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THE UNIVERSITY OF CHICAGO
CELIAC
DISEASE CENTER

IMPROVING LIVES THROUGH AWARENESS,
EDUCATION, AND RESEARCH

Celiac Neuropathy

By Kourosh Rezania, MD

Celiac disease is one of the most common human autoimmune diseases. It is characterized by an abnormal immune response against the wheat protein (gluten) as well as the patient's own intestinal cells.

Celiac disease usually manifests in childhood with diarrhea, weight loss and failure to thrive. Less commonly, celiac disease is diagnosed in adults. Different neurological diseases, including neuropathy, are often the heralding manifestations of adult onset celiac disease.

What is a neuropathy?

Peripheral nerves can be divided into sensory, motor and autonomic, based on their function. The sensory nerves carry impulses from the nerve ending in the skin, muscle, or joints to the spinal cord and brain. On the other hand, the motor nerves extend from certain areas in the brain or spinal cord to different muscles (Figure 1). The autonomic nerves regulate blood pressure, heart rate, sweating and body temperature, among other functions. Neuropathy is characterized by dysfunction of the peripheral nerves. Depending on the location and the type of the nerve fibers involved, patients with neuropathy can have different symptoms.

How does celiac disease neuropathy present?

The most common manifestation of celiac disease neuropathy is pain, tingling and numbness in the feet (Figure 2). Some patients present with asymmetrical sensory symptoms, or even pain in the face (Figure 3). Muscle weakness and autonomic symptoms are less common in celiac disease neuropathy. It is important to objectively prove the presence of neuropathy

in patients with neuropathy symptoms, as these symptoms can be caused by diseases other than neuropathy. These include diseases of the central nervous system, primary pain syndromes like fibromyalgia, and psychogenic diseases.

Why is celiac disease associated with neuropathy?

There are a number of possible reasons for the association of celiac disease and neuropathy:

1. A nutritional deficiency due to malabsorption. Deficiency of some vitamins (especially B12, B6 and E), and metals (especially copper) are well known to cause a peripheral neuropathy.
2. Patients who have one autoimmune disease are predisposed to another autoimmune disorder more than the general population. Neuropathy could be a manifestation of another concomitant autoimmune disease in patients with celiac disease. For example, antibodies to some of the components of the peripheral nerves (i.e. gangliosides) are found in some celiac disease patients with neuropathy.
3. It has been suggested that some of the antigens targeted in celiac disease (i.e. gliadin and tissue transglutaminase) have structural similarities to some of the proteins expressed in the nervous system. Therefore, it has been speculated that the autoimmunity in celiac disease could target intestinal cells and nervous system



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simultaneously. Other diseases of the nervous system have been reported in patients with celiac disease. As a matter of fact, lack of coordination (ataxia) is suggested to complicate gluten sensitivity with or without celiac disease. The majority of patients with ataxia associated with celiac disease also have a neuropathy.

Diagnosis

A nerve conduction study is generally used as the initial diagnostic step. However, the nerve conduction study is often normal in patients with an early neuropathy or a neuropathy that only involves the small fiber nerves. Quantitative sweat test and skin biopsy with measurement of intraepithelial nerve fiber density are other modalities that can be used in an appropriate setting.

Neuropathy is a common disease and neuropathy associated with celiac disease is probably a rare entity. Therefore, positive serology to celiac disease-related antigens (e.g. gliadin) in a patient with neuropathy does not automatically prove that celiac disease is the cause of the neuropathy. Importantly, a workup has to



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The University of Chicago Celiac Disease Center is dedicated to raising awareness and diagnosis rates and meeting the critical needs of people affected by celiac disease nationwide through education, research and advocacy.

The contents of this newsletter are not intended to diagnose or recommend treatment for celiac disease. Please consult your healthcare provider with questions about your condition.

