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 subgroup 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

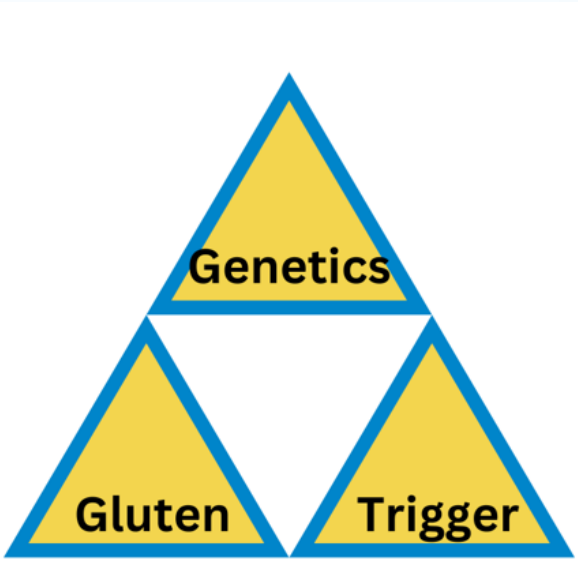
- Disclaimer: Please note that the volunteers at Celiac 101 and the information in this presentation are for informational purposes and should not be taken as direct medical advice for your individual case/needs, always consult a medical practitioner

Celiac 101

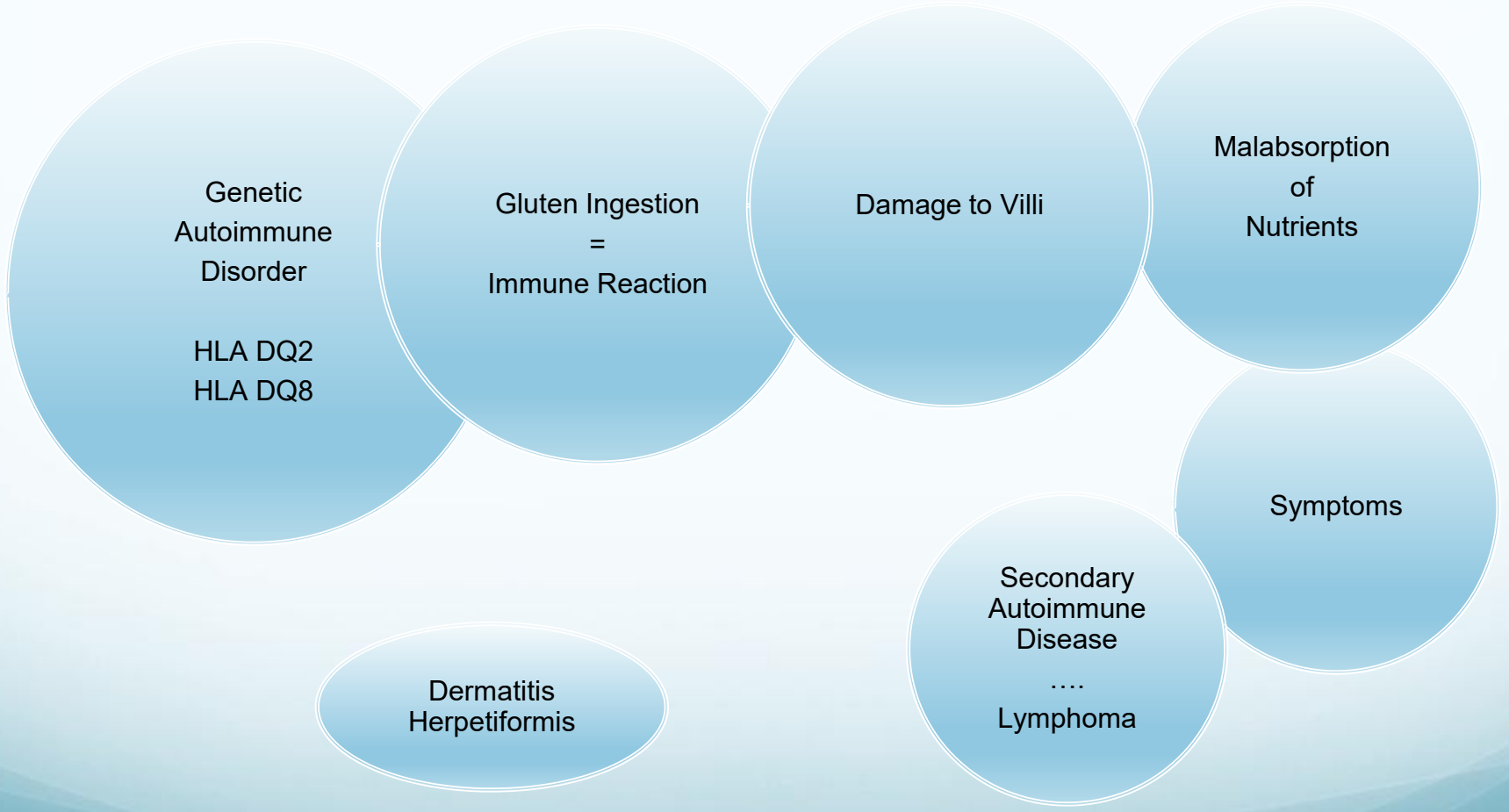
- Introductions
- Health and Celiac Disease
- Resources
- Daily Living
- Social Life
- Q & A

