



lonely child!"

**If you are interested –
The next planned International
Conference on Celiac Disease is
scheduled to be held in Belfast, Ireland,
from April 28-May 1, 2004**



*Be very thankful for every day
that we are healthy, and able to help others!*

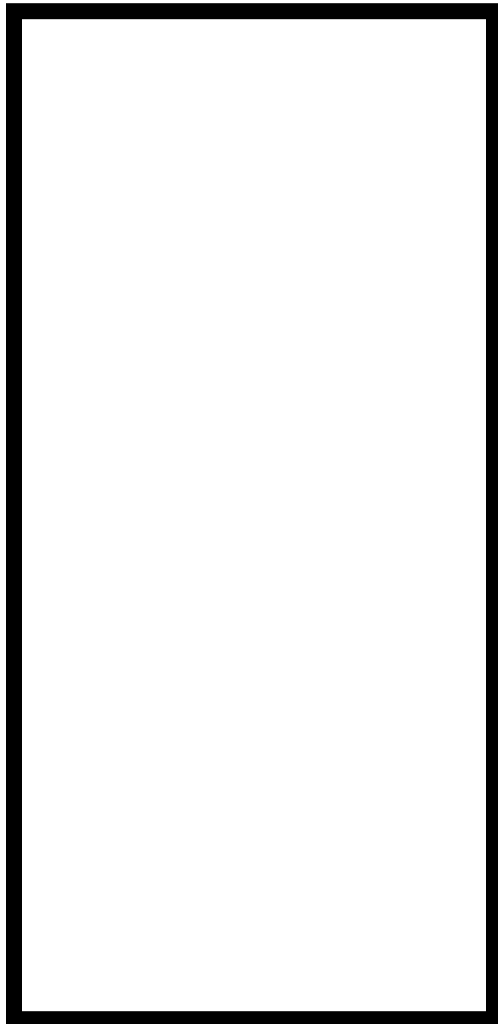
**Celiac Disease meets 4 of the 5 criteria
used to justify mass screenings –**

- 1) common condition that is**
- 2) frequently unrecognized, and**
- 3) can lead to serious complications
if left untreated while**
- 4) there is an acceptable, effective
treatment!!**

**The 5th criterion is that the cost of NOT
screening should exceed the cost of
screening, and THERE'S the rub...
Most studies concluded that until the cost
of the testing comes down, screening is
NOT warranted in the general population.
It may however, be justified for people
who have associated conditions – or in
some other way are at higher risk for
developing celiac disease. Certainly, as
testing reliability improves and costs**

**decrease, mass screenings will be more
justifiable...**

the above excerpted from "Gluten-Free Living"



**Gluten Free Living Conference -
Philadelphia, PA - August 2002**

Attending the GF Living Conference was a great experience. I met people with all kinds of backgrounds: some who had been diagnosed with Celiac Disease 10-20 years, 5 years or even less like 6 weeks, and parents of Celiac children. We were able to share stories, recipes, ideas, and offer each other hope and support.

Everyone was excited to meet Bette Hagman, the pioneer in GF cooking and baking. I was amazed to learn that she did not cook at all before her diagnosis in her 50's. She started by swapping recipes with a few people and then even took cooking classes to try out new things. She is an amazing woman, full of lots of energy and pep. She is truly an inspiration to all. Now in her 80's she writing is yet another cookbook. I received six recipes from her that may be in her new book and we, the Mohawk Valley Support Group get to test these recipes and give her our responses. Today I made Chicken Rice Salad and for the next meeting I plan on trying the New Oatmeal Cookies (with Quinoa Flakes) and Thousand Island Dressing with Reuben Sandwiches.

We also had the pleasure of hearing Danna Korn, author of Kids With Celiac Disease, A Family Guide to Raising Happy A Healthy, Gluten-Free Children and founder of R.O.C.K. (Raising Our Celiac Kids), the national support group created for support of children and families of Celiac and Autistic children. I was able to meet Danna and her son, Tyler, the reason she wrote the book, started the support group and continues to help Celiac families. Tyler is 12 now and was diagnosed at around 2 years old, about the same age my daughter, Cassandra was diagnosed. I feel so lucky to have the guidance and support that Danna and her family did not have and created for the rest of us. She has written a new book geared towards anyone who is gluten intolerant, not just children, called Wheat-Free, Worry-Free, The Art of

Happy, Healthy, Gluten-Free Living. Danna and her son, Tyler signed my book, that was worth the trip. We hope to have Danna speak here for our R.O.C.K. group some day.

