Celiac Disease FOUNDATION 25th ANNIVERSARY

INSIGHT

SUMMER 2015 | Vol. 24-5

Gluten-Free Community Unites at National Conference & Gluten-Free EXPO

Life-changing opportunity for individuals with celiac disease and other gluten-related disorders in Pasadena, CA, May 2-3, 2015

Celiac Disease Foundation (CDF) is pleased to announce that over 2,700 people – patients, family members, caregivers, healthcare professionals, and gluten-free foodies – attended CDF's annual National Conference & Gluten-Free EXPO on May 2-3, 2015, in Pasadena, CA. The May 2nd Conference focused on medical information and updates on celiac disease, one of the world's most prevalent and under diagnosed autoimmune diseases. The EXPO on May 2nd and 3rd celebrated food options now available for people with celiac disease, gluten sensitivity, and others who seek benefits from the gluten-free lifestyle. This year's event also included a 25th Anniversary GALA Dinner, honoring CDF's Founder, Elaine Monarch. For many of the conference attendees, this

was the first time they were surrounded by a community of people living with celiac disease or gluten sensitivity.

The Conference

"Celiac Disease Foundation is committed to raising awareness among the public and healthcare professionals about the importance of screening and treatment for celiac disease and other gluten-related disorders," stated Marilyn G. Geller, Chief Executive Officer of CDF. Attendees of the Conference were rewarded with presentations from members of CDF's Medical Advisory Board, including: Joseph Murray, MD, Sheila Crowe, MD, and Shelley Case, BSc, RD. Dr. Murray outlined the biological, symptomatic, and epidemiological basics of celiac disease, noting diagnostic methods, and speaking about future possibilities for managing and testing for the disease. Dr. Crowe followed Dr. Murray's talk, and delivered a presentation called, *A Balancing Act: Women's Health and Celiac Disease*. Though she primarily focused on women's health topics, such as the impact of celiac disease and treatment

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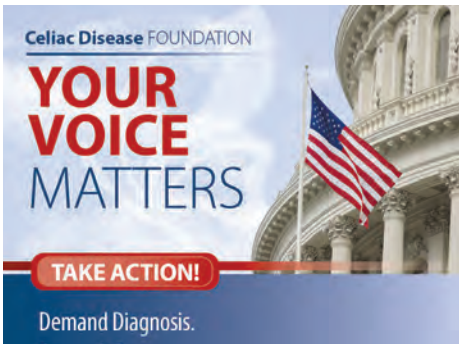

Your Voice is Heard in D.C.

Decision makers in the federal healthcare and health research industry are paying attention to a disease that impacts millions.

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Marketplace App Launch

CDF launches the first Gluten-Free Allergy-Free Marketplace App, available in July for iPhone and Android.

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A New Partnership

CDF partners with Children's National Health System through a generous endowment from the Resnick Family.

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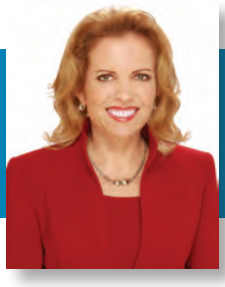


Marilyn's Message

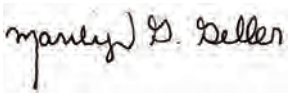
Every day, I talk to people who, like me, live with celiac disease – either personally or as a caregiver for someone they love. Each of their stories, while unique, share common underlying themes: the incredible suffering they either endured or witnessed until someone finally suggested getting tested for celiac disease, the difficulties adhering to a strict gluten-free diet, especially away from home, and the worry about the long-term implications of the disease. I want each of you to know that CDF is absolutely committed to working on those three issues. We have launched an ambitious set of initiatives around public and healthcare provider education, patient advocacy, and research to advance the agenda that is important to us all.

The toughest part of my job as CEO of Celiac Disease Foundation is to balance the overwhelming and compelling needs of the celiac community against our resource capacity to reach our goals. I have spent a lot of time articulating our needs and our agenda to address those needs. It would be imprudent of me not to comment on our resources. Our operating budget has nearly doubled over the last three years. We have been in a position to increase our investment in research, advocacy, and public and physician education as a result, with significant accomplishments. Realistically, however, we need to reach millions more who suffer from symptoms, and hundreds of thousands of physicians who either stubbornly or ignorantly refuse to order a celiac disease panel blood test. We need to increase our presence in Washington, D.C. to reach key individuals who decide how billions of federal medical research dollars are spent. We need to continue to invest strategically in research to unlock treatment possibilities, and address the long-term implications of the disease. Truthfully, we need more resources to continue the hard-fought progress we have achieved thus far.