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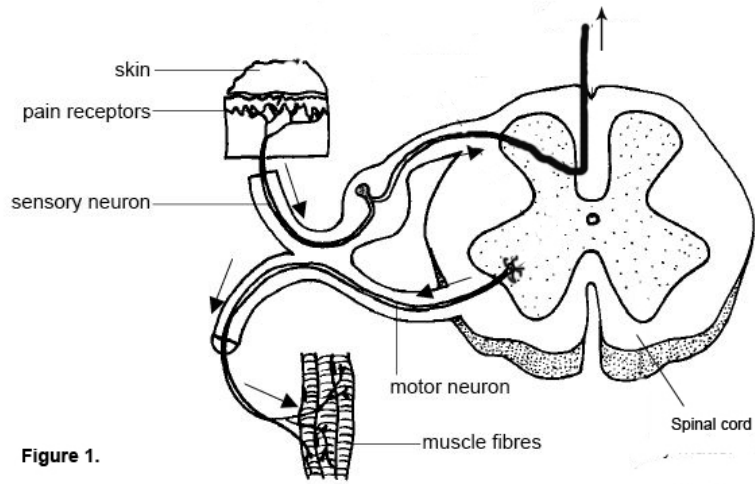


Figure 1.

Figure 1. Schematic representation of spinal cord, sensory and motor nerves.

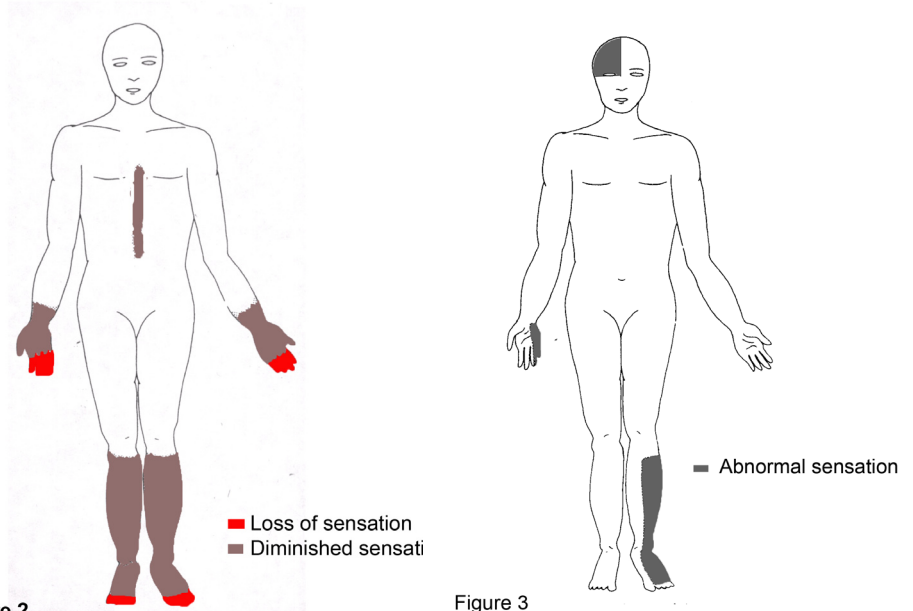


Figure 2

Figure 3

Figure 2. Length dependent neuropathy is the more common pattern of presentation of celiac disease neuropathy. Symptoms start in the toes earlier than the fingertips.

Figure 3. A multifocal neuropathy has often been reported in patients with celiac disease neuropathy.

be done to unravel other more common causes of neuropathy. Specifically, patients should be assessed for diabetes, nutritional deficiencies and other autoimmune diseases. Also, the existence of celiac disease should be proven with an intestinal biopsy if the serologic tests are positive. In patients with a rapidly progressive neuropathy, a nerve biopsy has to be considered to assess for other treatable causes of neuropathy (like inflammation in the nerves or blood vessels).

Treatment

A gluten free diet has to be started in patients with celiac disease and neuropathy, regardless of whether neuropathy is caused by celiac disease or not. It is unclear, however, if the institution of the gluten free diet results in improvement of celiac disease neuropathy. Vitamin and mineral supplementation may also be beneficial. The use of immunomodulatory treatments like intravenous immunoglobulin infusions or immunosuppressants for the treatment of celiac disease neuropathy remain a controversial issue.