Danna offered an inspiring story about a carrot, an egg, and a coffee bean. One day a child came home from school complaining about how difficult her day had been. School was hard, some of the other kids and teachers were difficult to get along with. Life in general was just plain hard. While the child complained the father put on three pots of boiling water. In one pot he put carrots, in another he put an egg, and in the last he put coffee beans. While the pots boiled he told the child that each person is different and each responds to adversity in a different way. He explained that when the environment is harsh, when life is difficult, one can be like a carrot after being put in the boiling water (the harsh environment) and can become soft and mushy, giving in. Or one can be like the egg put in the exact same conditions and can come out hard on the outside, unyielding, not letting anything in. Then he came to the coffee beans, and he explained that one could also be like the coffee beans, resistant to the harsh environment in which it was placed but instead changing the environment to make it something better. Finally, when his story was finished he asked the child, "Are you going to be a carrot, an egg or a coffee bean?"

Dr. Ranasamy Manikan, Ph.D. also spoke of handling the emotions of Celiac Disease. He offered the following in dealing with stressful situations; diagnosis of Celiac Disease and other situations. Make yourself prepared by having the proper **tools** for dealing with the situation in which you've found yourself.

Knowledge, of your body, self and the disease.

Skills, dealing with events on a daily basis, negotiating care, and navigating problems. **Plans**, dealing with feelings and coping with the disease.

Support, to lean on when needed.

AVAILABILITY AFFORDABILITY

ACCESSABILITY

These are keys to making the treatment for Celiac Disease, the gluten-free diet less stressful and more manageable. (See the attached Gluten Free Living sheet)

We had the privilege of hearing Dr. Alessio Fasano, MD from the University of Maryland, a pioneer in Celiac research. Dr. Fasano spoke of the advancements made in Celiac research in the past

year and his hopes for the future. He would like to increase education of this disease to physicians so that earlier diagnosis is possible. He is hoping for several advancements in the next ten years including a possible "pill" that Celiacs could take before ingesting gluten so that the autoimmune response is not activated and a possible vaccine. Dr. Fasano is a wonderful speaker who truly put much of the medical mayhem in layman's terms. He was a joy and actually took the time to speak to me one on one and answer some of my questions. He is a Godsend to the Celiac community.

Dr. Fasano was to speak to congress the Monday after the seminar regarding passing the labeling bill into a law. He was very excited and hoped for a good response. This is not the first time this bill has been presented to congress and the hope is that each time we will get a little closer to our goal. As most of know many companies are taking the initiative of addressing the labeling needs of it's consumers, however many companies are still lax and until this law passes we will have to question the products we are consuming.

Bob Levy of Bob and Ruth's Travel Club presented ideas on making eating out and traveling easier. He explained how he prepares the ships and restaurants for his tours and cruises. As this weekend was very *nice* for anyone who has to watch his diet regularly but didn't have to because everything served was gluten free, so are all of Bob and Ruth's vacations. They have many plans for upcoming events including a first time R.O.C.K. cruise.

On of the most exciting parts of the weekend was the presence of gluten free beer. Yes, I said BEER! Kevin Sepowitz of Bard's Tale Ale was giving out samples of his Pale Ale and surveying the tasters. From someone who likes a good beer and is not gluten intolerant I thought this beer was excellent. We were unable to purchase this beer as it is not on the market yet, but Kevin would be happy to come to our support group and demonstrate his wonderful product. Pam suggested that maybe this would work at our Holiday party. Hey, a party and beer (for the first time in many, many years for some.)

I believe that the conference was a success. Ann Whelan, editor of Gluten Free Living magazine, presented the speakers, vendors and the magazine. It was fun to meet vendors of gluten free products, see the new items they had to offer and we got to sample. The speakers were fabulous. I would attend another conference if and when the opportunity

presented itself. We are on the road to learning and living GLUTEN FREE.

Thank you for the support in attending this conference.

Tanya Clute

LATE BREAKING NEWS!!!! Pam & Eleanor are planning to attend a day long CD conference in NY City on Nov. 2nd.....