I know that you are committed to our common cause, and I trust that many of you give generously to support our efforts. If you can do more, please do so today. If that isn't an option (or even if it is), please consider making a planned gift to CDF. The simplest way is to designate CDF as one of the beneficiaries of your will and/or retirement plan. That way, your support of CDF – your commitment to end this needless suffering – becomes part of your enduring legacy.

For more information on how you can make CDF a part of your estate planning, please contact me or our Chief Development Officer, Deborah Ceizler, at 818-716-1513, x103.

Thank you.



Marilyn G. Geller
Chief Executive Officer

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Celiac Disease Foundation CEO, Marilyn G. Geller, has made six trips from her home in Southern California to Washington, D.C. this year. "For too long, celiac disease has been ignored as a major public health issue by the federal government," Mrs. Geller said last week. "For all of us in the celiac disease community, this neglect has meant serious delays not only in administering the tests for diagnosis, but also in research for possible alternative treatments for the disease. Finally, after a lot of work, we believe that the decision makers in the federal healthcare and health research bureaucracy are paying attention to a disease that impacts millions of Americans."

To understand why CDF's constant presence in Washington – testifying to policymakers, presenting key findings about the patient community, and meeting with key federal health executives and members of Congress – is important, one must appreciate the enormous and central role the federal government plays in healthcare. The government spends $1,000,000,000,000 on healthcare every year. This translates to more than one in every four dollars spent in the American healthcare economy. That is more than $3,000 in federal medical outlays for every person in the U.S. Most of the money goes to fund healthcare for seniors, the poor, and veterans. Only a little more than $40 billion of the federal healthcare budget, however, is spent on medical research, food and drug regulation, and disease prevention and education.

Last year's FDA-mandated gluten-free food labeling rule was a hh,

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Janelle Smith is a UCLA-educated Registered Dietitian Nutritionist. As CDF's resource to help our community live gluten-free, she is here to provide tips and tricks for simple and delicious eating throughout the year. Janelle hosts a webinar each month geared toward the time of year, co-occurring diseases, or any relevant news in the gluten-free world. This month, Janelle discusses the Nutrition and Dietetic Panel that took place at the recent CDF National Conference & Gluten-Free EXPO. The "Ask-the-Dietitian" section of our website provides the resources, tools, and advice you need to maximize your health. To view previous webinars, please visit *celiac.org/webinars.*

Food for Thought, with CDF's Dietary Leaders

"You almost have to have a PhD in Food Science these days just to read a nutrition label," Shelley Case, BSc, RD, CDF Medical Advisory Board Member, joked while addressing the confusion over ingredients to avoid on a gluten-free diet. Luckily, Case and two other leaders in gluten-free nutrition, Anne Roland Lee, EdD, RD, LD, and Yang Pan, MD, PhD, leant their expertise to clear up the confusion about safely and nutritiously following a gluten-free diet at the Dietitian Panel of the most recent CDF National Conference & Gluten-Free EXPO.

Case provided a summary of current research into the safety and nutritional content of gluten-free foods. Everything from sauces and salad dressings to seasoned nuts, soup bases, potato chips, and vegan proteins need to be examined for hidden ingredients containing gluten. Thankfully, now that the FDA has defined the term "gluten-free" for voluntary use in the label of food products, sources of gluten are more frequently declared. However, even naturally gluten-free foods, such as whole grains, which do not themselves contain gluten, may contain inadvertent gluten, meaning gluten coming from cross-contact with wheat, barley, or rye, during cultivation, harvesting, and/or processing. Case cited three studies on oats (Hernando et al 2008, Koerner et al 2011, and Korner et al 2013) that examined the oat supply for incidental gluten. In these studies, the majority of oats examined were found to contain inadvertent gluten, ranging from several hundred to several thousand parts per million – up to several hundred times more than the maximum safe threshold for gluten content in foods for those with celiac disease (20 ppm). These studies led to the current recommendation for those with gluten-related disorders to only consume oats that are validated to contain less than 20 ppm of gluten.

