



Calgary Celiac News

February 2021

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Message from the Calgary Chapter President

Marcia Bruce, President

It has been my pleasure to be serving on the Calgary Chapter of the Canadian Celiac Association Board of Directors for the last couple of years. At our AGM in the fall, I transitioned into this new role and I am excited to continue to work with our staff and the great volunteers at our chapter to help make a difference to people living with celiac disease and gluten sensitivity. My husband and I both have celiac disease and our children, who have not been officially diagnosed, are gluten sensitive so we are a completely gluten free family of five. I am passionate about raising awareness about celiac disease and about making the lives of people with celiac disease better.



The past year was a year full of changes around the world and our chapter has gone through a transformation as we adapted to operating a charity during a global pandemic. We successfully moved a number of our events online, including our Celiac 101 class, Kids Meetups, a fun Easter event and even a Christmas cooking class for kids. We also saw some pretty big changes to our team. We have a number of new people on our board of directors and I would like to welcome Lisa Cerato, Brooke Barrett, Jen Shrubsole and Meg Furler to our team. They each bring a diverse skillset to our chapter and we eagerly anticipate working with them. You can learn a bit more about them and the other members of our board in this issue of the newsletter. We also had some board members complete their terms and move on to other opportunities. We would like to thank Karen Wickerson, James King and Leslie Steeves for their outstanding contributions to our chapter and we look forward to continuing to work with them as volunteers in the future. We also had some operational transitions; our Events Coordinator Cheryl Richmond and our Office Manager Linda Cooper are no longer working in the chapter office. We would like to thank them both for their immense contributions to the chapter over the last several years, both in the office and as volunteers at our chapter. Our new Office Manager, Joanne Godsman who joined us in December, is quickly getting up to speed and we are excited to have her on the team.

Priorities for the board this year include raising awareness about celiac disease, continuing to provide education on celiac disease, planning some entertaining events (even if they have to be virtual) and working on internal processes and policies to ensure the long-term success of our chapter. As the COVID-19 vaccine gets rolled out across the province, we hope to be able to welcome you back to in-person events in the fourth quarter of this year. In the meantime, we would love to hear from you to ensure our priorities align with what you want and need from our chapter. You will find a survey in this issue asking you to help us prioritize and make sure that we are on the right track to serve the celiac community in Calgary and area.

Thank you for your continued support of our Chapter.

A handwritten signature in blue ink, appearing to read 'MB', with a long horizontal line extending to the right.

Community Survey

We Want to Hear from YOU !!

The Calgary Chapter of the Canadian Celiac Association is in the process of refreshing its strategy for 2021-2023. We want to hear from you about how we can work together on priorities for our celiac and gluten free community in Calgary and surrounding areas.



Please tell us what you think by answering a few short questions.

Your answers will be kept confidential and used to confirm what the we will focus on over the next two years

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- Zest of 2 lemons (about 4 teaspoons)
- 2 teaspoons lemon extract
- 1/2 teaspoon vanilla extract
- 1/2 cup finely chopped almonds (optional)
- 1-1/2 cups powdered sugar for coating

Whisk together flour, cornstarch and salt in small mixing bowl and set aside.

In large bowl, mix butter until creamy on medium speed. Blend in 2/3 cup powdered sugar. Add in zest, lemon extract and vanilla extract.

Set mixer to low speed and slowly add flour mixture until just combined. Stir in almonds. Cover bowl and chill dough for 1 hour.

Preheat oven to 350°F. Grease cookie sheets or cover in parchment paper.

Scoop dough out 1 tablespoon at a time and roll into ball. Space balls about 2 inches apart.

Bake for 14-16 minutes. Allow to cool a few minutes. Place remaining powdered sugar into a bowl and roll warm cookies in powdered sugar. Transfer to wire rack to finish cooling. You can roll in powdered sugar again if you like.

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We are Excited to Introduce our New Team !

Marcia Bruce, President

Marcia joined the Board of the Calgary Chapter in November 2018 and was voted in as President in November 2020. Both she and her husband, along with a number of other family members, have celiac disease. She also volunteers with Alberta Health Services as a Patient Advisor on the Digestive Health Strategic Clinical Network where she strives to be a voice for patients with digestive issues. She is excited to continue her work with the Calgary Chapter and help others diagnosed with celiac disease or other gluten related disorders.

Lisa Cerato, Vice President

Lisa was diagnosed with Celiac Disease in 2008 and shortly thereafter 2 other family members were also diagnosed. She recently joined the board of directors as the Calgary Chapter vice president to promote research and development in supporting the community at large with Celiac Disease. Professionally, Lisa has worked with Alberta Health Services since 2006 providing clinical expertise and healthcare planning in the areas of chronic disease management, public health and health promotion. Lisa holds degrees in Kinesiology and Master of Science in Clinical Exercise Physiology from the University of Regina. She is also actively involved in working in exercise rehabilitation for those with chronic disease and her recent interests include the effects of exercise on gut health.

Ralph Barnett, Treasurer

Ralph joined the Calgary Chapter Board in the mid 90s. He served two terms on the National Board from 2002 to 2006. Since then he has taken a couple of breaks. Since roughly 2014 he has been the Calgary Chapter Treasurer. Ralph also picked up the Casino Coordinator role after the long serving George Waite retired. Ralph and his 6 year old grandson have Celiac Disease.

Stacey Hilscher, Secretary

Stacey joined the Calgary Chapter Board a year ago last October. A native Calgarian, Stacey is passionate about empowering others to take control of their health and live a healthy, fulfilling and still incredibly fun life within their communities. She and her son battle Celiac Disease together and strive to take away all stigma that gluten free food tastes bad or that life cannot be “tasted” to the fullest on a gluten free diet!

Jen Shrubsole, Member

Jen joined the Calgary Chapter Board in the fall of 2020. She has been a registered dietitian for almost 20 years with Alberta Health Services with a focus on gut health. Jen was diagnosed with celiac disease about five years ago and her hope is to give back to the celiac community as a member of the Calgary Chapter Board. Jen’s experience will be a great addition to the Calgary Chapter in creating a supportive community for anyone living with celiac disease.



