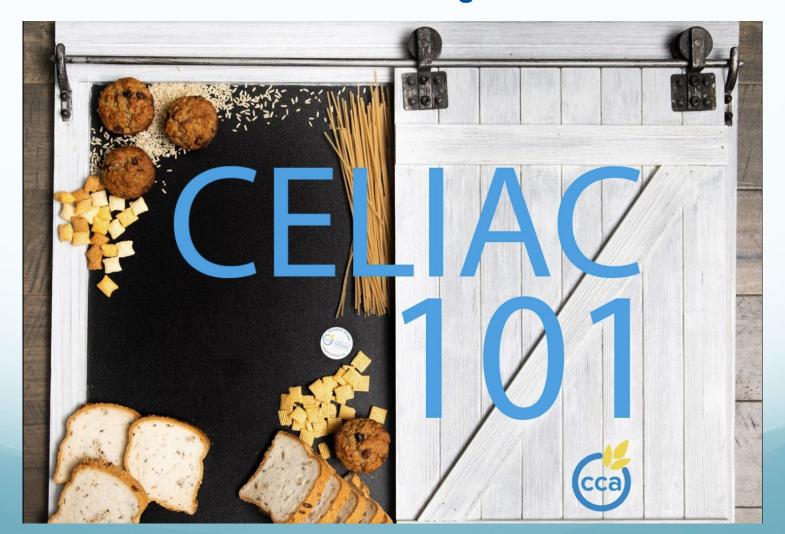
### Calgary Celiac Association Celiac 101 Information Night



### About Us & Disclaimer

#### Meet our volunteers

Some of us are celiac, some of us love a celiac (or more than one) and we are here to help support your celiac journey

We are part of the **Calgary Celiac Association**, a sub group of the **Education Committee** and a chapter of **Celiac Canada**.

Memberships are valuable for events! \$10/yr gets you early access!

Purchase your membership on calgaryceliac.ca

- Membership also includes local business discounts
- Disclaimer: Please note that the volunteers at Celiac 101 and the information in this presentation are for informational purposes and should not be taken as direct medical advice for your individual case/needs, always consult a medical practitioner