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

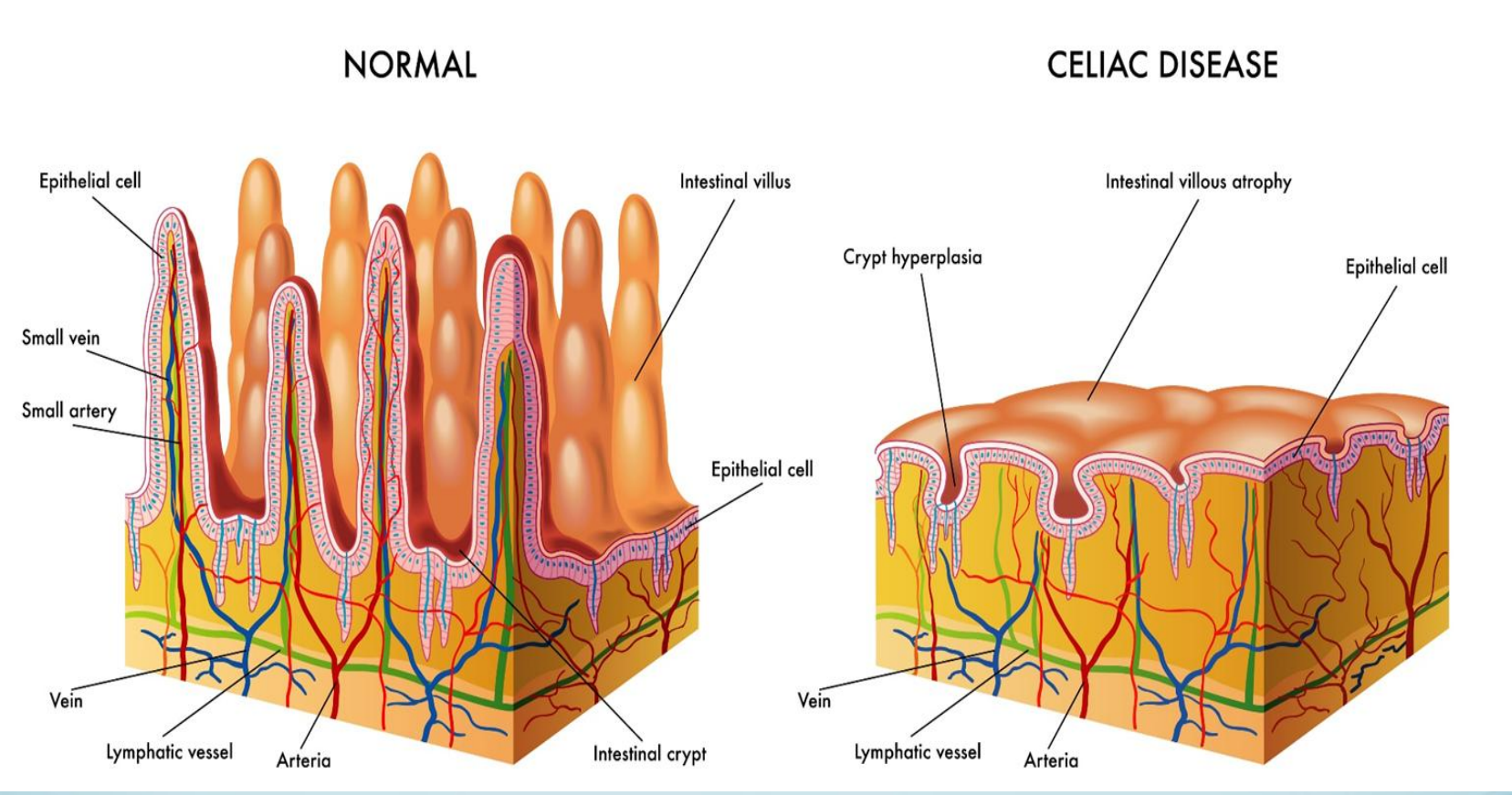
- Genetic Predisposition
  - HLA-DQ2 & HLA-DQ8
- Gluten Ingestion
  - resulting immune response
- Possible Triggers
  - Turns “on” the reaction to gluten



