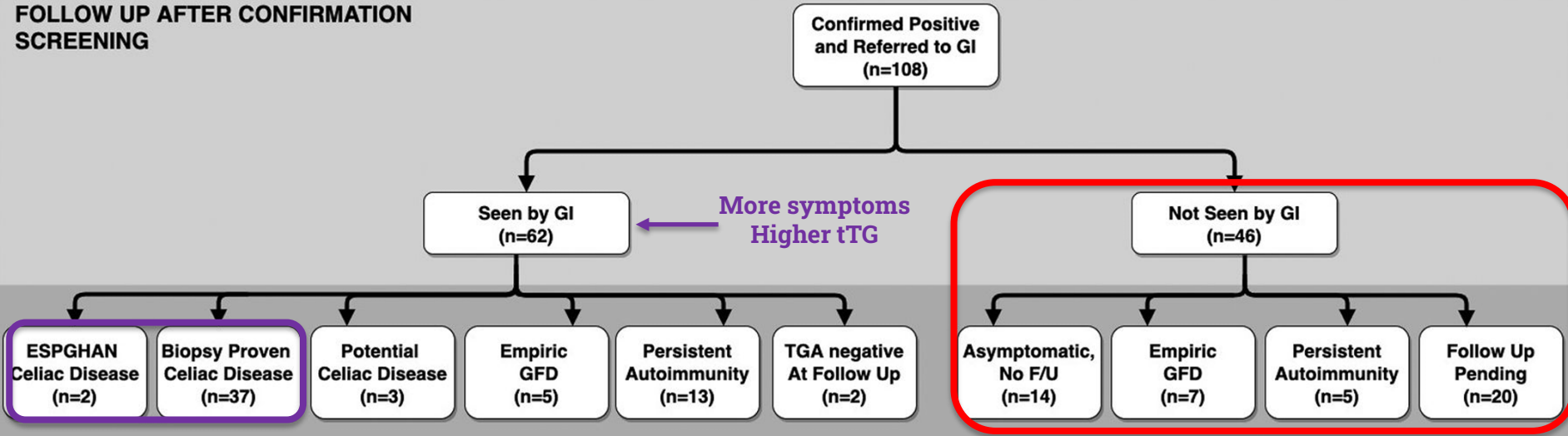
# ASK: the first 10,000 screened

Projected TGA+ prevalence of 1.9%

- 51.6% Hispanic (vs 21.7% in Colorado)
- Of all TGA+ cases, 90% did not have a family history of celiac disease or T1D

- Symptoms not a predictor of TGA+
  - 30% TGA positive have symptoms
  - 30% TGA negative have symptoms

## FOLLOW UP AFTER CONFIRMATION SCREENING



# Attitudes and behaviors surrounding CD screening

## **Families who came to see GI were:**

- Generally amenable to endoscopy
- Don't like the long wait times to see GI
- Amenable to GFD if CD is diagnosed – with or without symptoms

## **We are learning about the barriers to follow-up care - not all saw GI**

- There was a tendency for some families to accept a CD diagnosis without further testing or endoscopy
- Some did not follow-up because their PCP discouraged it
- Some declined follow-up because their child was asymptomatic
- The problem of access to a provider in a timely fashion

## **From the biased GI perspective:**

With a positive test, a CLINICAL referral to GI for further management is appropriate.

Importance of integration of the screening process into the system

- tests results readily visible by providers
- test results familiar to providers
- able to place referrals directly to GI

# **In the US, the CD lags behind T1D in terms of readiness for mass screening**

- Growing US data on benefits and potential harms of CD screening, but still lack cost data
  - At what point is the data enough?
- We need to better understand general public and provider attitudes about mass screening
  - If they don't buy into it, they aren't going to do it (regardless of the data)
- Screening is just half the battle - the other half is knowing what to do with a positive test
  - We're responsible for them, how do we get them in to be seen?

# Can screening for both diseases help us advance mass screening?

**YES**

- Shared screening costs
- Could result in increased public awareness
- Could increase screening acceptance

# Priorities and challenges



- Best practices for managing a positive screening test
  - Includes timely access to care
  - Who will take care of all these kids?
- Better understanding of attitudes towards screening
- Better understanding of barriers
- Cost studies
- Start the conversation with stakeholders

Patient groups  
Health care providers  
Professional healthcare associations  
General public

Payors  
Industry (diagnostics and therapeutics)  
Policy makers  
Government agencies

# Acknowledgements

## ASK team

Marian Rewers, P.I.

Cristy Geno Rasmussen

Kim Bautista

Judy Baxter

Fran Dong

Daniel Felipe-Morales

Brigitte Frohnert

Tricia Gesualdo

Michelle Hoffman

Xiaofan Jia

Rachel Karban

Maricela Munoz

Holly O'Donnell

Meghan Pauley

Flor Sepulveda

Crystal Silva

Kimber Simmons

Andrea Steck

Iman Taki

Kathy Waugh

Joey Wong

Liping Yu

Brett McQueen

Rick Bacher

David Roth

Laura Pyle

Jill Norris

*And also the thousands of children and their families participating as "Junior Scientists" in these long-term birth cohort and screening studies*

## The DAISY and the TEDDY Study Groups

- The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)
- National Institute of Allergy and Infectious Diseases (NIAID)
- National Institute of Child Health and Human Development (NICHD)
- National Institute of Environmental Health Sciences (NIEHS)
- Juvenile Diabetes Research Foundation (JDRF)
- Centers for Disease Control and Prevention (CDC)

## Children's Hospital Colorado

Edwin Liu, Marisa Stahl

Mary Shull, Pooja Mehta, Ed Hoffenberg,

Monique Germone,

Sadie Nagle, Erin Sandene, Kevin Carney,

Amy Lewis, Chrisann Karr, Sondra Valdez,

Chris Martin, Alison Brent