### Celiac 101

Introductions

Health and Celiac Disease

Resources

**Daily Living** 

Social Life

Q & A



### What is Celiac Disease?

Genetic Autoimmune Disorder

> HLA DQ2 HLA DQ8

Gluten Ingestion = Immune Reaction Damage to Villi

Malabsorption of Nutrients

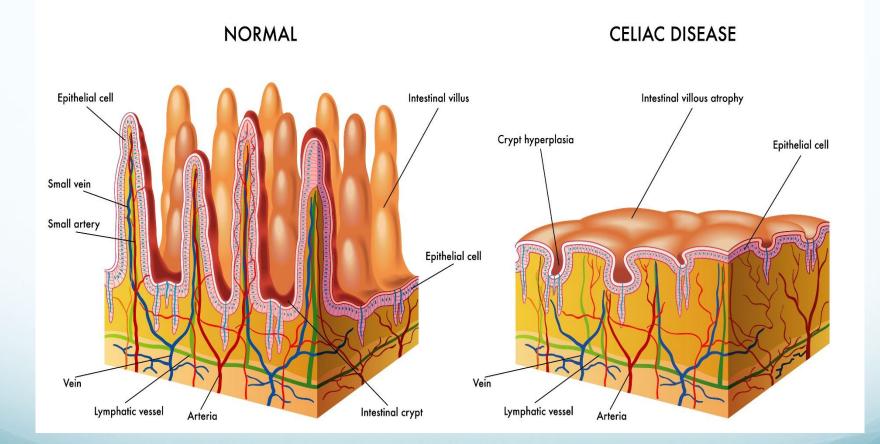
Symptoms

Secondary Autoimmune Disease

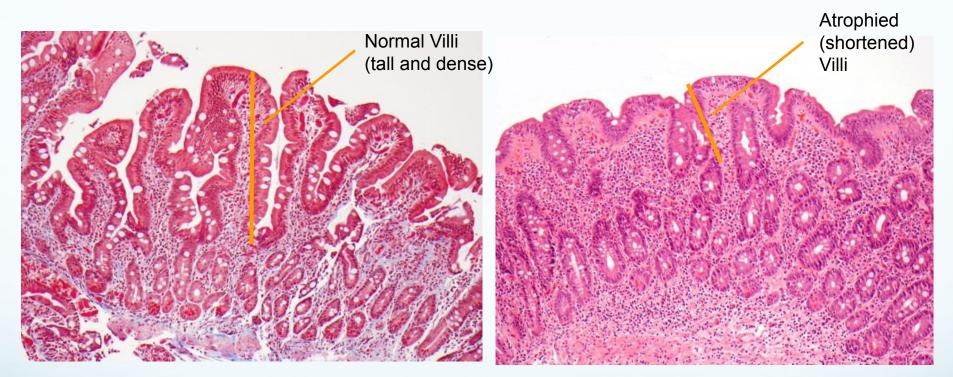
.... Lymphoma

Dermatitis Herpetiformis

# Villi - Normal vs. Celiac



# Villi - Microscopic View



#### **Normal Villi**

#### Villi of Celiac Patient

### Celiac Disease: A TRIAD Genetics --> Exposure --> Trigger

Genetic Predisposition
HLA-DQ2 & HLA-DQ8

Gluten Ingestionresulting immune response

Possible Triggers
Hormonal changes, growth

- Gut microbiome
- Major life events



### **Celiac Disease Facts**

- □ The onset can occur at any time
- It is a lifelong disease with NO cure
- □ Celiac disease affects ~ 1% of the population
  - □ May be as high as 20% in certain populations



- Highly under diagnosed, only 1/146 people with Celiac disease has been diagnosed.
- Chance of developing Celiac disease in relatives
  - $\Box$  1<sup>st</sup> degree is 5 20%
  - $\Box$  2<sup>nd</sup> degree is 5 8%
- On average it takes 4-10 years before a correct diagnosis is made
- A strict GF Diet is the current treatment to manage Celiac disease and DH

Prepared by Acalgan Caling, for your health is a key part of any chronic condition

# **Celiac Disease Symptoms**

- There are over 300 symptoms that can impact any part or organ of the body
  - □ Gastrointestinal (classical Celiac disease)
  - Other organ systems (atypical or silent Celiac disease)
  - □ The brain/mental health/behavior (neuro-Celiac disease)
- Symptoms and intensity vary among each person and can change over time



### (Mis)Diagnosis

- Celiac disease symptoms overlap many other conditions often leading to a <u>misdiagnosis</u> of Crohn's, Colitis, Lupus, IBS, Unexplained Infertility, Fibromyalgia, Anemia etc.
- A few examples of associated conditions that Celiac patients also have:
  - □ Type 1 Diabetes (4 8 %)
  - □ Autoimmune Thyroid Disease (2 5 %)
  - Down Syndrome (2 5 %)
  - Unexplained Infertility (4 -8 %)
  - Multiple Sclerosis (11%)

### What do I do now?

- 1) Continue to eat gluten If Celiac is SUSPECTED but unconfirmed
- 2) Complete Blood Test
- 3) Complete Intestinal Biopsy
- 4) Stop eating gluten Celiac Confirmed
- 5) Review current medications and supplements\* Acute/singular tx vs. long term chronic meds
- 6) Complete Nutritional Counselling with a registered dietician
- 7) Re-organize your kitchen, educate family members sharing your kitchen

Prepared Brcagary Cefier Association scan

### What do I do now? cont'd

- 9) Encourage 1<sup>st</sup> (2<sup>nd</sup>) degree relatives to be tested
- 10) Continue or begin to exercise
- 11) Join support groups such as the Canadian Celiac Association and/or online reputable groups
- 12) Repeat blood work within 3 to 6 months after diagnosis; annually after that
- Repeat intestinal biopsy if symptoms do not improve after 6-12 months, or screen for other associated disorders
  - Refractory Celiac Disease

# **Gluten Associated Disorders**

	Celiac Disease	Non Celiac Gluten Sensitivity	Wheat Allergy
Autoimmune	*		
Intolerance		*	
Allergy			*
Genetic	*		
Dermatitis Herpetiformis	*		
Villi Damage	*		
IBS Symptoms	*	*	*
~% of pop.	1	0.6 - 6	0.1
Testing	*		*

### **Current Research**

Unfortunately, there are no drugs approved to treat or cure Celiac Disease.