Brooke Barrett, Member

Brooke Barrett, a born and raised Calgarian, joined the Calgary Chapter Board this year after becoming interested in the programs and education provided by the Calgary Chapter of the Canadian Celiac Association since her own diagnosis with Celiac Disease a year and half ago. Brooke is a practicing lawyer who is eager to volunteer her time on the Calgary Chapter Board and is excited to meet more of the Celiac/Gluten free community in person (and virtually) going forward.

Tracy McMillan, Member

Tracy joined the Calgary Chapter Board in 2016 and has been the Chair or Co-chair of the Education Committee since 2017. Tracy learned that both her children had Celiac Disease when they were 2 and 3 years old and she has been determined to offer all the normal foods kids love while learning how to keep them safe and healthy. Tracy works as a Nurse Practitioner with adults and children, and in her spare time loves to bike ride, swim, scrapbook, and teach.

Michelle Venus, Member

Michelle is a born and raised Calgarian and joined the Calgary Chapter Board at the end of 2019. She was diagnosed with Celiac Disease in the previous year after 10 years of misdiagnosis. Michelle is passionate about Celiac awareness and is always excited to discover new gluten free foods and recipes.

Meg Furler, Member

Meg joined the board in November 2020 after her celiac and DH diagnosis the year before. She has a background in non-profit leadership and event management. Currently, she works in the museum industry as a Costume Designer. She looks forward to working with the board and supporting Calgary's gluten-free community.

Courtney Brown, Volunteer Bookkeeper

Courtney joined the Calgary Chapter team in December as the Bookkeeper. She was diagnosed with Celiac Disease 15 years ago and was very active in the association. She attended multiple Celiac Kids Camps, volunteered with the Stampede Breakfast and Kids Christmas Parties. Courtney is currently attending Mount Royal University and is excited to be gaining industry experience while working closely with other Celiacs.

Joanne Godsman, Office Manager

Joanne was hired as Office Manager (Newsletter Editor) at the end of December. Joanne has been actively following the Calgary Chapter since her son was diagnosed with Celiac Disease 7 years ago. She is a gluten free baking enthusiast, an active volunteer in the community and will be the friendly voice you hear when you call the Calgary Chapter office.



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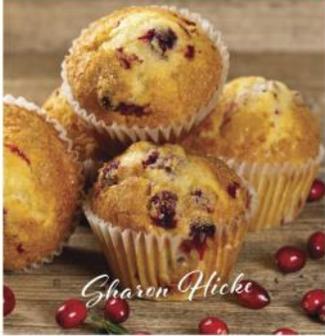
Upcoming Events

The Calgary Celiac Association is happy to be offering the following events to our Celiac community. Please check the website for further information about each event and to register.

- **March 15 : Celiac 101 Information Night**, Information for newly diagnosed & family (Next Date: May 6)
- **March 23 : Kids Meetup**, Virtual Meetup with supportive fun activities for Celiac youth (Next Date: May 18)
- **March 20: Easter Event** : Fun & games for the whole family
- **May 16: Calgary Tower Light-up**: Green for Celiac Awareness Day

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Celiac 101 Information Sessions



The Calgary Celiac Association offers bi-monthly Information Sessions to those seeking information about Celiac Disease and gluten related disorders.

This session is FREE but we ask that you pre-register so that we can plan accordingly.

Visit our website at www.calgaryceliac.ca to register.



Calgary Celiac Kids Meetups



The Calgary Celiac Association hosts an online Celiac Kids Meetup every other month. All youth are invited to participate and siblings are welcome too. The Meetups are free but we ask you to register so we can plan accordingly.

Visit www.calgaryceliac.ca and look for the Kids Meetup under Event Registration to register.

The virtual Meetups are one hour long and hosted by our volunteer coordinator, Cinde Little. The majority of the kids are between ages 6 and 12 but all ages are welcome. Cinde facilitates introductions, fun games and sharing among all the participants.

Cinde has also tried different ideas to create a Teen Meetup group but has met many challenges. If you have some teens in your house feel free to contact Cinde if you have ideas to engage them.

If you would like to volunteer to help with the Meetup, contact cinde.little@gmail.com