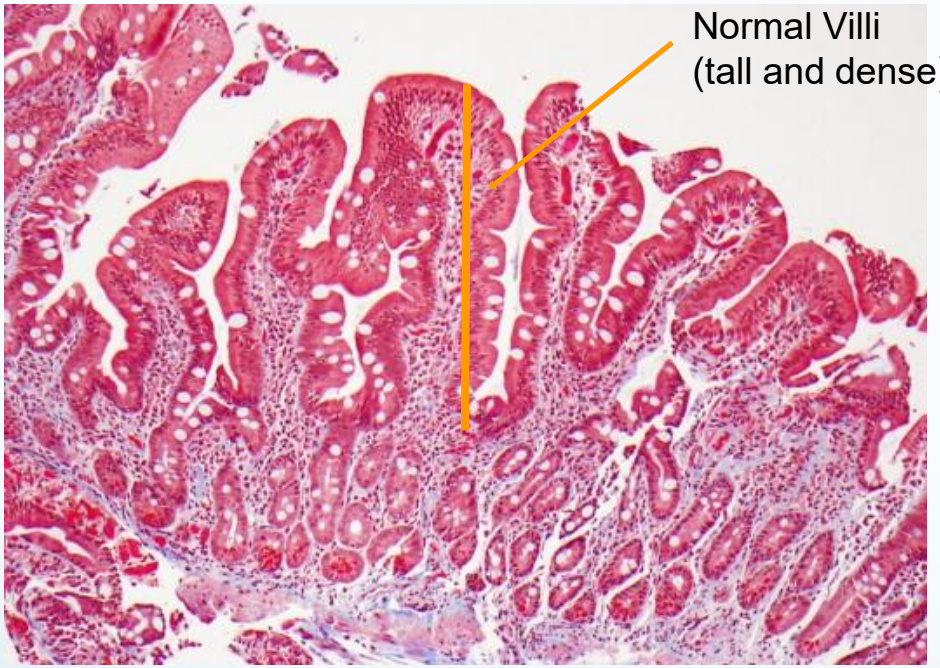
What is Celiac Disease?