In a presentation titled, *Truth or Consequence,* Dr. Anne Lee, Director of Nutritional Services for Dr. Schar USA, Inc., addressed myths in gluten-free labeling requirements. She encouraged consumers to always read ingredient labels and never assume that a gluten-free label is accurate, especially in the case of voluntary advisory statements (like "processed in a facility" or "may contain"), or USDA-regulated foods that are not regulated by the FDA definition of "gluten-free." As an insider tip, she recommended that consumers call companies directly to determine the source of ingredients, and, if necessary, to talk to the quality assurance department of a company rather than customer service in order to get knowledgeable answers. Dr. Lee then tackled the question: is the gluten-free diet as nutritious as a regular diet? She cited the studies Thompson, Dennis, Higgins, Lee & Sharrett (2005), Dickey & Kearney (2006), and Hallert, Grant, Grehn & Granno (2002) that found inadequate micronutrient intakes and weight gain in individuals following gluten-free diets. When substituting common grain-based foods, like cereals, crackers, breads, and muffins for gluten-free versions, individuals with celiac disease and gluten sensitivity are likely to be lacking adequate iron, folate, and fiber. Most people also gained 20-25 pounds from following a gluten-free diet, regardless of whether they were underweight when starting the diet. By substituting just the grain portion of the diet, Dr. Lee cited her study (Lee et al 2009), which illustrated how using these naturally gluten-free alternative grains can close the nutritional gap. Case echoed these concerns on nutritional quality of the gluten-free diet, and offered several suggestions for increasing nutritional value. Whole grains like gluten-free oats, quinoa, millet, and amaranth were cited as better alternatives for products made with white rice flour, corn starch, and tapioca starch. Case especially encouraged attendees to experiment with bean flours and nut flours in baked goods for a naturally rich source of vitamins, minerals, protein, and fiber.

Dr. Yang Pan, Principal Scientist of Global R&D Nutrition Sciences Team at PepsiCo then shared her insight into the challenges and successes of Frito-Lay's multi-year initiative for validating gluten-free foods that the company labels and sells. Dr. Pan spoke about the extensive processes that Frito-Lay took to ensure that products labeled "gluten-free" are safe

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Celiac Disease Foundation Partners with Children's National Health System for Broader Mental Health Education, Awareness, and Support Nationwide

Living with a chronic illness that requires a lifelong commitment to a strict gluten-free diet can be difficult for anyone. For children and teens, the emotional and psychological impact associated with celiac disease can have particular and profound challenges. We know from emerging brain research, for example, that the teenage brain is especially sensitive to peer approval as they develop the ability to see themselves as others see them. No wonder, then, that celiac disease and the need for strict adherence to a gluten-free diet can cause severe stress on families and social relationships, and can contribute to a sense of social alienation, feelings of worthlessness, low self-esteem, and depression.

In the first national effort to systematically address the emotional and psychological issues of young people with celiac disease and other gluten-related disorders, Celiac Disease Foundation (CDF) and Children's National Health System (Children's National) have launched a new partnership to expand mental health education around this specific issue and to empower healthcare providers and community-based peer support facilitators to provide counseling. CDF is the nation's leading disease advocacy organization for celiac disease; Children's National is based in Washington, D.C., and is recognized as one of the nation's top pediatric teaching hospitals by U.S. News & World Report. CDF is grateful for this partnership, funded by a generous endowment from the Resnick Family, longtime supporters of the Foundation.

"Living a gluten-free life is just the beginning for young people diagnosed with celiac disease," stated Peter Resnick. "While the gluten-free diet is absolutely critical, at the same time, we often overlook the emotional impact on children who are alienated by their peers because they can't eat the same foods. Without learning how to cope with this alienation," Resnick continued, "children can withdraw and become prone to depression. That is why we are thrilled to see this partnership form and that this important project is underway."

"Celiac Disease Foundation and Children's National will stand together to provide help and hope," said CDF Chief Executive Officer, Marilyn G. Geller. "We are pleased to be working with one of the nation's most distinguished pediatric hospitals to help individuals and families affected by celiac disease. Our common mission will include training healthcare providers and community-based peer support

Continued page 23

Summer Recipes

Oatmeal Berry Bars

Ingredients

1 cup **Bob's Red Mill** White Bean Flour
1 cup gluten-free rolled oats
½ cup packed dark brown sugar
1 ½ tsp xanthan gum
¾ tsp cinnamon
¼ tsp ground allspice
¼ tsp table salt
½ cup (1 stick) unsalted butter, melted (or non-dairy alternative)
2 tsp pure vanilla extract, divided
⅔ cup berry preserves or jam

Directions

Preheat oven to 350°F. Line 8-inch square nonstick pan with foil and grease with butter. In medium mixing bowl, whisk together white bean flour, oats, sugar, xanthan gum, cinnamon, allspice, and salt until thoroughly blended. Add melted butter and 1 tsp vanilla; mix with spatula until crumbly. Press 1 cup of this mixture firmly and evenly on the bottom of the pan.

Mix the remaining tsp of vanilla with the preserves and spread evenly on top. Sprinkle the remaining oat mixture on top and pat firmly to make an even crust. Bake 20-25 minutes on middle rack, or until top is lightly browned. Cool bars in pan for 10 minutes before removing and cutting.