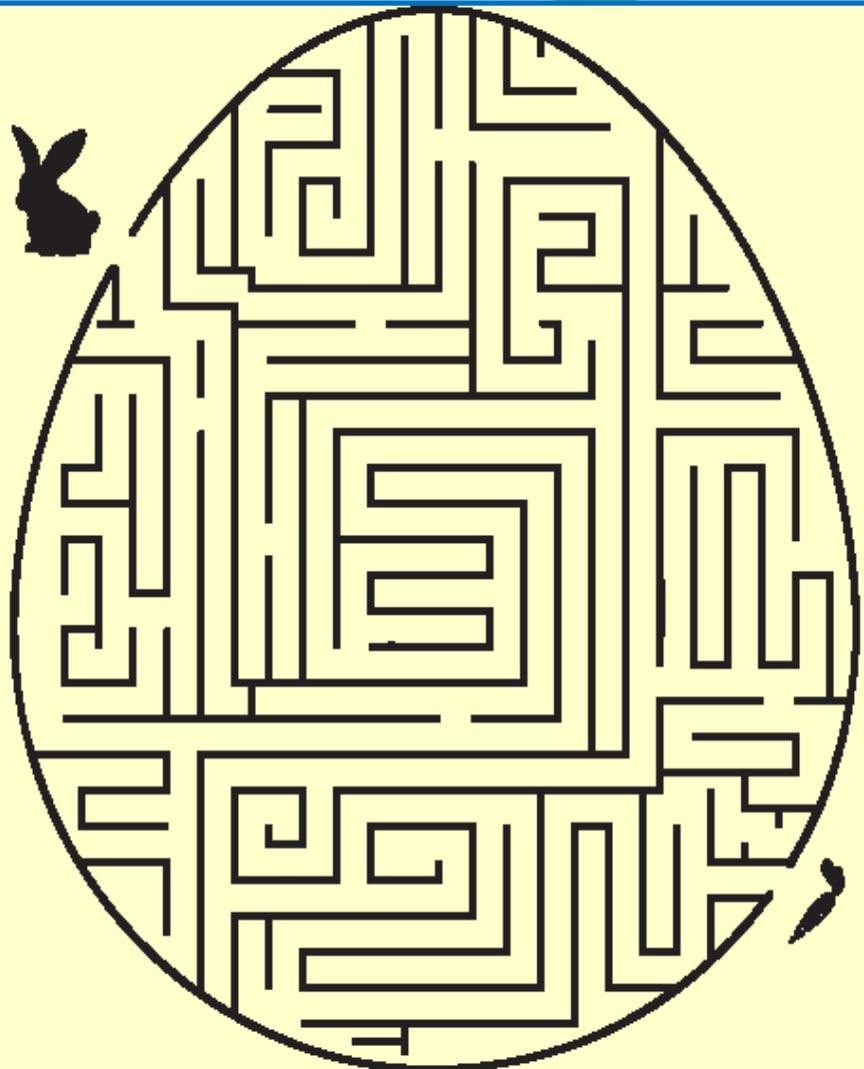
Calgary Celiac Association

Easter Education Event

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The Need for a Biopsy

By JoAnne Murray,

Active Member of the Calgary Chapter for over 20yrs

The need for a biopsy to confirm a diagnosis of Celiac Disease remains one of the most misunderstood controversies in the celiac community. And unfortunately, the relevance of the biopsy is not well understood amidst the general practitioners in the medical community.

I'll talk about the general standards of adult diagnosis in this article and address other alternatives that may be available for some children as well as some first degree relatives of people who have had biopsy diagnosed celiac disease in the next newsletter.

The introduction of reliable serology testing in ~2003 in Canada changed the medical approach to Celiac Disease diagnosis and it changed it very rapidly. There had been earlier blood tests available, but none that provided the level of consistency and accuracy of the IgA tTG blood test.

So what is serology testing? It is the testing of the blood serum to detect the presence of antibodies against a specific antigen. The presence of these antibodies serves as a marker of inflammation, but does not provide a measure of tissue damage that can result from a disease such as Celiac Disease. Though the marker is most commonly associated with Celiac Disease, it can also be present less commonly with the inflammatory processes associated with other diseases such as Type 1 Diabetes, Hashimoto's Thyroiditis, Autoimmune Liver Diseases, IBD (including Crohn's Disease and Colitis) and some general infections.

Once your family physician has determined that you have clinical symptoms that are consistent with the myriad of symptoms associated with Celiac Disease and has determined that you have a positive antibody test, s/he should refer you to a gastroenterologist for a more complete diagnosis that will usually include an intestinal biopsy.

It is at this pre-referral point, with a positive blood screening result in hand, that many people, with or

without consultation with and guidance from their family physician, will decide that they don't need the biopsy to confirm the diagnosis and instead begin self-treatment with the gluten free diet. I cannot overstate the need for the referral to a gastroenterologist for a complete diagnosis.

Let me offer an analogy that may help you understand the need for the referral. If you have money you want to invest in mutual funds at your bank, you will not be allowed to do this with a visit to a teller or to a loans manager. You will be required to meet with a certified investment advisor who has the additional training and credentials to assist you in making investment choices based on your financial goals and needs. In like manner, a definitive diagnosis of Celiac Disease should always be made by a gastroenterologist and will usually include an endoscopy/biopsy. The gastroenterologist has the additional training and credentials to perform the procedure and make this diagnosis. It then becomes a diagnosis that has credibility inside and outside the medical community as you journey through life.

So let's look at the process of the biopsy. The endoscopy is performed by a gastroenterologist who will take a careful look at all the anatomy of your upper gastrointestinal tract looking for any irregularities that could account for various types of diseases. The gastroenterologist will then take a number of biopsies from several locations which will be sent to a pathologist in the lab who will review them under a microscope to determine if they are characteristic of Celiac Disease. Most pathologists now classify the damage to the tissue based on the Marsh classification scale which registers the types and degree of damage. This is histology which is the study of anatomy at the microscopic level and deals with the microscopic identification of cells and tissues and the damage they have sustained. This is a very different process from the serology of the blood test. Serology and histology compliment each other in leading to a definitive diagnosis.

Many people expect that high serology numbers will translate into severe intestinal damage, but this often is not the case. There are many people with off the chart serology numbers who have minimal damage in the histology review. There are others who will have near normal serology numbers yet have massive tissue damage at the histology level. And there are yet others who will have serology and histology that seem to mirror each other. It is from this broad range of results that it becomes evident that having the results of both investigations is so very important. And to understand how there can be this broad range of results, we need to recognize the value of both types of tests. The tTG is a marker of inflammation as expressed by the presence of antibodies while the histology review of the biopsies assesses the extent of tissue damage. And again, by way of analogy, there is a huge range of effects for various people when exposed to the sun. Some people will show the beginning of sunburn (inflammation) within minutes of sun exposure. Others can tolerate more lengthy sun exposure without evidence of sunburn. However both are experiencing histological changes at the cellular level to increased risk of developing skin cancer and it is the microscopic evidence of these cellular changes that leads to the diagnosis.

What are the risks of not having a biopsy diagnosis? The first and most important is the lack of credibility within the medical community. Nothing is more perplexing to any physician than a patient who has self-diagnosed a condition and self-treated. You may feel very confident that you have self-diagnosed accurately and self-prescribed the optimal treatment. After all, your health has improved and you are feeling so much better. However, if and when symptoms of other (autoimmune) conditions appear, they will not be looked at for first line investigation because there is no definitive diagnosis of Celiac Disease as the anchor diagnosis.

You are likely to be excluded from some medical opportunities when new treatments become available because you do not have that formal diagnosis. This could include potential drug therapies that are making their way down the pike. No ethical physician will prescribe medications without a definitive measure for diagnosis.

You will be excluded from research studies that could advance the scientific knowledge about Celiac Disease. I and my family had the privilege of participating in the family study done in 2003 and the follow-up study in 2018. Our participation in the initial study was

predicated on the research group being able to access my medical records from 35 years earlier and verifying my biopsy diagnosis.