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RESEARCH COORDINATOR NURALIMA GRANDISON JOINS THE CENTER



The University of Chicago Celiac Disease Center recently added the position of study coordinator to step up clinical research efforts. Some of the current projects and initiatives are listed below:

1) CELIAC DISEASE DATABASE: The nation's most comprehensive research database of information regarding celiac disease patients. Information on new and existing patients of the University of Chicago Medical Center is currently being gathered to allow the research team to examine clinical, epidemiologic, and pathological features of our patient population. We are one of the leading celiac disease medical centers in the world and the studies using information gathered from this database will greatly contribute to our understanding of the disease. This will ultimately lead to an improvement in the nature and quality of care we can provide to patients, and empower us with useful tools to reach our ultimate goal of finding a cure for the disease.

2) PROBIOTIC TREATMENT FOR CELIAC DISEASE: Irritable Bowel Syndrome (IBS) symptoms are often present in celiac patients, and in many cases they do not respond to a gluten-free diet. This represents a frustrating experience for newly diagnosed patients, as they expect their gastrointestinal symptoms to regress after diagnosis and the implementation of a gluten-free diet. The Celiac Disease Center is currently applying for funding to investigate the efficacy of probiotic therapy in treating IBS symptoms in celiac patients on the gluten-free diet.

3) THE ROLE OF BREASTFEEDING IN THE PREVENTION OF CELIAC DISEASE: Studies have shown that breast feeding at-risk infants at the time of gluten introduction prevents the development of celiac disease. The risk of developing celiac disease is reduced by prolonged breast feeding, and introduction of gluten during breast feeding, in the right "time window" and in small amounts. Dr. Guandalini and The University of Chicago Celiac Disease Center will be partnering with the University of Maryland Center for Celiac Research on a study to further investigate the effect of early versus late gluten introduction in at-risk infants on developing celiac disease.

4) IMMUNOLOGICAL MECHANISMS OF CELIAC DISEASE: NurAlima is assisting Dr. Bana Jabri and her research team on several

studies investigating the immunological mechanisms of celiac disease by recruiting patients. Dr. Jabri is creating the first successful mouse model for celiac disease and this will allow her to study the developmental and functional aspects of immune function in the mouse and human intestine. Dr. Jabri's ground-breaking work with the immunological mechanisms of celiac disease will most certainly lead to novel insights into inflammatory intestinal diseases such as celiac disease.

5) EATING BEHAVIOR STUDY: The University of Chicago Celiac Disease Center is partnering with Rutgers University on a survey study investigating eating behavior in healthy young adults and young adults with a diet-related chronic health condition. By investigating factors that are associated with both "healthy" and "unhealthy" concern for one's body weight, diet, and health condition treatment, we hope to gain useful information that will aid parents and healthcare providers in their efforts to help young adults develop and maintain a healthy concern for their overall wellbeing.

If you have thirty minutes to participate and are between the ages of 18 to 25 years, please complete this eating behavior survey. You may be invited to complete a twenty minute follow-up survey, as well. To complete the survey, please visit this link and click to accept participation on the first two pages: <http://nutrisci.rutgers.edu/eating100/>.

Nuralima brings with her a strong background in healthcare, research, and early childhood education. NurAlima is a graduate of Connecticut College and the rigorous post-baccalaureate premedical program at Columbia University. She grew up in western Massachusetts, and is the oldest of four children. She worked in various research capacities at both at Columbia Presbyterian Hospital and Mount Sinai Hospital in New York City. We are thrilled to have NurAlima join our team.



This year's Annual Spring Flours Fundraiser promises to be our best ever. There are more chefs and restaurants participating than ever before—a total of 31 of Chicago's finest will offer their very best gluten-free cuisine for what promises to be a memorable evening. Come help us celebrate our 10th year by joining us at Spring Flours at Chicago's Swissôtel on May 14th. Tickets go on sale on April 1, and are available on our website, www.CeliacDisease.net, or by calling us at (773) 702-7593.