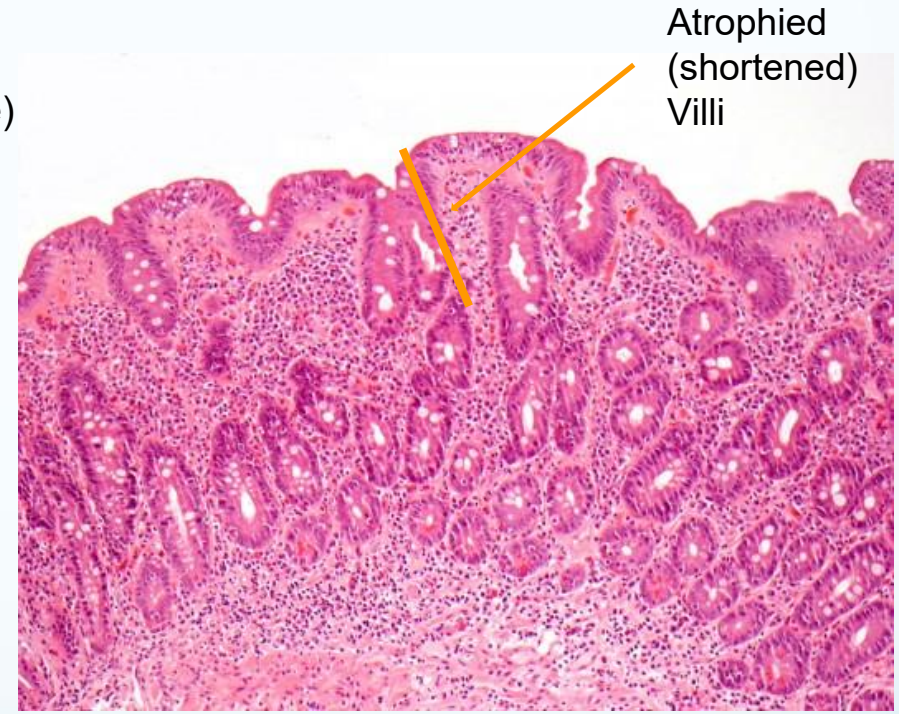
Villi - Normal vs. Celiac



Villi - Microscopic View



Normal Villi



Villi of Celiac Patient

Celiac Disease Facts

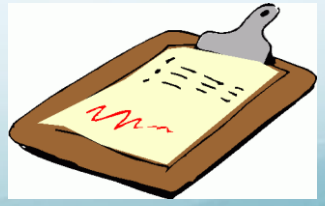
- The onset can occur at any time
- It is a lifelong disease with NO cure
- Celiac disease affects ~ 1% of the population
  - May be as high as 20% in certain populations
  - Highly under diagnosed, only 1/146 people with Celiac disease has been diagnosed.
- Chance of developing Celiac disease in relatives
  - 1st degree is 5 - 20%
  - 2nd 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

Advocating 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 *misdiagnosis* 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
   Both single use treatment and long term medications.
6) Complete Nutritional Counselling with a registered dietician
7) Re-organize kitchen, educate family members sharing your kitchen
8) Arrange for bone scan (DEXA)

What do I do now? cont'd

9) Encourage 1st (2nd) degree relatives to be tested

10) Continue or begin to exercise

11) Join support groups such as Celiac Canada and/or online reputable groups

12) Repeat blood work within 3 to 6 months after diagnosis; annually after that.

    a) TTG scores should trend down over time.

13) Repeat intestinal biopsy if symptoms do not improve after 6-12 months, or screen for other associated disorders like Refractory Celiac Disease.