Research is ongoing, and there are a number of active clinical trials.

One of the best ways to help is to volunteer for a trial if you are able to, or participate in research studies online. Please see some of the links below for further information.

www.beyondceliac.org www.celiac.org www.clinicaltrials.gov



Please refer to "Newly Diagnosed Resource Road Map"

for further information.



### Learn to Read a Label for Gluten in 3 Easy Steps



All packaged food products have an ingredient list that lets us identify if the food contains gluten. There may be visible claims and symbols as well to help us identify gluten.

#### By reading labels, we can recognize if the food is safe to eat.

2

3

#### Steps

Flour, Canola Oil,

Bicarbonate, Baking

Contains: Milk, Wheat. 4

Papain, Amylase,

Natural Flavour.

May contain: Soy.

Ingredients: Enriched Wheat

Glucose-fructose, Modified Milk Ingredients, Salt, Ammonium

Sugar,

Soda.

Protease.

#### Read the Ingredients

In the ingredients, check for B.R.O.W (barley, rye, oats, wheat). If you see any of these ingredients, the product contains gluten and is not safe for those with celiac disease.

#### Check the 'Contains Statement'

If the food contains a priority allergen, it will be stated here. The two allergens that contain gluten are wheat and triticale. If you see either of these ingredients, it contains gluten.

Does this food contain gluten? Yes. It contains wheat.

#### Check the 'May Contain Statement'

These statements are not regulated, and therefore, optional; not all ingredient lists will have one. If present, check for B.R.O.W ingredients.

If no gluten-containing ingredients are present on the label, the product is gluten-free. However, there are some exceptions.

#### Exceptions

Some foods are at high risk of gluten cross-contamination. The following products should only be consumed if they have a gluten-free claim.

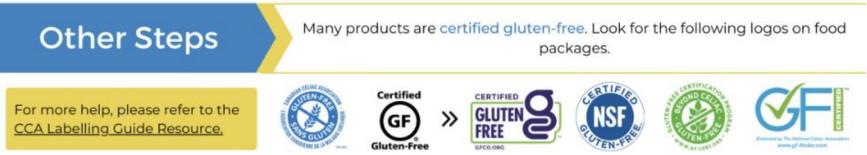


Prepared by: Calgary

- Most grains, like oats, quinoa, sorghum, amaranth and buckwheat
- Pulses, like beans, peas and lentils
- All flours made from these grains and pulses
- CerealsPastas
- Flax seeds
- Hemp seeds
- Baked products

## Daily Living – Shopping

- The Gluten Free Certification Program is the only Canadian voluntary certification program, manufacturer's are listed on the CCA website
- Recheck "ingredient list" and "labels" of food every time you purchase them
- "When in doubt .... go without"
- Avoid Bulk Bins
- Prepackaged foods not required to include allergy label i.e. mini roasted chickens





# ?

- In Canada, "Gluten free" means that the product contains less than 20 parts per million (20ppm)
- For a product to have a "Gluten Free" certification it must be tested to have less than 20ppm
  - Some products may have a "gluten free" claim, but are not certified
  - High risk products: Corn meal/flour, pulses (lentils), grains and oats

# Daily Living – Kitchen

#### It is important to prevent cross contact of GF food by gluten containing foods

- Airborne particles of gluten containing foods can contaminate GF foods.
  - Use boldly labelled, separate, air tight containers
- Designate a separate cupboard (top shelves) and preparation area in your kitchen for GF foods
- Designate a specific area for gluten free prep, like toasters

### Daily Living – Cooking

- Always wash hands before handling GF products
- Prepare GF food before other food
- Thoroughly clean all food preparation surfaces, cooking surfaces and cooking utensils
- Use individual portions and/or squeeze bottles for condiments
- Prevent cross contact when using:
  - Thermometers, BBQ grill and cooking utensils
- Use fresh water for boiling, poaching and steaming