Recipe from *Pulsecanada.com*, developed by Carol Fenster and Shelley Case, BSc, RD
Makes 16 squares. Each square contains: 194 calories, 4g protein, 7g fat (4g saturated), 29g carbohydrate (3g fiber), 58g sodium, 217mg potassium, 28mcg folate, 41mg calcium, 1mg iron

Multigrain Penne Rigate with Vegetables

Ingredients

1 box **Schar** Gluten-Free Multigrain Penne Rigate
1 medium zucchini, sliced
½ white onion, finely chopped
¼ cup white wine
½ small bunch chives, chopped
½ clove garlic, finely chopped
2-3 fresh mint leaves
2 tbsp extra virgin olive oil
½ tbsp red peppercorns

Directions

Heat olive oil, garlic, and onion in a frying pan until browned, then add white wine. Add zucchini and chives, then season with a dash of salt, and cook for six minutes. Remove from heat and cover with a lid. Add cooked pasta, mint, and red pepper to pan and mix; let stand for 1-2 minutes before serving.

Recipe from *Schar.com/en-US*
Makes 2 servings. Each 3.5 ounce serving contains: 214 calories, 4.1g protein, 4.3g fat, 39g carbohydrate

For more recipes, please visit celiac.org and choose 'Gluten-Free Recipes' under the 'Live Gluten-Free' tab.

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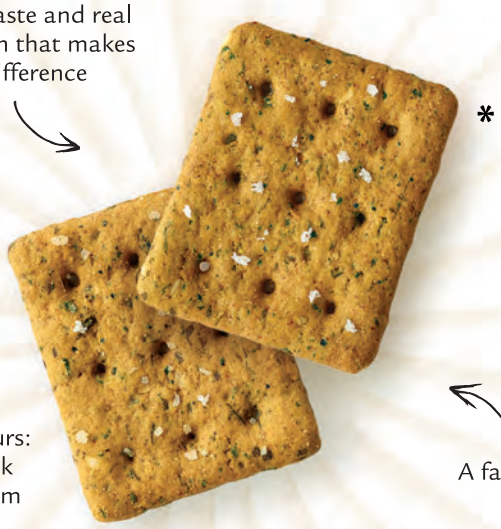

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Are You a CDF Champion?

by Deborah J. Ceizler, Chief Development Officer

There is a perception among some that Celiac Disease Foundation is supported primarily through corporate sponsorships and donations. That is not true.

While we value our corporate partners (each of whom is carefully screened to ensure that their policies are consistent with our mission) and appreciate their support, in truth, more than 70% of our financial support comes from individuals like you. What is also true is that for CDF to continue to grow, as we must if we are going to better serve the celiac disease community by funding more research, advocacy, and public and healthcare provider education, we need more tax-deductible donations.

We love our donors. Their sustained commitment to improving the quality of life for the celiac disease community is truly making a difference. Many of you have expressed a desire to do more, but wondered how you could do so and stay within your budgets. I suggest becoming a monthly donor to CDF.

Please understand why CDF's monthly donors are special. The consistency and predictability of their giving helps us budget our investments in the mission. We hear from our monthly donors all the time about how delighted they are that this kind of donor plan empowers them to give more than they otherwise thought they could. Additionally, we stop sending you so many fundraising solicitations – we both like that benefit!

If you think that becoming a monthly donor is a tax-deductible giving option that might make sense for you, let me share with you a couple of details.

- Setting up a monthly donor program for CDF is easy. Go online to *celiac.org/monthlygiving* and enter your information there. Once a month, on the date you choose, your credit or debit card will be charged with your monthly gift.
- You can cancel or change your monthly gift at any time for any reason; we understand that circumstances change. We are here to help you, no questions asked, or you can change your status securely online.

I invite you to join a select group of monthly donors to CDF today by going online to *celiac.org/monthlygiving*. Our average monthly gift is $20, but you can elect to give more or less. At whatever level you choose, we thank you.

Summer Recipes Continued from page 13

Dill Encrusted Trout

Ingredients

3 trout fillets
1 tbsp olive oil
2 tbsp hummus
1 tbsp fresh dill, chopped
1 tsp lemon juice
½ cup crushed **Frito-Lay** Tostitos® Original Restaurant Style Tortilla Chips

Directions

Preheat oven to 425°F. Lightly coat a baking dish with olive oil and place trout skin-side down. In a bowl, combine hummus, dill, and lemon juice. Spread over top of fish. Top with crushed chips, pressing lightly to adhere to fish. Bake for 12 minutes, or until fish flakes easily with a fork. Serve with steamed wild rice.