Some care facilities (including acute care hospitals and long term care facilities) will not provide a Gluten Free Diet without confirmation of the medical need related to Celiac Disease.

The CRA will disallow the tax credit for the differential cost of gluten free foods without a medical letter confirming the Celiac Disease diagnosis.

By our current medical standards, a complete and accurate diagnosis of Celiac Disease includes both serology and histology results. Are there changes occurring with these requirements? The answer is yes, and I'll outline some of these variances in the next newsletter. Are there further changes to these requirements on the horizon? Probably. And once again, I'll look at some of the winds of change that may occur in the foreseeable future. But until we have widely recognized and accepted new parameters of diagnosis, the fact remains that too many people sell themselves short of an accurate diagnosis with either an incomplete diagnosis from a family physician's failure to refer to a gastroenterologist, or even worse, a self-diagnosis from an unrecognized non-medical source (you).

Until there are some significant diagnostic changes, the intestinal biopsy remains the definitive gold standard diagnostic tool for the diagnosis of Celiac Disease.

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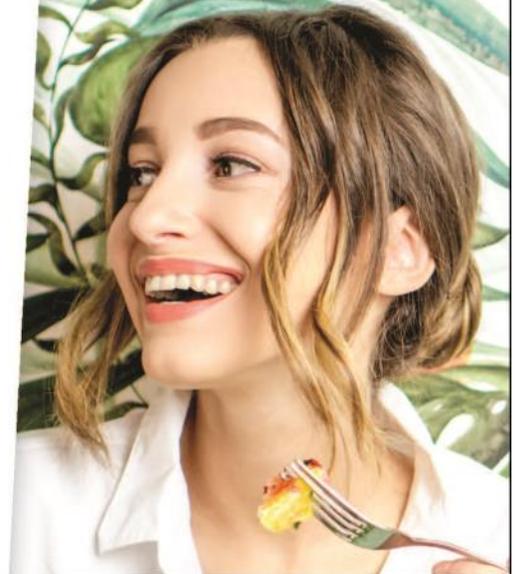


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Are you ≥ 15 years old & diagnosed with celiac disease or a parent of a child/youth diagnosed with celiac disease?

A research team led by Diana Mager PhD RD at the University of Alberta is conducting an **ONLINE SURVEY** to obtain feedback on layout and content of a gluten free food guide for children/youth (4-18 years) with celiac disease.

If you would like to complete the survey, please use the link below to access the survey. The survey will take about 15-20 minutes to complete.

<https://redcap.link/foodguide>

If you have any questions about the survey or this study, please email Samantha RD at scyrkot@ualberta.ca.



Calgary Chapter, Casino Update

Ralph Barnett, Calgary Chapter Treasurer

Happy New Year!! 2020 is over, and frankly... As you may have heard, Alberta Casinos were closed down again in mid-December as part of the latest lock-down. We were truly fortunate to squeeze in our Casino in early September. Thank you again to all the volunteers who jumped in quickly to make it happen.

The money hasn't hit our bank account yet, I have no idea how much to expect, but whatever it is will be massively better than zero. We should see the cash by end of February.

In view of the further delays in for charities scheduled December, January, February and potentially much longer, we should plan for the next Calgary Chapter Casino event to be in early 2023. It's a long time but keep the faith. This is an excellent fund raiser for our Chapter. I will keep you posted.



Financial Update

Sadly we are bidding farewell to Lynn Dudley who has kept the books brilliantly for Calgary Chapter for many years. We welcome Courtney Brown who joined us in December to take over from Lynn. Courtney is a 3rd year business student at Mount Royal University.

The Calgary Chapter continues to be in good financial health. 2020 was a break-even year for the Chapter. In 2020 most of our program were toast, no Kids Camp, no Stampede Breakfast, no SAIT dinners, no GF Oktoberfest, no Volunteer Appreciation brunch, it was a quiet year!! Consequently, we didn't spend much money. Fundraising continued, but lets face it, people had other things on their minds. Thank you very much to all of the donors who did find a way to donate in 2020. We appreciate you more than ever in the difficult times. We very much look forward to getting back in the saddle with our program in 2021.

The full year 2020 financial statements will be out within the next month or so, and will be presented at the AGM this fall. Hope to see you there.

Stay well, stay safe.

Ralph



Works of Art, by the Education Committee

Tracy McMillan, Calgary Chapter Education Committee Chair



It is no shock to say that 2020 has been a very different and challenging year. COVID-19 has changed the way we live, work, and interact with each other. Our Education Committee took some time to sort out which priorities we wanted to achieve this year, and assess the skills and resources we had on board to fulfill the goals made.

We have a fantastic group of eight volunteers... all different backgrounds, economic, professional, and experiential circumstances bring us together to provide education to our Celiac community and beyond. As part of our visioning (or re-visioning) this year, we put together a wish list of projects and activities we would like to complete in the next year or so. In preparing this, I took time to reflect on all of the work that has been done by this committee in the last five years, and felt it was important to highlight these works of art.

In 2016, I joined this committee and much work was being developed on dental information. Posters were created and presentations were delivered to dental hygienists and dentists. A compilation of commonly used dental supplies that contained and did not contain gluten was

also created. Considerable awareness was brought to the dental community, aiding in recognizing Celiac Disease through periodontal disease.

In 2017, we focused on Diabetes and the link between Celiac Disease and Type 1 Diabetes. Again, educational resources and materials were created and we were invited to speak at the Diabetes Association, to explain more about Celiac Disease and provide teaching and education. Through these connections, we discovered Chris Jarvis, who is a former Olympic Gold medalist, and also speaks of his battles with Celiac Disease and Diabetes. He kindly participated in a Fun & Forum event we held a couple of years later in 2019, interacting with children to show them that anyone can be successful with the right supports and enough knowledge.

