

ADVOCACY leading the way

Marilyn Geller of the Celiac Disease Foundation Leading the Way in Celiac Advocacy

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We all know the Celiac Disease Foundation (CDF) is one of the most highly regarded celiac organizations, but do we know the great minds behind the organization itself? I am excited to introduce you to one of the driving forces behind this wonderful non-profit, Marilyn Geller. Marilyn is the Chief Executive Officer for CDF and this month's Delight Hero.

Marilyn received her undergrad in psychology and then went on to receive her MSPH degree from UCLA. She has used her public health advocacy and software expertise to lead the way in celiac advocacy, research and education. As a mother to a son with celiac disease, this advocacy has become her lifelong mission.

In 2014, Marilyn worked with CDF to make sure the tools were in place for visitors to their site to fill out a symptoms checklist and get doctor referrals. This year she and the CDF team have made it their mission to expose as many people as possible to diagnosis and treatment information. With their recently launched **Gluten Allergy Free Marketplace** they are doing just that. The site is now also available via Android and iPhone so folks can access all of this information as well as labels, company information, coupons and meal plans on the go. Directly from the site or app, visitors can purchase food they find on Amazon. The great news is that CDF will receive a percentage back from each person who buys anything on Amazon when



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linked through from the CDF Gluten Allergy Free Marketplace.

This year Marilyn also made a splash in Washington D.C. as she worked with the director of FDA's Center for Food Safety & Applied Nutrition. She and other CDF team members attended an FDA patient-focused drug development workshop. They will continue working with the FDA as they collect hard data on what consumers would like to see a potential celiac disease drug do for them.

Looking ahead at 2016, Marilyn says they will be focusing on patient-centered outcome research. This year they collaborated with 10+ genetically based disease organizations to create a new patient

registry software known currently as CENA or Community Engaged Network for All. This one-of-a-kind software is CDF's current patient registry project. You can learn more about the collaborative project at geneticalliance.org. By working together with many different disease organizations, it provides the opportunity for individuals to answer questions for multiple diseases in one place. This will then allow researchers to draw links between the different diseases.

In addition to this cutting edge project, "CDF has collaborated with Children's National Health System to develop mental health training programs," says Marilyn. With this partnership they hope to identify celiac disease and treat from a psychosocial perspective helping with much of the anxiety and depression that exists (but is rarely addressed) in those with celiac disease. Both

organizations are excited to develop and provide training for medical professionals in the form of live workshops as well as in online CEU's.

When asked if the Celiac Disease Foundation has seen significant growth over the past few years, Marilyn said that the Internet and Facebook specifically have helped them make a big breakthrough in the number of people they can reach. They expect that to increase to 1 million monthly visitors very soon.

Be sure to visit celiac.org for more information on all of their exciting new projects as well as get details about their next conference and gluten-free expo. ■