Recipe from *Fritolay.com*
Makes 3 servings. Each fillet contains: 255 calories, 15g fat (2g saturated), 46mg cholesterol, 146mg sodium, 323mg potassium, 12g carbohydrate (1g fiber), 18g protein, 2% daily value vitamin A, 3% vitamin C, 7% calcium, 12% iron

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Celiac Disease 101, with Joseph Murray, MD

by Victoria Hornstein

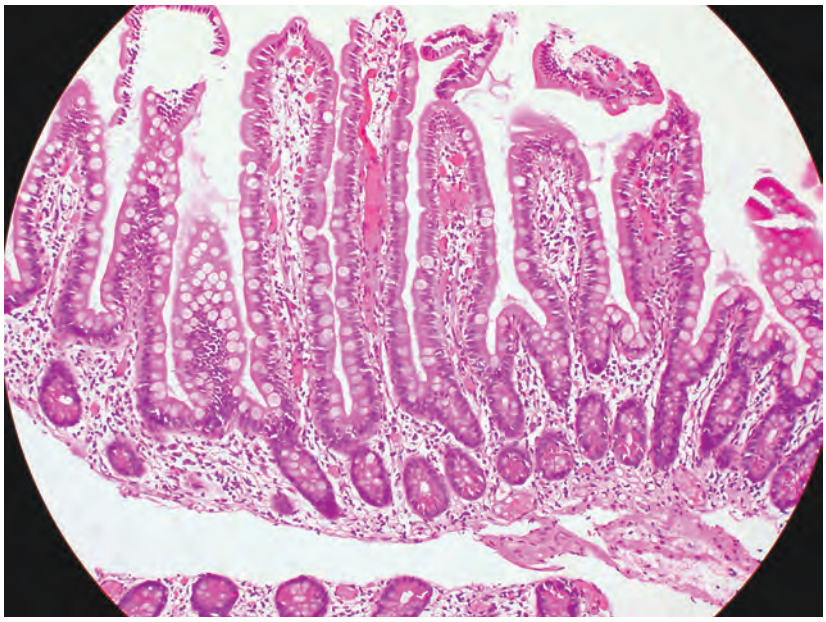
At the 2015 Celiac Disease Foundation National Conference & Gluten-Free EXPO, Joseph Murray, MD, a member of Celiac Disease Foundation's Medical Advisory Board, and President of the North American Society for the Study of Celiac Disease (NASSCD), gave a presentation that outlined the biological, symptomatic, and epidemiological basics of celiac disease for conference attendees. He stressed that although the biology of the disease may be the same in everyone, the time and presentation of symptoms may vary.

Dr. Murray opened with a case study which displayed one presentation of celiac disease. He then continued to explain more about the normal composition of the gut and intestines, and was able to show the difference between healthy villi and flattened or damaged villi present in those with untreated celiac disease. He concluded this segment with the basic definition of the disease as an inflammatory state of the small intestine, and quickly mentioned celiac disease's origins and discovery in the 1950s.

Following this, Dr. Murray focused on symptoms. He made clear that not all are related to the gut, and presented some classic symptoms from stomach and gastrointestinal problems, to joint pain and memory problems. Iron deficiency, rashes, other skin problems, enamel defects, bone problems, and lastly, reproductive effects of the disease, were focused on in detail and later elaborated on by Sheila Crowe, MD.

Dr. Murray explained testing for celiac disease; he clarified for the audience the details of the genetic test for celiac disease, which can only rule out celiac disease, but cannot confirm a diagnosis. A strong positive result of the common serological test, the anti-tTG, means having a greater chance of having the disease. As Dr. Murray continued to enforce the idea that an endoscopy must be done and a biopsy must be taken to confirm the presence of celiac disease, he showed examples of endoscopy results so the audience could better understand anatomically how the damage can differ among individuals.

"83% of the population with celiac disease has yet to be diagnosed and is needlessly suffering."



"The disease is changing over time, and though in some cases is less severe (which may also be leading to the problem of misdiagnosis), it is becoming more common."

Furthermore, Dr. Murray mentioned that onset can be sudden, and that celiac disease may not display itself until a person becomes much older. Information was also presented about the increasing rate of the disease. Dr. Murray was sure to note this is not just due to higher diagnostic rates, and added that current statistics show that only one out of five are properly diagnosed. In other words, 83% of the population with celiac disease has yet to be diagnosed and is needlessly suffering. Dr. Murray made clear that the disease is changing over time, and that though in some cases is less severe (which may also be leading to the problem of misdiagnosis), it is becoming more common.