2018 highlighted a focus on Children with the Education Committee. We designed, developed, created, and produced educational resource packages for children who were newly diagnosed at the Alberta Children's Hospital. Within each package, children and parents would find stickers, business cards, "I have Celiac Disease"

information cards, a “Follow Me to Gluten Free” book, various gluten free information sheets, follow-up guidelines, and a Calgary Celiac Chapter pamphlet.

We advertised our programs and events so that families with newly diagnosed children would know what activities were occurring through the Chapter. The Education Committee wrote various articles in the newsletters over the course of the year answering survey questions from a community poll that was conducted. We also participated in many trade shows and organized our information sheets into transportable boxes so that we could easily share information with those who came by to visit our booth.

As structural changes within the organization began to occur at both National and local levels, our focus on Education did not. In 2019, we adopted the Celiac 101 Information Night under our committee, and the volunteers that facilitate the class updated and referenced the materials as well as revamped the presentation style. We developed a Kids Activity Book full of coloring and education puzzles for children, and after reading and reviewing the nationally published “Growing Up Celiac” book, we amended our packages for the Children’s Hospital to include the publication.

We hosted a Fun & Forum event for children and parents which was a great success. Activities and a magician kept the kids busy while the parents were treated to a fabulous guest speaker panel. Speakers included Dr. Diana Mager who is currently developing a Canadian food guide for Celiac Children, Dr. Gidrewicz who is a pediatric gastroenterologist in Calgary, and Chris Jarvis who is an elite athlete who also spoke separately to the children about Olympic rowing and gluten free snack foods! The other highlight of 2019 for our group was the finalization of almost two years worth of work on a parent handout about Celiac Disease in children. In collaboration with the Canadian Pediatric Society, we wrote and published an information sheet called “Celiac Disease and Your Child” which is now posted on their website for parents to access.



2020 began with many projects and ideas on the table, only to be challenged in the face of the pandemic spreading across the world. We revamped and transitioned our in person Easter Trivia Event into a virtual event that was a great success. The Calgary Food Bank reached out to the Calgary Celiac Association for assistance with gluten free food sorting, and not only did we provide a few volunteers, we created information sheets for them to use when our volunteers were not on shift. We are currently developing a PowerPoint presentation for the Calgary Food Bank to provide education on label reading and sorting.

Two of our biggest projects at the moment are creating a slide presentation for Canadian Medical Education Programs, and developing Grand Rounds Presentations for physicians and health care professionals. Our aim is to increase education for our physicians, so that they are better equipped to diagnose and care for all people with Celiac Disease in our community, and possibly nationally. This work is highlighted in greater detail in one of our other articles in the newsletter this month.

2021 forges ahead with COVID still strong, and we have a choice to sit and wait it out, or tap into our creativity to develop online resources, tools, and events that continue to educate people we serve. We have a great group of dedicated volunteers that I am honored to work with. The canvas is blank for 2021... what will we artfully create this year?



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We love our volunteers!

Last spring, we were unable to host our annual **Volunteer Appreciation Brunch** to celebrate our 2019 volunteers. Under the current restrictions in the province, it doesn't look like we will be able to celebrate our 2020 volunteers anytime soon either.

So, we wanted to take the time so **STOP** and say **THANK YOU** to our amazing 2019 & 2020 volunteers.

VOLUNTEER



In 2019, you helped us pull off a number of great in person events like our much-loved *Wendy T's Stampede Breakfast*, our highly anticipated **OKTOBERFEST DINNER**, and our formal **SAIT Gourmet Dinner**, just to name a few. You helped us get the word out and **educate** people by volunteering at our **Celiac 101** classes, the **Gluten Free Expo** and our informative **Fun and Forum** event. You **made a difference** in the lives of children with celiac disease and gluten sensitivity at **Kids Meetups** and at a fun **Christmas Party** for kids.

In 2019 and 2020, you **helped** us behind the scenes in the office, with bookkeeping, on Chapter committees and with fundraising during the *Scotiabank Marathon* and by volunteering to work at our **CASINO**. 2020 was a challenging year, but you **rose to the challenge** and helped continue to make our Chapter great by moving some of our programs online like **Kids Meetup**, **Celiac 101** and our **Kids Christmas Party**. You continued to **help** us behind the scenes in the office and on committees to help us continue to push forward.

2020 Volunteer of the Year !!

For 2020, we have selected **Karen Wickerson**. Karen has volunteered with our Chapter since 2008 and has held a number of different positions on the board. Karen's latest term on the board was Secretary, a position she held from 2013 to 2020. A highlight from Karen's time at the Chapter included organizing gluten free markets for local vendors, including one for the Chapter's 30th anniversary. One of her favorite memories is working on *Stampede Breakfasts* with Wendy Turnbull, a dedicated volunteer for whom the *Stampede Breakfast* is now named. We would like to thank Karen for her many contributions to the Calgary Chapter over the years. We are excited that she will be continuing to work with us on events like **Celiac 101** and our *Wendy T's Stampede Breakfast* when it returns.



Note: If you volunteered with us in 2019 or 2020, watch your email for a special surprise from the Calgary Chapter Board of Directors to let you know that you are appreciated even if we can't gather together. We are looking forward to the next time we can gather in person to celebrate YOU!

Calgary Celiac Education Committee Reaches Out to the Medical Community

Submitted by Dr. Jenny Jagers, PhD

Many times, a medical doctor can solve our biggest woes, and their investigations can lead to a diagnosis that changes a life. For patients with Celiac Disease, these answers can still take as many as 10+ years to find and, for some, many of the problems that come along with Celiac Disease don't end with the diagnosis. Many of those with chronic illnesses, can eventually feel that their medical team is sometimes lost or even less knowledgeable of their situation than they are. Many are hungry for further knowledge after a diagnosis, especially if health doesn't return quickly. Even if/when recovery does occur, many patients will still wonder if they can do more. For an individual patient, focused on their own illness, feeling that their physician isn't their ultimate source of information can feel isolating and scary.