Spring Flours will also feature a silent and live auction, and a raffle. Come bid on amazing opportunities: two tickets to Dancing with the Stars in Los Angeles, a weekend at the spectacular Kenwood Inn in Napa Valley and a week at a luxurious vacation home in Michigan, just to name just a few. Buy a raffle ticket and put yourself in the running to win a new Apple iPad.

The wonderful restaurants and caterers joining us this year are:

- Ben Pao
- Bistro 110**
- Carnivale
- Centered Chef Food Studios**
- Cooper's Hawk Restaurant & Winery
- Da Luciano's**
- Deerfields Bakery
- Fogo de Chao**
- Food Life
- Francesca's Tavola**
- Kendall College

- Kona Grill**
- L & J Popcorn
- Maggiano's Chicago**
- Marcello's: A Father & Son Restaurant
- Mon Ami Gabi & Café Ba Ba Reeba**
- Osteria Via Stato
- P.F. Changs**
- Pear Tree Catering
- Pinstripes**
- RL
- Rose's Wheat Free Bakery**

- Roy's
- Shaw's Crab House**
- Smokin' T's BBQ
- Swirlz**
- Swissôtel
- Tavern at the Park**
- Wildfire
- Zapatista Mexican Grill**
- ZED 451

We also wish to thank our generous sponsors, without whom this very special evening would not be possible.



The Gluten Free Cooking Expo For any one interested in the gluten-free diet, whether you've been at it for years and just need some new ideas, or whether you are new and just learning, the Gluten-Free Cooking Expo is a must. The Expo, which takes place on **April 17th and 18th** at the Wyndham Hotel in Lisle, IL, offers demonstrations and information on quick and easy meal preparation, bread baking and much more. There are professional chefs, restaurant owners, cookbook authors, nutritionists and vendors participating. The event will also feature a children's area and vendor fair open to the public. For more information or to purchase tickets, please go to <http://www.gfreelife.com>.



CARE PACKAGE PROGRAM

The University of Chicago Celiac Disease Center's Care Package Program continues to grow, sending out more Care Packages each month and adding new partners regularly. For the first two months of 2010, Care Packages are up 34 percent over the number sent out last year, and the numbers show no sign of abating.

So far this year, Care Packages have been sent to 29 different states around the country, including the first one ever to Alaska. We are pleased to be working with so many wonderful sponsors to make this program a reality, and to introduce those new to the gluten-free diet to so many wonderful products. The Care Package Sponsors include:

Bakery on Main
Bhuja Snack Mix
 Bob's Red Mill
Chebe Bread
 Crunchmaster
Enjoy Life
 Kettle Soup
Mary's Gone Crackers
 Mr. Krispers
Namaste
 Pamela's Products
Peanut Butter & Co.
 Protein Plus Peanut Flour
Purefit Bars
 Rice Chex
San-J Soy Sauce
 Schär
Udi's Granola

May is Celiac Awareness Month

May is the official Celiac Awareness Month. To celebrate, The University of Chicago Celiac Disease Center is holding our Spring Flours fundraiser (see previous page), and we also want to bring you news from some of our partners in the ongoing effort to increase celiac awareness.

The American Celiac Disease Alliance

The American Celiac Disease Alliance (ACDA), which was cofounded in 2003 by 15 major celiac organizations, is based in Alexandria, VA. It works on the global issues that affect so many individuals with celiac disease, and advocates for the disease and favorable legislation in the halls of federal agencies around Washington, D.C. Some of its recent initiatives are:

Working with the Food and Drug Administration:

The ACDA continues to press the Food and Drug Administration (FDA) on the need to set the standard for labeling products as 'gluten-free.' In a recent letter to Dr. Peggy Hamburg, FDA commissioner, the ACDA expressed concern about the undue delay in finalizing the gluten-free rules, and that the term "gluten-free" is now being used as a marketing phrase without any tools being used to ensure the accuracy of such claims. This has created an ongoing burden to the growing number of individuals diagnosed with celiac disease.