So how is research moving forward? Dr. Murray explained that the medical community is working toward a less invasive means of diagnosis and more accurate testing. "Right now, the gluten-free diet is the only way to effectively manage celiac disease," Dr. Murray claimed. But the question remains – will people with celiac disease or gluten sensitivity ever be able to eat gluten again? Celiac disease should not be burdensome, and Dr. Murray's primary goal is to make sure it is not such a heavy burden as it is now.

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CDF Awarded Taproot Foundation Annual Report Service Grant

The Taproot Foundation Service Grant will aid in the production of CDF's Annual Report, as part of the Foundation's 25th Anniversary celebration

Celiac Disease Foundation (CDF) has received a prestigious Service Grant from the Taproot Foundation, valued at $45,000, to produce its Annual Report, in celebration of the Foundation's 25th Anniversary. A Taproot Foundation Service Grant, earned through a rigorous, eight-week application and screening process, is an award of pro-bono services to qualified 501(c)(3) non-profit organizations. The Taproot Foundation assembles a large network database of top-level industry professionals who are willing to offer pro-bono services to organizations working to improve society.

"We are honored to have been awarded this significant service grant, and are elated to be working with such high caliber professionals," says CDF Chief Executive Officer, Marilyn G. Geller. "We have undergone an extensive organization re-brand, from changing our logo, to launching our new website and online tools, to re-focusing our mission statement. The Annual Report is the final piece of that puzzle. It gives us a chance to demonstrate to our stakeholders how much our organization has grown, and the impact that we are having in making the patient voice heard in the medical, research, and legislative communities." Taproot has assigned a team of five consultants (an Account Director, Marketing Manager, Copy Writer, Graphic Designer, and Photographer) through a six-month production process, who will help design and develop CDF's 2015 Annual Report in a way that best encapsulates the organization's new image and brand.

The new brand strategy reflects the organization's mission to drive diagnosis and treatment of celiac disease through online tools to empower and educate constituents. CDF's Online Education Toolkit includes a comprehensive website with a national Advocacy Program, a Symptoms & Conditions Checklist, a nationwide Healthcare Practitioner Directory, a 7-Day Gluten-Free Meal Plan, and the Gluten-Free Allergy-Free Marketplace. Since inception in late 2013, more than 3,000,000 people have used these tools, and this number continues to grow exponentially.

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Working to Reduce the Burden of Celiac Disease, with Francisco Leon, MD, PhD

by Victoria Hornstein

Francisco Leon, MD, PhD, and CEO/CMO of Celimmune, a clinical-stage biopharmaceutical company currently developing drugs for people with non-responsive and refractory celiac disease, delivered a presentation on his company's work regarding the pharmaceutical end of celiac disease. Dr. Leon explained that current medical literature suggests that the gluten-free diet is not helping all individuals with celiac disease, and noted that upwards of 50% of celiac disease patients on a gluten-free diet continue to have disease activity. He also pointed to a 2014 study, which analyzed disease burden in patients with multiple diseases, and recognized that the gluten-free diet places a significant burden on individuals with the disease.

This brought Dr. Leon to the discussion of Celimmune's efforts, which include research into celiac disease that is unresponsive to the gluten-free diet, and refractory celiac disease, or celiac disease-triggered T-cell lymphoma. Dr. Leon then briefly discussed the biology behind the autoimmune processes of celiac disease, and why symptoms like intestinal atrophy occur. He specifically mentioned IL-15, a central regulator for refractory celiac disease, and AMG 714, an anti-IL-15 antibody on which Celimmune is focused. Dr. Leon ended by discussing a tool that may be used in the future, which measures gluten in the stool. The monitor, iVYDAL, is not yet available in the United States, but would be valuable to those attempting to follow a strict gluten-free diet who continue to be symptomatic. Dr. Leon's presentation suggested that through companies like Celimmune, drug advancements and general testing advancements are being made for celiac patients to provide better ways to manage celiac disease.