Physicians, as much as they want to help, often face steep hurdles in their practices. These can stem from time constraints, system limitations, and restrictions on resources. Additionally, science is moving forward at an incredible pace. The knowledge amassed within a year of graduating medical school is overwhelming and doesn't slow down over years spent in practice. Even the education regarding Celiac Disease within current gastroenterology classrooms is sometimes sadly minimal amidst the bevy of other intestinal disorders and diseases. Having resources that are easy to access and up to date can be invaluable when trying to keep up, resolve a patient's issues, and perform follow up care, but these resources are incredibly hard to find. Even the time needed to find them is often a barrier for physicians.

This problem is multi-layered and complex, but for the past year, progress towards greater awareness and education for medical professionals has been underway within the Calgary Celiac Association's Education Committee. The Committee, along with key members from other chapters such as British Columbia, have been developing an educational program aimed at medical professionals who are most likely to suspect, diagnose and treat those



with Celiac Disease. This includes general practitioners, nurse practitioners, gastroenterologists, endocrinologists, rheumatologists, and even reproductive and fertility specialists among many others.

The program focuses on current knowledge of Celiac Disease and summarizes years of research into actionable practices that promote early diagnosis and appropriate follow up care. Within the program, non-medical aspects such as where a patient may find more peer supports, like the Canadian Celiac Association, as well as when to rely on dietitians and other consultation resources are simplified and provided. As a priority, this program appeals to medical practitioners in terms of actionable items and easy solutions, with end goals of shorter time to diagnosis, improved follow up care and delivery of resources to the newly diagnosed. The program also is respectful and realistic of the expectations and time a physician may have when working within a busy practice. These aspects make this program very different from the usually care-orientated, and interpersonal supports typically seen within organizations such as the CCA, which could mean it will be impactful to a group not currently impacted by recent efforts for awareness and education.

By approaching support from a new perspective, the program aims to help physicians navigate the ins and outs of Celiac Disease from an educational point of view, alerting them to the high prevalence, and providing guidance for follow-up care. This may relieve some anxieties of the unknown, reduce stereotypes/misinformation, inform physicians of the numbers of patients they should expect to find having Celiac Disease, and how to ensure their time is optimized. Potentially having the information available will also inspire those physicians who are unaware of Celiac Disease, to pursue this prospect for the first time.

The program is currently under development and will hopefully be launched with medical professionals in Alberta and BC in fall 2021. The long-term plan is to work with several educational institutes who support and develop continuing medical education in Canada where the materials will be provided at no charge so that they can be offered to the widest audience possible. The committee is hopeful to see the outcomes of this in as little as 1 year after distribution within our local community. Potentially, the program may be available through other avenues such as patient advocacy, universities, medical schools and various conferences.

As a team, the Education Committee, is a diverse group, ensuring a well-rounded perspective on this project. The project was spearheaded and initiated by Dr. Jenny Jagers, PhD, shortly after attending medical school and realizing the deficits surrounding current medical education. Jenny has been a volunteer with the education committee since 2019. Jenny was diagnosed in 2003 and has been an active Celiac advocate since, running a dinner club, a kids' camp, and now as a member of the Education Committee and Celiac 101. Tracy Mackie joined the Calgary board in 2016 and has been the Chair or Co-chair of the Education Committee since 2017. Tracy learned that both her children had Celiac Disease when they were 2 and 3 years old and she has been determined to offer all the normal foods kids love while learning how to keep them safe and healthy. Tracy works as a Nurse Practitioner with adults and children, and in her spare time loves to bike ride, swim, scrapbook, and teach. James King, has since left the committee, was instrumental in the project

having brought his current graduate education in epidemiology and current celiac knowledge to the group. Hannah Klappstein joined the education committee about a year and a half after being diagnosed with Celiac Disease. Even after a year and a half, the memories of how lost, discouraged, and frustrated she felt in those first few months were fresh in her mind. Hannah joined the education committee in hopes of making it easier on those who are newly diagnosed, and to help spread awareness about the disease to ultimately make it easier on all of those who live with Celiac Disease. Jenna Wenkoff was very recently diagnosed and joined the Education Committee to help others learn while she was learning. Jenna offers a fresh perspective and experience, essential to understanding current trends, diagnostic conversations and initial impressions. Emily Halliday is a strong celiac advocate and ally, who joined the committee in 2015. She has focused on travel safety, raising a Celiac child, and cooking and baking gluten free. Emily brings the awareness of Celiac Disease into perspective for daily and social life. Emily currently functions as secretary of the Education Committee. The most recent addition to the committee is Lisa Cerato. Lisa joins the education committee with an inter-provincial background in healthcare and education curriculum design.

Significant contributions were made to the project during 2020 by key members of the Canadian Celiac Association British Columbia (CCA BC). Lizbeth Wall, past President of the CCA BC, met with Jenny in early 2020 to help introduce her to the CCA BC and its members and has been integral to the groups' coming together and its support. Jessica Pirnak, registered dietitian advisor, provides dietetic perspective and information on the referral processes essential to the project. Julie Clement, director on the CCA BC board, has provided an international viewpoint, research on trends, internet use and prevalence of Celiac related topics. Val Vaartnou, past President of the CCA BC, has contributed years of peer-reviewed journal summary knowledge and references from her literature reviews and summaries published in the CCA BC newsletters.

Call for Submissions

Is there something you would like to see in the next issue of our Newsletter? We would love to hear from you and we want to feature more content from our Calgary celiac community.



Ideas for submissions include:

- ◆ Your favorite Gluten Free recipes
- ◆ Product or restaurant reviews
- ◆ Travel stories
- ◆ Jokes, Humor, Kids Art / Stories
- ◆ Do you have a great idea for an article or would you like to write one? Would you like to share your celiac journey with our readership?

Please send your submission to:

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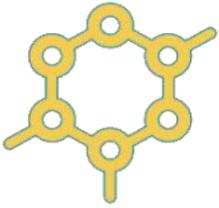
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Our staff is available anytime to help navigate the decisions toward achieving gluten-free certification for your business. For more information please contact:

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RESEARCH REPORT

Epidemiology & COVID-19
James King, MSc



There has been a mounting awareness surrounding the field of epidemiology over the past year as we are being regularly inundated with various statistics, modelling, and research on COVID-19. This has been particularly interesting to me personally and professionally, as my educational background and work focuses on epidemiological research. While these constant facts and figures have undoubtedly contributed to ‘COVID fatigue’ and we are hoping to put the pandemic behind us as soon as possible, it has also highlighted just how important the study of epidemiology is to public health and society. While this discipline has come into the mainstream during the pandemic, epidemiology offers tremendous value in many contexts – most pertinent to us, of course, is that of celiac disease.