Gluten Associated Disorders

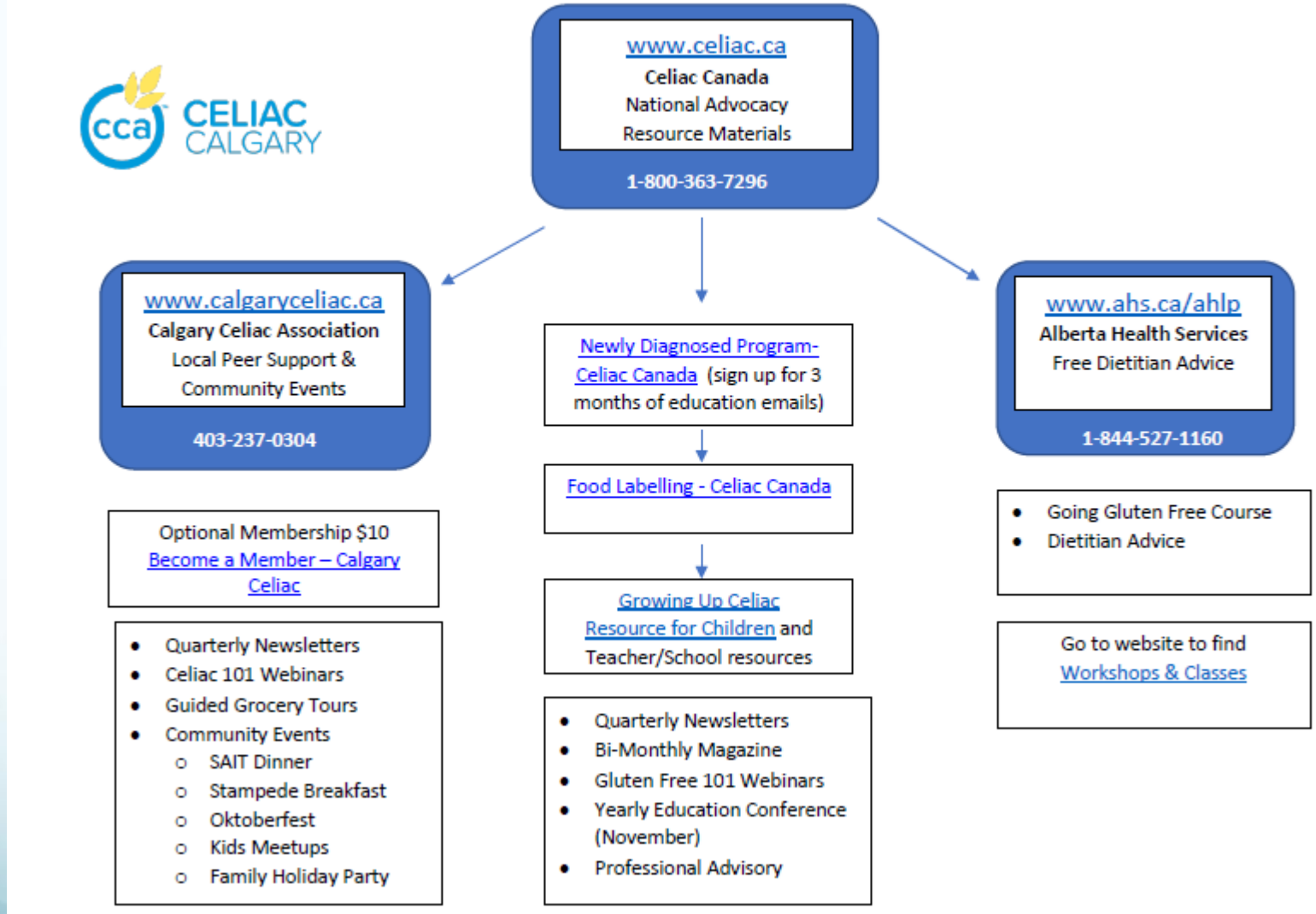
	Celiac Disease	Non Celiac Gluten Sensitivity	Wheat Allergy
Autoimmune	*		
Intolerance		*	
Allergy			*
Genetic	*		
Dermatitis Herpetiformis	*		
Villi Damage	*		
IBS Symptoms	*	*	*
~% of pop.	1	0.6 – 6	0.1
Testing	*		*

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

Newly Diagnosed Resource Road Map



Learn to Read a Label for Gluten in 3 Easy Steps

CELIAC CANADA

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.

Steps

Ingredients: Enriched Wheat Flour, Canola Oil, Sugar, Glucose-fructose, Modified Milk Ingredients, Salt, Ammonium Bicarbonate, Baking Soda, Papain, Amylase, Protease, Natural Flavour.
Contains: Milk, Wheat.
May contain: Soy.

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

1 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.

2 Check the 'Contains Statement'

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

3 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 (barley, rye, oats, wheat) 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.

GLUTEN FREE

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

Other Steps

Many products are certified gluten free. Look for the following logos on food packages.

For more help, please refer to the CCA Labelling Guide Resource.

Let's take a closer look…

Steps

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Prepared by: Calgary Celiac Association

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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

