

History of Celiac Disease and Calgary Chapter - Canadian Celiac Association

Updated June 2015

Celiac disease has been known of since before the time of Hippocrates in 400 BC. At that time the affliction did not have a name nor was there any known cause or treatment.

In 1888 Dr. Samuel Gee was the first to declare that treatment for this affliction must be done by diet, and suggested the name Coeliac Disease. This led to the creation of many strange and even bizarre food combinations.

A diet often recommended during the 1920's and 30's was the banana diet. Bananas in the morning, at noon and again in the evening, as well as for any snacks. People actually survived on this diet, and for some their favorite food was a banana, although there are no statistics to confirm this.

Also, during the 1930's, since coeliac disease was considered to be a childhood disease, when a child reached age 7 they were declared "cured", and expected to resume a "normal" diet with regular food.

In 1936 a concerned mother took her sick child to a doctor, and observed that the child seemed to get better when bread was removed from the diet. That doctor was W. K. Dicke, who later became the Medical Director at Juliana Children's Hospital in The Hague, Netherlands. During 1940 to 1945 Dr. Dicke cared for and took extensive notes and observations of 4 children with coeliac disease under his care at the hospital. Dr. Dicke published his thesis in May, 1950 where he declared that wheat was the offending food in coeliac disease.

During the 1950's and 60's there was much controversy in the medical community whether coeliac disease was real, and if so was it important enough to be concerned about. Coeliac disease was considered to be rare (only 1 in 5000 persons) and only a child's disease.

1973 First efforts in Canada to form a support group for people with celiac disease - started by Kay Ernst in Kitchener, Ontario, based on information obtained from the Coeliac Society in England.

- 1976 First efforts to form a support group in Calgary.
 - an article in Chatelaine Magazine on celiac disease and a new organization in Ontario for celiac support spurred Marilyn Sawford to start a group in Calgary similar to the one started by Kay Ernst in Kitchener.
 - correspondence started between Calgary and Kitchener;
The Canadian Celiac Sprue Association of Waterloo Region
- 1977 October First general meeting in Calgary
- 1978 April 28 Resolution passed by Calgary Chapter to abide by constitution of Canadian Celiac Sprue Association
- 1978 May Dr. Donald Kasarda published his paper “ *The Relationship of Wheat Proteins to Celiac Disease*” in the ‘CEREAL FOODS WORLD’ journal
 - Dr. Kasarda is a plant scientist with the Western Regional Research Laboratory, USDA, Berkley, California
 - Dr. Kasarda describes the relationship within the grass family of wheat, rye, and barley to other grass family members such as oats, rice and corn
- 1978 June 7 Certificate of Affiliation, Calgary Chapter recognized as affiliate chapter of Canadian Celiac Sprue Association
 - the third chapter of the Association
- 1978 June 7 Calgary Chapter recognized as a charity
 - Revenue Canada assigns number 0535260-11-24 as official tax registration number
 - Finances \$688.00
- 1979 December 1 Consent given by Head Office – Kitchener – to register Calgary Chapter under Alberta Societies Act
 - Finances - \$674.00
- 1980 March 28 Certificate of Incorporation issued by Alberta Consumers and Corporate Affairs number 50240061 - Finances \$4,068.00
- 1985 Board of directors meetings held in Room 1302 – Alberta Children’s Hospital on Richmond Road in .S.W. Calgary
- 1988 February First discussions on taxation deductions on gluten free food
- 1988 March Calgary Chapter hosts the National Conference of the Canadian Celiac Association at the Palliser Hotel - 140 attended
 - the theme of the conference was “100 years after Dr. Gee”
 - keynote speakers were Dr. Kagnoff from La Jolla, California, and Dr. Don Kassarda, a plant scientist with USDA, Oakland, California
 - Dr. Kassarda did a study of wheat by breaking it down to the amino acid level (a chain of more than 200 amino acids) and revealing the presence (more than 2

times) of the gluten chain of amino acids that cause the toxic reaction to people with celiac disease. He also was able to grow a variety of wheat without the toxic components, bake a loaf of bread with his special wheat, but found the bread to be very unpalatable (only good use for the bread would be as a boat anchor).