What is Epidemiology?

Epidemiology aims to understand the distribution and determinants of a disease. One core assumption of epidemiology is that a disease is not randomly distributed throughout society – rather, how it is spread amongst a population is fundamentally linked to its determinants. In terms of celiac disease, there are many ways in which epidemiological research can help us better understand important questions such as:

- 1) How many people in the population have celiac disease?
- 2) What factors increase the risk of developing celiac disease?
- 3) How can the health outcomes of those affected by celiac disease be improved?

There are different types of epidemiology – this pandemic has required the understanding of infectious disease and the mechanisms in which a highly contagious illness can spread. But, as many parts of the world throughout the 20th and 21st centuries have significantly reduced the impact of (or even eradicated) certain communicable diseases, there has also been a growing exploration into the epidemiology of chronic conditions like celiac disease.

Prevalence & Incidence

We often hear that approximately 1% of people have celiac disease, although there is evidence to suggest it remains a significantly underdiagnosed condition.¹ Consequently, this discrepancy can make it challenging to obtain an accurate estimate of celiac disease prevalence. However, considerable work has gone into understanding how common celiac disease is throughout the world. Recent research has highlighted that approximately 0.7% of people throughout the world have a biopsy-confirmed diagnosis of celiac disease and about 1.4% of the population having elevated blood levels suggestive of celiac disease based on screening tests.² In addition to our understanding of celiac disease prevalence, there is evidence for the rate at which celiac disease is being diagnosed has significantly increased throughout industrialized parts of the world over the last several decades.³ While there are many possible explanations for this increase, the improved ability to detect celiac disease and a genuine increase in the occurrence itself are major contributing factors.

'Causes' of Celiac Disease

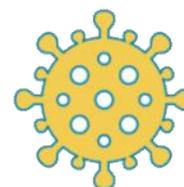
There is some debate around using the word 'cause' in epidemiology, particularly in the context of chronic disease. This is because epidemiology typically aims to understand factors that are associated with an increased *risk* of developing a particular condition – such factors will rarely (if ever) be wholly responsible for causing a chronic disease to occur. Rather, epidemiology aims to show that being exposed to a certain risk factor will lead to a higher probability of developing a disease. For example, the HLA genes DQ2 and DQ8 predispose someone to develop celiac disease – but, on their own, they are not sufficient to 'cause' celiac disease since most individuals with these genes will not develop celiac disease.⁴ The literature around risk factors in celiac disease onset are only just emerging or remain inconclusive. Infections and/or antibiotic use in childhood have been explored and suggest a potential risk, although further research is needed to confirm this mechanism.⁵⁻⁸ In conjunction with research exploring these risk factors in more detail, there are now several efforts testing novel, non-dietary therapies as a way help treat celiac disease beyond the gluten-free diet.

Celiac Disease & COVID-19

As with just about everything in the world, COVID-19 will affect celiac disease epidemiology in many ways. We are likely to see research for years to come on various chronic illnesses in the context of COVID-19 – how has the radical shift in our healthcare systems and the resources used impacted the care of complex health conditions and/or delayed the diagnosis of other conditions, for example? Understandably, the vast majority of research in the context of COVID-19 to date has primarily focused on the virus itself. However, an early initiative in relation to celiac disease from Columbia University has already come into the fold. The Surveillance Epidemiology of Coronavirus Under Research Exclusion (SECURE-Celiac) database is an international effort to identify individuals with celiac disease who have contracted COVID-19. This database will allow researchers to analyze and improve our understanding of how this coronavirus impacts those with celiac disease. As this registry is relying on others to submit data, if you or someone you know with celiac disease has had COVID-19, please consider sharing this resource with your family physician as they can submit information easily at this website: <https://covidceliac.org/>

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Italian Wedding Soup



- 6 Hot or Mild Italian Gluten Free Spolumbo Sausages

Remove sausage from casing and fry sausage meat in stock pot on low heat, cooking thoroughly and breaking meat apart. Alternatively, form sausage meat into small meatballs and roast in 350 oven for 15 minutes to keep shape, then add to stock pot.

Add all remaining ingredients (except pasta):

- 1 bag of chopped spinach (3 cups)
- 2 carrots diced small
- 1 small bunch fresh basil
- 3 Liters of GF chicken broth
- ½ cup diced onion
- 1 cup diced celery
- 2-3 cups small Gluten Free, cooked pasta



Let simmer.... As long as you want.

Before serving, stir in the cooked Gluten Free pasta.

Top with grated parmesan cheese.



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Chocolate Earthquake Cake

OMG! Chocolate heavenly goodness with a coffee espresso filling.
Recipe created by Kinnikinnick Corporate Chef Lori Grein



Ingredients :

Cake

- 1 package **Kinnikinnick Chocolate Cake Mix** (500 g)
- 1 package chocolate instant pudding mix (gluten-free) (102 g)
- 4 large eggs (240 g)
- 1 cup cold water (237 g)
- 1 tsp pure vanilla extract (3 g)
- ½ cup vegetable oil (109 g)
- 4 oz white chocolate - coarsely chopped (118 g)
- 2 oz milk chocolate - coarsely chopped (57 g)
- 2 oz dark chocolate - coarsely chopped (59 g)

Simple Syrup (optional)

- 1 cup granulated sugar (240 g)
- 1 cup water (240 g)

Espresso Mascarpone Filling

- 1 cup butter (227 g)
- ½ cup mascarpone (80 g)
- 2 cups icing sugar (480 g)
- ¼ cup cocoa powder (38 g)
- ¼ cup water (50 g)
- 1 tbsp espresso powder (3 g)