Schools:

The ACDA works to ensure that students with celiac disease have access to gluten-free school lunches. There are a number of excellent examples of schools which are accommodating special diets and more specifically the gluten-free diet including the Rochester Public Schools in Minnesota and Alexandria City Schools in Alexandria, VA. Sample menus are available on the ACDA website (www.americanceeliac.org) If your child's school offers gluten-free lunches, please send a copy of the menu to info@americanceeliac.org for inclusion on this list.

The National School Lunch Program (NSLP) is under review this year and it is critically important that lawmakers hear from parents of celiac kids. One of the biggest reasons schools don't provide gluten-free meals is cost. Please take a few minutes and send a letter to your Representative and Senators and ask that they increase funding for the NSLP so that ALL children, especially those with medically prescribed diets, are able to have lunch at school.

Get Involved

We encourage you to visit the ACDA website, www.americanceeliac.org/advocacy.htm, to find out how you can take action to improve the lives of those with celiac disease.

L&J POPCORN SUPPORTS THE UNIVERSITY OF CHICAGO CELIAC DISEASE CENTER'S MODEL MOUSE PROJECT

L&J Popcorn is a new gluten-free popcorn company. As standard practice, the company provides a portion of its proceeds to The University of Chicago Celiac Disease Center, but it is increasing its donation through the end of May to celebrate National Celiac Awareness Month and support our research to develop of mouse model for celiac disease (for more information please visit <http://www.celiacdisease.net/mouse-model-video>).

L&J Popcorn will donate a portion of every tin of popcorn sold to the Model Mouse project. To participate, go to www.LandJpopcorn.com. When you get to the "check out" portion of your order simply type "UCCDC" in the message box. L&J Popcorn will donate \$2 for every 1 gallon tin, \$3 for every 2 gallon tin and \$4 for every 3 ½ gallon tin, and an additional \$1,000 if 300 tins are sold.

Keep checking the website: At the end of each week L&J Popcorn will post the total number of tins sold. Visit www.LandJpopcorn.com and feed the mouse!



Wildfire chef Larry Donahue with Wildfire Sales and Marketing Manager Laura Rosen and Wine and Spirits Director Brad Wermager.

WILDFIRE

The Wildfire Restaurant in Glenview, IL, opened its doors one evening in February for a very special event—a gluten-free gourmet dinner with wine pairings, to benefit the University of Chicago Celiac Disease Center. Wildfire's chef, Larry Donahue and his staff truly outdid themselves preparing an incredible meal for all attendees, including gluten-free pizza, pan-seared ahi tuna with field greens, braised short rib with roasted root vegetables and mashed potatoes and poached pear tartlet. Each course was accompanied by a delicious wine, carefully selected by Wildfire Wine and Spirits Director Brad Wermager and generously donated by E&J Gallo Wine Estates, Folio Fine Wine Partners, Constellation Wines US and W.J. Deutsch & Sons, Ltd.

Wildfire and its president, Howard Katz, have long been supporters of the University of Chicago Celiac Disease Center and have been so dedicated to educating themselves and their staff and creating viable options for celiac patients at Wildfire Restaurants around the country. We wish to thank Wildfire and the Lettuce Entertain You company for all their efforts and support on behalf of the celiac community.

Celiac Skate

The 2010 Celiac Skate event, which took place on February 21 in Highland Park, IL, was once again a resounding success. Those who came enjoyed skating, a fun silent auction and delicious gluten-free baked goods. Everyone had a wonderful time, and the event raised thousands of dollars to support The University of Chicago Celiac Disease Center's programs and research. We are so appreciative of the wonderful group of women who make this event a reality: Cindy Ginsburg, Stephanie Isaacson, Sari Kovitz, Caryn Kahn, Laura Rubin, Amy Scramberg and Nicole Sommerfeld.