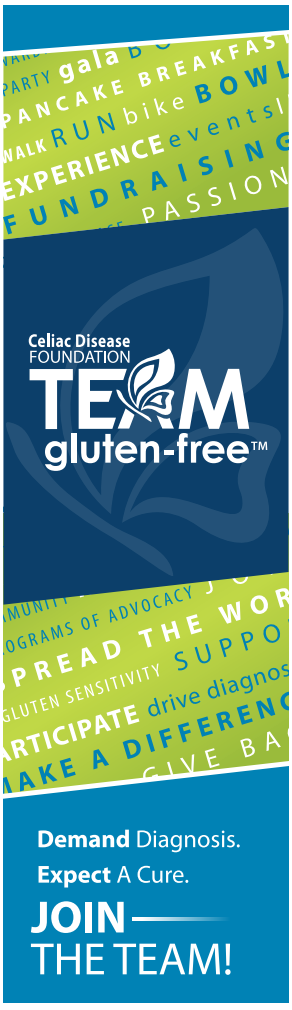
TGF is Making a Difference

Celiac.org/TGF

Team Gluten-Free (TGF) is a community fundraising program that provides a simple way for athletes and non-athletes alike to raise awareness and funds for Celiac Disease Foundation's programs for advocacy, education, and advancing research. Fundraising efforts may include any event from marathons to triathlons, bake sales, movie nights, wedding favors, community service projects, or any way that you can imagine raising funds. The money raised by Team Gluten-Free members supports CDF's mission to drive early diagnosis and treatment of celiac disease to improve the quality of life for all people with gluten-related disorders.

On April 25th, 2015, Celiac Disease Foundation's Team Gluten-Free teamed up with YouTube Star, Julien Solomita, to host a Celiac Awareness Meetup in Woodland Hills, CA. Julien was diagnosed with celiac disease as a child, and is passionate about raising awareness for the disease. The event featured a photo booth with Julien, autograph signing, Team Gluten-Free t-shirt sales, and plenty of gluten-free snacks! The more than 200 attendees were eager to meet their favorite YouTube star and learn about celiac disease. It is through events like this that Team Gluten-Free is helping fulfill the mission and purpose of CDF.

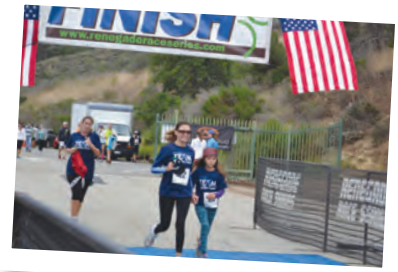
(From left to right): Matthew Clark, CDF Marketing Coordinator; Talia Hassid, CDF Community Coordinator; Jenna Marbles; Julien Solomita; Gillian Entin, CDF Development Coordinator



On May 16, 2015, Team Gluten-Free members of all ages conquered the Renegade XTERRA Triathlon, Duathlon & 3 Mile Trail Run in San Dimas, CA. Team Gluten-Free was thrilled to be named the Official Charity Partner of this race series! Leading up to the event, participants had an opportunity to create a team, fundraise for Team Gluten-Free, or make a donation. TGF members showed up in their gear for this event, and the beautiful trail was filled with friends, family, and Foundation staff who were there to support and cheer on the runners. The 2015 Renegade XTERRA TGF Team raised over $1,200 for celiac research!

Interested in planning your own event or in running for Team Gluten-Free? Visit *celiac.org/tgf* to get started!

Cromwell Family, CDF Team Gluten-Free Members



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Food For Thought Continued from page 11

for those with celiac disease and gluten sensitivity. To help develop procedures and protocols for their gluten-free products, Frito-Lay enlisted the help of CDF and the Food Allergy Research and Resource Program years before the FDA finalized its regulations on gluten-free labeling. Production schedules were coordinated and cleaning procedures were defined to ensure that the production of gluten-free foods would consistently yield products with a gluten limit of less than 20 ppm. Batches of individual products are tested using strict protocols for detecting gluten to validate that the finished product will not exceed 20 ppm of gluten before a gluten-free label is put on the package. Procedures such as those taken by Frito-Lay and Dr. Schar USA, Inc. are setting the standards for best practices in producing gluten-free products. The investment made in the gluten-free food industry by companies like Frito-Lay, Dr. Schar USA, Inc., and other CDF Sponsors is significant, and all panelists agreed that these gluten-free foods are here to stay for those with celiac disease and gluten sensitivity wherever the "gluten-free trend" goes from here.

Children's National Health Continued from page 12

facilitators in supporting the psychological needs of young people living with a gluten-related disorder."

About Children's National Health System

Children's National Health System, based in Washington, D.C., has been serving the nation's children since 1870. Children's National is Magnet® designated, and is consistently ranked among the top pediatric hospitals by U.S. News & World Report. Home to the Children's Research Institute and the Sheikh Zayed Institute for Pediatric Surgical Innovation, Children's National is one of the nation's top NIH-funded pediatric institutions. With a community-based pediatric network, seven regional outpatient centers, an ambulatory surgery center, two emergency rooms, an acute care hospital, and collaborations throughout the region, Children's National is recognized for its expertise and innovation in pediatric care and as an advocate for all children.