Chocolate Butter Cream Icing

- 1 cup butter (222 g)
- 1 tsp vanilla extract (3 g)
- 4 cups icing sugar (640 g)
- ¼ cup cocoa powder (38 g)
- ½ cup milk 2% (70 g)



Ganache Drip

- 100 g dark chocolate - chopped fine
- 120 g cream 33%

Optional: chocolate food colouring

Optional Decorations

- Chocolate KinniTOOS® Truffles
- Kinnikinnick Chocolate KinniTOOS®**
- assorted chocolates (gluten-free)

Directions:

Cake Base

Preheat oven to 350°F (179°C). Generously grease (2) 8 x 8 round cake pans. In a medium bowl combined eggs, oil, water and vanilla. Add **Kinnikinnick Chocolate Cake Mix** and pudding mix. Mix until combined. Fold in white, milk and dark chocolate. Divide batter equally between cake pans. Bake in preheated oven for 40 minutes. Remove from oven and let cool for 10 minutes. Invert pan and remove cake bases. Let cool completely before assembly.

Simple Syrup (optional)

Bring sugar and water to a boil, do not stir. Boil for 3 minutes. Let cool completely. Simple Syrup can be stored in the refrigerator for up to 3 weeks.

Espresso Mascarpone Filling

In a small bowl combine water and espresso powder. Set aside. In a medium bowl combine icing sugar and cocoa powder. Set aside. In a separate bowl mix butter until smooth. Add mascarpone and mix until smooth. Slowly add in cocoa icing sugar mixture 1 cup at a time alternating with espresso water. Mix until smooth and incorporated. Cover and set aside. Do not refrigerate.

Chocolate Buttercream Icing

In a medium bowl combine icing sugar and cocoa powder. Set aside. In a separate bowl mix butter until smooth. Slowly add in cocoa icing sugar mixture 1 cup at a time alternating with milk. Mix until smooth and incorporated. Cover and set aside. Do not refrigerate.

Ganache Drip (make prior to use/do not make ahead of time)

Heat cream in a small pot. Heat over medium-low heat until milk just comes to boil. Remove from heat and add chopped chocolate. Mix until chocolate is melted and mixture is smooth. Cool slightly and place mixture in squeeze bottle or piping bag.

Assembly

Filling

Trim the top of each cake base using a serrated knife. Cut each cake base into two layers for a total of 4 layers. Place one cake base on an 8" cake board (bottom cake side down). Spray cake base with Optional Simple Syrup. Spread a layer of Espresso Mascarpone Filling evenly on cake base. Repeat with next two layers. Place top layer on (bottom side up). Do not spray with Simple Syrup.

Crumb Coat

Using Espresso Mascarpone Filling, fill edges of layers to create even sides. Using a large scraper, scrape off excess filling and smooth sides. Cover the top of the cake with a thin layer of Espresso Mascarpone Filling. Using a pallet knife, smooth top (don't use too much icing). Add remaining Espresso Mascarpone Filling to the side of the cake and smooth using a large scraper. Finish with the

top of the cake using a pallet knife to create a smooth top. Let crumb coat set in refrigerator for 20 minutes.

Chocolate Buttercream Coat

Using Chocolate Buttercream Icing, place a dollop of icing on top and smooth working your way to the edges using a pallet knife. Add a generous coat of icing on the side of the cake. Use a large scraper to scrape off excess from sides and create a smooth finish. Finish with top of cake using a pallet knife to create a smooth finish working towards centre of cake. Place iced cake in the refrigerator for 20 minutes. Place remaining Chocolate Buttercream Icing in a piping bag with a star tip. Use for decorating cake and attaching assorted chocolates or **Chocolate KinniTOOS®**.

Ganache Drip

Prepare Ganache Drip. Let cool slightly in pot, then transfer to a squeeze bottle or piping bag. To check that the Ganache Drip is cooled enough to drip slowly and stand up, test the drip on the lip of a glass bowl. Once Ganache Drip is at desired consistency pull cake from refrigerator. Apply Ganache Drip using a squeeze bottle or piping bag in a continual motion. Start by applying Ganache Drip slightly in on cake top and continue creating a drip over the edge every couple of inches. Once drip has set up slightly. Fill in top of cake with Ganache Drip, careful not to go over edge of cake. Use a pallet knife to smooth top. Work quickly as Ganache Drip with set up fast.

Decorations

Create your own Chocolate Earthquake Cake using your favourite gluten-free chocolates or **Kinnikinnick Chocolate KinniTOOS®**. Try adding **Chocolate KinniTOOS® Truffles** - recipe available at <https://kinnikinnick.shoutcms.net/recipe>. Use remaining Chocolate Buttercream Icing to attach your design. Use chocolate and cookies to create height. Add decorations to the side and top of the cake to create your masterpiece.



Pancakes

Fluffy pancakes are a breakfast staple that you don't need to miss out on! These pancakes are light, airy and full of the flavour that you've come to expect. The kids will love starting their day with a giant stack!

- In a mixing bowl, combine dry ingredients - CUT flour, sugar, baking powder, baking soda and salt. Mix well.
- Add the eggs, melted butter and milk to mixture and mix very well with paddle attachment.
- If you don't want to use a mixer, you can use a whisk and mix by hand. Make sure you whisk well after each addition.
- Turn stovetop to medium temperature and heat griddle or frying pan.
- When warmed, begin pouring small amounts of batter into pancake size rounds onto griddle or pan.
- When bubbles start to form on top of batter, flip and cook other side. This total cooking process won't take long, approximately 3 minutes.
- You made need to adjust your temperature slightly if you find your pan gets too hot.
- When all the batter is made into pancakes, smother with your favourite toppings! Our families love whipping cream, hazelnut spread, fruit and syrup

INGREDIENTS

- 1 ¼ cup CUT Flour**
- 1 tbsp sugar**
- 2 tsp baking powder**
- ½ tsp baking soda**
- ½ tsp salt**
- 2 eggs**
- 2 tbsp butter (melted)**
- 1 ½ cup milk**



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Newsletter 2021

First Edition (**February**)

Second Edition (**May**)

Third Edition (**August**)

Fourth Edition (**November**)

E-mail submissions to Joanne Godsman

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