- 1988 March Resolution passed wherein the Calgary Chapter consents to abide by the constitution and by-laws of The Canadian Celiac Association
- 1988 March 8 Certificate of Affiliation signed by chapter president Corrine Craig and national executive director Rosie Warteher.
- 1988 spring Calgary Chapter holds a GF family wiener roast and picnic at Edworthy Park
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- 1989
Calgary is first chapter to have an office
- Rehabilitation Society Building, #7 - 11 Street N.E.
- very small, room enough for a small desk, 1 filing cabinet and 2 chairs
- our first computer – an IBM-XT with 2 floppy drives
- 1990 spring Calgary Chapter holds a GF family wiener roast and picnic at Edworthy Park
- 1990 late fall
Calgary Chapter holds a car raffle as a fund raising effort
- prize of a new Mercury Marquis
- the intent was to sell to Christmas shoppers, but the draw date had to be extended to sell enough tickets to cover costs
- a lot of work for a small return
- other fundraising efforts included coin boxes, but most desirable locations to place the boxes were already occupied by other charities
- 1991 first casino at Riverside Casino near the stampede grounds
- 1992 April
bylaws changed at AGM
Board of Directors will serve for 2 years; Board to consist of; President, Vice President, Treasurer, Secretary and 7 other members at large
- 1992 August
name of chapter is officially changed with Alberta Consumers and Corporate Affairs
Canadian Celiac Association, L'Association Canadienne de la maladie coeliaque, Calgary Chapter
- 1993
Calgary Chapter is awarded the first chapter achievement award
- the award is a gold and white banner wall hanging
- the award is given for the 1992 production of a 60 second radio public service announcement that was produced by the Calgary chapter and distributed to all chapters across Canada to be broadcast during the October 4-10, 1992 celiac

awareness week; funding assistance was also provided to other chapters

- the announcement was aired in Calgary on two radio stations throughout the week
- the announcement was aired in Calgary and elsewhere for several years following, during Celiac Awareness week
- this project was lead by Marla Carroll

- 1993 Canadian Celiac Association national office names the national research fund as the *J. A. Campbell Research Fund* in honor of Dr. J. Alexander Campbell who died in 1993.
- Dr. Campbell was a member and advisor to the Ottawa Chapter, a member of the Professional Advisory Board, and a long time advocate for the CCA. Dr. Campbell did the studies of distilled alcohol to demonstrate that the gluten protein does not pass through the distillation process, therefore alcoholic spirits (whisky, gin, vodka and others) and white vinegar that are distilled are considered safe for people with celiac disease. Note that beer is fermented, not distilled, and not considered gluten free (in 1993 there was no gluten free beer, except maybe a rice brew from Japan that was not widely available commercially).
- 1994 April Trademark Agreement signed by President Anne Johnson
- 1994 June Motion to donate 40% of Casino proceeds to research
- Casino Fund-raising resolution is signed
- 1994 June First research project.
- eight students from Western Canada High School and Sir Winston Churchill High School were interviewed for two research positions available
 - interviews were conducted at the office location by Esther Pisio and Allister Boorse, assisted by Dr. Lay.
 - Roy Shelley helped to coordinate the students while waiting for their interview
- 1994 July & August Two high school students are selected to do summer research at the Calgary Health Science Center under Dr. G. Gall and Dr. Hardin (Jonathan Fung) and Dr. Lee (Sue Pederson).
- 1995 July First gluten free children's camp, 12 attend
- held at Girl Guide camp *Jubilee* near Cochrane, beside Bow River
 - organized and run by Calgary member Anne Livesey
 - first in Canada, there are 1 or 2 in USA
- 1995 November Motion carried that President or Membership Chairman can give free memberships up to 10 persons after proof of financial need
- 1996 January 19 Calgary Chapter holds a member Pot Luck supper evening at the office location in the Calgary Rehab building

- this is one of several pot luck suppers or pancake suppers held for members while the office was located in this building