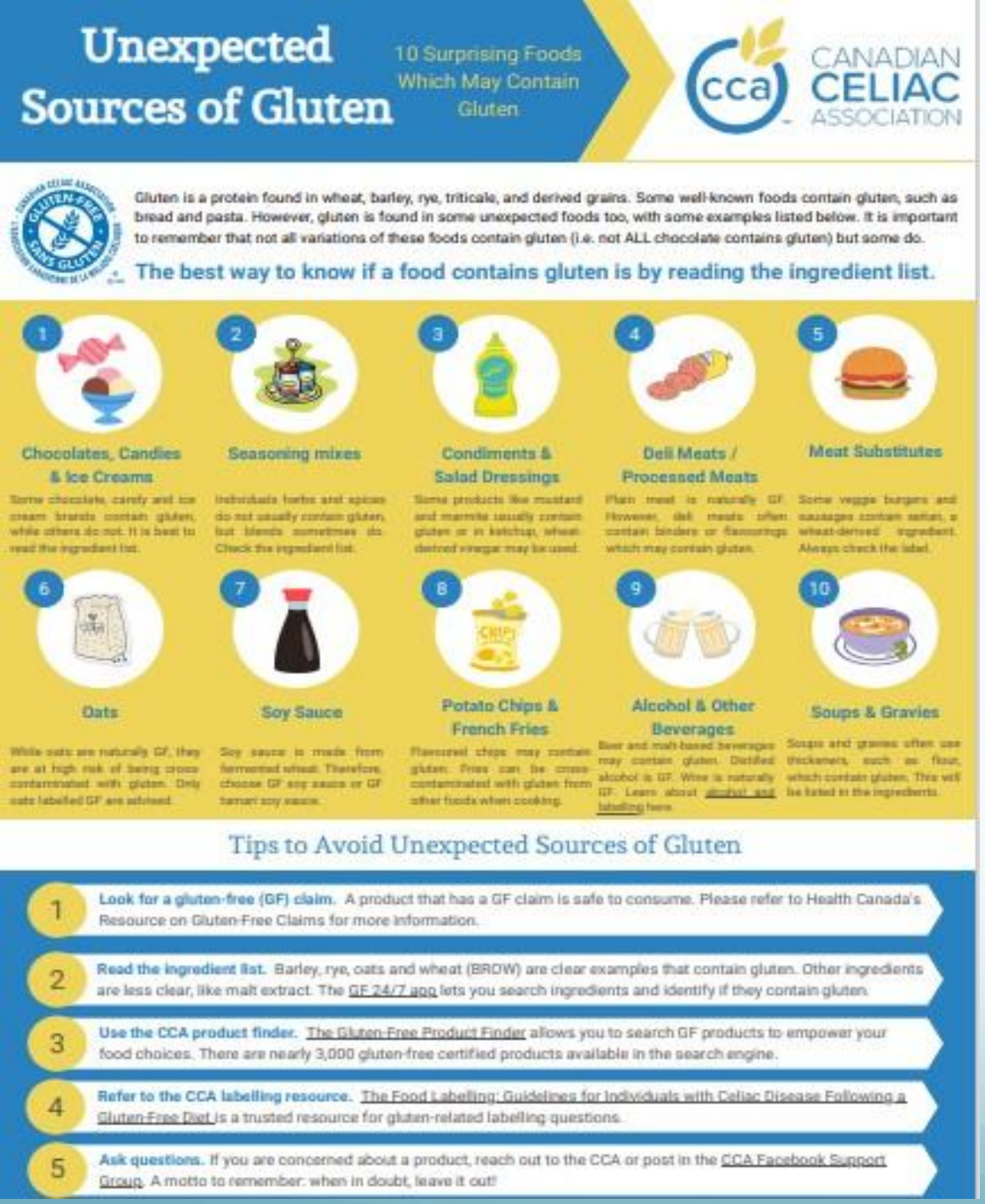
Other Steps

Many products are certified gluten-free. Look for the following logos on food packages.

For more help, please refer to the CCA Labelling Guide Resource.

What is “Gluten Free” ?

- 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: Cornmeal/flour, pulses (lentils), grains and oats



Unexpected Sources of Gluten

- Read the label every time
- Look for a GF claim
- Refer to the CCA labeling resource
- Ask questions

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 toaster

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, chapstick
  - Mouthwash, toothpaste, hairspray, hand sanitizer
  - Play-doh, and paper mâché - GF recipes available online for little ones to minimize any risks
  - 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 1st 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

Dining Out

- Call ahead
- Follow the question guide: Communication → Ingredients → Procedural → Personal
- Use Apps like “find me gluten free”, Gluten Dude, and Aptly
- Ask the Celiac Community

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!

Have Questions?

Email info@calgaryceliac.ca

Don't forget to sign up for the Calgary Celiac 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 www.universityhealthnews.com
- Pg 7 – Villi biopsy credit to CCA 2017 national presentation
- Pgs - 8-14, 18-24 – CCA & Beyond Celiac (www.beyondceliac.org)
- Pg 9 - Picture copied from Bing website (author unknown)
- Pg 10 – Picture copied from www.clipart-library.com
- Pg 11 – Verywellhealth.com (MS study)
- Pg 16 – Alberta Health Services
- Pg 17 - Limits & labelling details credit to Canadian Celiac Association (www.celiac.ca)
- 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.…
  - www.Celiac.com, www.Glutendude.com, www.Gluten.org (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