Use a dedicated GF toaster or toaster bags when sharing a Prepared by Calgary Celiac Association

### Daily Living – Non-food Items

**Gluten protein cannot pass through the skin.** 

- Any food or non-food item may contain gluten
  - Medication, vitamins and supplements
  - Lipsticks, lip gloss, chap stick
  - □ Mouthwash, toothpaste, hairspray, hand sanitizer
  - Play-doh, paper mâché, straws
  - Personal hygiene products (hand soaps, lotions, hair care products)
  - Pet food

Ensure all health professionals are aware you have Celiac disease

Kissing

### Impact To Social Life – Family & Friends

- □ Inform them of your diagnosis
- Provide them with information
- Offer to host dinners



- Offer to bring food when invited to house parties
- Be the 1<sup>st</sup> in line at potlucks and the snack table
- Do not expect everyone to accommodate you

### Impacts To Social Life – Restaurants

- Gluten free/Gluten friendly/Gluten Aware
- Always precheck the menu
- Advise server you are Celiac



- Gluten-ed"? call the restaurant and discuss this with the Chef or Owner.
- Be careful of deep fried foods, buffets and kitchens that have airborne particles

### Impacts To Social Life – Travel

- Always plan ahead
- Use translation cards/apps
- What are the GF standards and logos
- Always carry GF snacks
- Make sure you have a fridge or a kitchenette



### Impacts to Social Life - Alcohol

	Safe	Not Safe	Research
Distilled Alcohol			
Whiskey, Scotch, Brandy, Gin, Rum, Tequila, Vodka	*		*
Liqueurs (Cordials)			
Amaretto, Baileys, Cointreau, Grand Marnier, Kahlua	*		*
Wines			
Red, White, Rose, Sparkling, Port	*		
Beers			
Gluten Containing, Gluten Reduced, De-glutened		*	
Gluten Free	*		
Hard Ciders			
Fruit Based	*		*
Specialty Premixed Alcoholic Beverages			
Hard Lemonade, Coolers, Wine Coolers, Caesars	*		*

### Q&A's and Questionnaire

Feel free to join us again! All Celiac 101 sessions are free and you can come back anytime!

Got Questions?

Email info@calgaryceliac.ca

Don't forget to sign up for the Calgary Chapter quarterly newsletter.

### References & Resources

- Pgs 3, 5, 8, 15, 21, 23, 24, 27 Pictures copied from CCA Toolkit (Shutterbug)
- Pg 6 Villi picture credit to <u>www.universityhealthnews.com</u>
- Pg 7 Villi biopsy credit to CCA 2017 national presentation
- Pgs 8-14, 18-24 CCA & Beyond Celiac (<u>www.beyondceliac.org</u>)
- Pg 9 Picture copied from Bing website (author unknown)
- Pg 10 Picture copied from <u>www.clipart-library.com</u>
- Pg 11 Verywellhealth.com (MS study)
- Pg 16 Alberta Health Services
- Pg 17 Limits & labelling details credit to Canadian Celiac Association (<u>www.celiac.ca</u>)
- Pg 25 various logos copied from Bing.com, CCA, and various European Celiac websites
- Pg 26 Shelley Case "Gluten Free the Definitive Resource Guide"
- Pg 27 https://clinicaltrials.gov, www.pvpbio.com, www.courpharma.com, www.innovatebiopharma.com, www.immunogenx.com
- Misc....
  - <u>www.Celiac.com</u>, <u>www.Glutendude.com</u>, <u>www.Gluten.org</u> (gluten intolerance group)
  - celiacdiseasecenter.columbia.edu (Columbia University) Pg 35 Burger JPW, de Brouwer B, IntHout J, et al. Systematic review with meta-analysis: dietary adherence influences normalization of health-related quality of life in coeliac disease. Clin Nutr. 2017;36(2):399-406.
- Resource handout credit to Calgary Chapter (CCA) 101 volunteers
- Symptoms handout credit to CCA