- 1997 Esther Pizio publishes her "*Tips and Quips*", a 47 page booklet for those newly diagnosed with Celiac Disease. It contained known information of what celiac disease is, tips for shopping, cooking and travel among other useful information. This booklet and other office practices of Calgary volunteers was a basis for the national "*Peer Counseling*" program developed shortly after.
- 1997 January Motion carried that materials not be sent out on request, but only after membership in the association
- 1997 March Motion carried that newsletter not be forwarded to National Office before it is printed.
- 1997 April Motion carried that the Newsletter be printed 4 times per year.
- 1997 June Motion carried that \$11 per member be sent to National Office
- annual membership fee is \$21.00.
- 1997 Dr. Butzner conducts a one year study of CD children and oats
- children ages 4 to 17 must be biopsy proven to have CD and follow a gluten free diet
- the research project is funded by the Calgary Chapter
- the study found much the same results as other research projects conducted within the next few years; that children (and people generally) with celiac disease can tolerate eating small amounts of oats without adverse reactions
- 1997 September Motion carried that \$3000 be allocated to an account for Celiac Kids Camp
- 1997 November Motion carried that plates for Celiac Santa just be gluten free unless word is received of special needs, such as no peanuts, etc.
- Celiac Santa meant a plate of cookies for each new chapter member signed up that year, sometimes also for a few select shut in seniors.
- Celiac Santa was an idea of the office volunteers as a way to show new members that a gluten free diet did not mean having to give up all the good things in life.
- The program was carefully coordinated each year by Esther Pizio
- 1998 Canadian Celiac Association celebrates 25 years at the National Conference held in Kitchener, Ontario. One of the keynote speakers was Kay Ernst's son, who is a celiac and the reason all of this started 25 years ago.
- 1999 Calgary Chapter hosts the National Conference and gluten free market at the Calgary Convention Center - over 450 attend
- the theme for the conference was "*Road To Wellness*"

- keynote speakers were Michael Marsh from England and Joseph Murray from USA
- 2000 the first “*Celiac Community Kitchen*”, where 6 to 12 people get together in a community hall with kitchen facilities to cook meals for a week or two;
 - cost savings are gained by buying in bulk and preparing some common dishes for all participants
- 2000 July 8 First Stampede Breakfast
 - organized by Betty Saleweicz
 - held at the Calgary Rehab office location
 - complete with plenty of gluten free pancakes, gluten free sausages, square dancers, straw bales and sunshine
 - for several years following, George Waite arranged to have the official Stampede Chuckwagon present to cook the pancakes
- 2002 May 4 Calgary Chapter participates in first International walk “*Making Tracks For Celiacs*”
 - after 3 months organization, 170 participated and over \$8,000 was raised
- 2002 spring Calgary Chapter moves the office location to new facilities in the Calgary Epilepsy building in N.W. Calgary
 - new furniture for the new office was purchased as “flat paks” and assembled in the new office, a one day chore for Richard White and Allister Boorse
- 2002 Calgary Chapter hires a paid person to handle office duties and coordinate chapter activities
- 2002 Canadian Celiac Association does a nation wide survey of members
 - the results of this survey are studied by the medical community in many parts of the world
- 2003 May 24 Calgary Chapter sponsors a first degree relatives study
 - held in conjunction with the annual “*Making Tracks For Celiacs*” walk.
 - Research done by Dr. Butzner, Dr. Srivastava and Dr. Meddings.
- 2003 New Canadian crossed grain trademark unveiled at National conference held in Kamloops, BC
- 2003 October 18 Calgary Chapter hosts a regional mini conference
 - keynote speakers Dana Korn, USA and Dr. Switzer, Edmonton
- 2004 October 30 Calgary Chapter hosts a regional mini conference
 - keynote speakers Dr. Alessio Fasano, Dr. Butzner, Dr. Alan Lomax, Marilyn Sawford (the founder of the Calgary chapter)

- 2004 fall Efforts to develop an education program on Celiac Disease started by JoAnne Murray, a member of the Calgary chapter.
- the aim of the program is to educate and provide information to the food services industry, cooks, chefs and others involved in food preparation
- 2005 January 11 first presentation of education program material to SAIT students in the Baking course.
- The education program continued to evolve as new material, diet guidelines and cross contamination guidance sheets were developed.
- 2005 September 11 Pasta Frenzy
- pasta provided and cooked by Maplegrove Food and Beverage Corp.
- 120 attended
- also a fund raising evening
- 2005 – 2010 The education program material circulated to other chapters, as well as being revised as new research and other information on Celiac Disease became known.
- 2006 February 12 Brunch at the Legion
- 91 attended
- 2006 October 28 Calgary Chapter hosts a regional mini conference
- keynote speakers Dr. Alaa Rostom, Shelly Case, Dr. Decker Butzner and Kelly McGowan
- Kelly presented the findings of her research, the same material she will present in New York the following month
- Kelly was the recipient of the “*CCA Young Investigators Award*” in 2005
- Kelly has been a rider in the *Cycling for Celiacs* event, organized by the Edmonton Chapter, for the past three summers
- 2006 fall Calgary Chapter surveys members about eating in local restaurants
- survey results were published in the 2007 newsletter, first edition, and posted on the website
- 2006 November 9-11 Kelly McGowan presents her research at the *XII International Celiac Symposium* in New York, at the Celiac Disease Centre, Columbia University
- over 1400 delegates attended
- Kelly McGowan had been doing research on screening tests, follow up treatment and the prevalence of celiac disease in children
- She was a summer student, working in the labs with Dr. Butzner, sponsored by the Calgary Chapter
- the Calgary Chapter also sponsored her trip to New York.
- in the call for papers at the symposium, 208 applications were submitted, 11 were chosen, including the application by Kelly
- during the 3 day event, many other abstracts and reports were presented
- three summary reports of the symposium were presented in the March 2007