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A Balancing Act: Women's Health and Celiac Disease, with Sheila Crowe, MD

by Victoria Hornstein

Sheila Crowe, MD, CDF Medical Advisory Board Member, Vice President of the American Gastroenterological Association, and Professor in the Division of Gastroenterology in the Department of Medicine at the University of California, San Diego (UCSD), delivered her presentation, *A Balancing Act: Women's Health and Celiac Disease*, at the 2015 Celiac Disease Foundation National Conference & Gluten-Free EXPO. Though she focused on women's health topics, such as the impact of celiac disease and treatment in women, as well as diagnosis and the gluten-free diet, men in the audience could still find value in her presentation, as celiac disease can also affect fertility in men.

Dr. Crowe opened with a case study, and then touched on the effectiveness and interpretation of the anti-tTG blood test. Echoing what Joseph Murray, MD, spoke to earlier in the day, Dr. Crowe stressed the importance of understanding its results. An anti-tTG test result of a strong positive means you have an increased chance of having the disease. Dr. Crowe believes that women and men both have the same seroprevalence, or anti-tTG test rates, as men, but women tend naturally to seek out more healthcare. She advocates that celiac disease is multi-system, and more than just gastroenterologists should be familiar with the signs and symptoms so diagnosis for everyone improves.

"Celiac disease can be frustrating and disruptive, but proper information allows individuals to make more informed choices to positively impact their well-being."

She followed with a brief statement on fertility – that most women's health and fertility issues caused by celiac disease are improved with the gluten-free diet. For women attempting to get pregnant, the question is whether or not to be screened for celiac disease. Dr. Crowe mentioned that there is an increased number of gynecologists screening for the disease, and overall, women with celiac disease need a diagnosis so they can be put on a gluten-free diet, and a regimen of vitamins, such as folic acid, and additional supplements. Dr. Crowe also informed the audience that taking more supplements does not always mean more positive effects, and to check with your healthcare provider about dosage. She then answered another question about diagnosis: what if someone is gluten-free and needs to be tested for celiac disease? What do you do? Dr. Crowe explained you should be tested immediately, and believes some tests, such as the anti-tTG, the endoscopy, and especially the biopsy, have predictive value even after months, and up to a year of refraining from gluten. She also recommended that younger siblings and children of those with celiac disease be screened as well, as they can benefit from being diagnosed. Relatives who have the common symptoms of the disease should undergo diagnostic testing.

Dr. Crowe also discussed the basics of the gluten-free diet. She noted that the amount of household gluten-free kitchens is rising, and is now at 11%. For those who are gluten-free, foods have become more accessible in the past few years, but it is important to keep in mind that gluten-free food is something that those with celiac disease and gluten sensitivity need to stay healthy. Positive effects of the gluten-free diet include: feeling better sooner, symptom alleviation, and overall improved quality of life. Negative aspects include: the limitations of the diet when dining out, the cost of gluten-free food, and the potential for nutritional deficiencies, like anemia.

Dr. Crowe's most important message for the evening was to advocate for yourself first and then your family. She reminded everyone that with a gluten-free diet, women with celiac disease have increased fertility and a better pregnancy. Celiac disease can be frustrating and disruptive, but proper information allows individuals to make more informed choices to positively impact their well-being.

Celiac Disease FOUNDATION CELEBRATING 25 YEARS

National Conference

GLUTEN FREE EXPO

Bottom left: National Conference

Top right: Gluten-Free EXPO

Bottom right: Gluten-Free EXPO

Celiac Disease FOUNDATION

25th ANNIVERSARY DINNER

a Night of Magic

(From left to right): Marilyn G. Geller, CDF Chief Executive Officer; Deborah J. Ceizler, CDF Chief Development Officer; Elaine Monarch, CDF Founder; Shelley Case, BSc, RD, CDF Medical Advisory Board; Sheila Crowe, MD, CDF Medical Advisory Board

(From left to right): Joe Murray, MD, CDF Medical Advisory Board; Shelley Case, BSc, RD, CDF Medical Advisory Board; Sheila Crowe, MD, CDF Medical Advisory Board; Yang Pan, MD, PhD, CDF Allied Health Committee

(Left) Suzanne Frieder, CDF Southern California Chapter Vice President; (Right) Jackie Schaffhauser, CDF Southern California Chapter Secretary

(From left to right): Francisco Leon, MD, PhD, National Conference Speaker; Janelle Smith, CDF Registered Dietitian Nutritionist; Shelley Case, BSc, RD, CDF Medical Advisory Board

Jessie Hines; Chad Hines, CDF Vice Chair

Marianne Brooks, CDF 2015 Volunteer of the Year

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