issue of the national newsletter
- Dr. Butzner refers to Kelly as “A rising star in the medical community.”

- 2006 December PAC formed (Professional Advisory Committee)
The role of the Professional Advisory Committee (PAC) is to serve as a resource to the Board of Directors of the Calgary Chapter of the Canadian Celiac Association (CCA-CC) as they plan and develop strategic priorities and execute programs, including but not limited to the following areas:
- Awareness and Advocacy
- Education and Publications
- Research and Projects
- Fundraising
Original members were: Dr. Decker Butzner, Dr. Paul Beck, Dr. Alaa Rostom, Jacqueline Gates, RD, Julia Wood, RD, Monique Chambefort, RD and Cheryl Richmond (liaison to the Calgary Chapter Board of Directors).
- 2007 spring Calgary Celiac News goes digital
- the second edition of the 2007 newsletter is the first to be made available on the website
- 2007 the Calgary Chapter provides gluten free supplies to the food bank
- volunteers met with food bank personnel to inform and educate them about the needs of people with celiac disease
- 2008 Calgary Chapter hosts a regional mini conference and gluten free market located at the University of Calgary student center,
- almost 400 people attend
- keynote speakers; Dr. Alessio Fasano, Dr. Decker Butzner and Dr. Trey Petty, the first time attention was focused on oral aspects of celiac disease
- other speakers gave presentations at 6 separate breakout sessions
- 2009 September 19 Calgary Chapter hosts a family BBQ at Bowness Park for members
- 2010 The education program is adopted by the national office.
- 2010 May 15 Calgary Chapter Hosts a gluten free market for members and the public at the Airport Hotel in N.E. Calgary.
- 2011 April 16 Calgary Chapter moved to a new, larger office location, the lower level of the HandiBus building in N.E. Calgary
- 2012 November 17 Calgary Chapter hosts a gluten free market at Parkdale Community Center for members and the public.
- 2013 April the Stampede breakfast is designated as the *Wendy T's Gluten Free Stampede breakfast* in memory of Wendy Turnbull who was killed in a car accident. She was a long time member and volunteer of the Calgary Chapter.

- 2013 November 2 Calgary Chapter Hosts a gluten free market at Sunnyside Hillhurst Community Centre for members and the public.
 - 200 attend in spite of a snowstorm that day
- 2013 – 2014 The education program has been developed into a national online course, offering a certificate upon completion. It is one of very few online courses of its kind in the world. Course material continues to evolve.
- 2014 May 30 Calgary hosts the National Conference and gluten free market at the Calgary Convention Center
 - the theme for the conference was “*Celiac Stomp*”
 - a less than expected attendance at this conference was an indication that many people are relying on the sometimes dubious information on the internet rather than local support groups.
 - 500 attend the gluten free market
- 2014 August 18 Calgary Chapter hosts a kids camp, 19 years after the first one
 - camp has been held every year, making this the 20th year
 - the camp is sponsored by patron Rod McDaniel
 - also co-sponsored by the Edmonton Chapter, and has been for the past 3 years
 - 60 children attend, ranging in age from 7 to 17 years; 11 from Edmonton and area, 49 from Calgary and area
 - throughout the past many years there have been children attend camp from all parts of Alberta, several places from Saskatchewan, and from British Columbia, as far away as Victoria
- 2014 November 22 Calgary Chapter hosts a mini gluten free market at Marda Loop Community Centre
 - 300 attend
 - the 2014 children’s Christmas party is also held at the same time and location, 42 children were there, ages infant to 13 years, plus several parents, and of course Santa