How a
Concerned Mom
Made a Difference
in Congress

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Like 11 million Americans, most of whom are children, 3 year old McCartney has a LIFE THREATEN-FOOD ALLERGY. He is allergic to eggs. Until there is a cure for food allergies. we need clear, easy-tofood labels to keep kids like Ewan Please help protect Ewan's life by safe. co-sponsoring The Labeling and Consumer Protection Food Allergen

Act, HR 3684. For more info, please contact Ewan's mom and dad, Colin and



ittle Ewan McCartney was 10 months old when he first tasted a scrambled egg. Within minutes he developed a swollen area on his forehead. It grew, then another appeared, and both eyes swelled shut. The hives appeared next, soon covering his torso.

By the time the emergency medical team arrived, Ewan was in full anaphylactic shock, limp in his mother's arms, with no detectable heartbeat. Luckily, the medics were equipped. They immediately gave him epinephrine, and he began to revive. They took him to the hospital, watched him for six more hours to make sure there would not be a repeat reaction, and released him, handing parents Anna and Colin a prescription for auto-injectable epinephrine – the emergency medication recommended for treatment of the severe allergic reaction called anaphylaxis.

It was Anna McCartney's first exposure to food allergy. Since then, like so many other parents of children with food allergy, she has read up on the subject, consulted multiple physicians, joined support groups and learned to interpret the complex terminology of food labels.

In fact, Anna learned that egg protein is not always listed as "eggs" on food labels. Rather it appears with scientific names such as albumin, globulin, livetin, ovalbumin, ovomucin, ovomucoid, ovobitellin, and even lysozyme in Europe. She also learned to avoid ingredients such as egg substitutes, mayonnaise, meringue and Simplesse.

When she heard there were efforts in the U.S. Congress to require easier-to-read labels on foods, she decided to contact her representative and ask for his support.

It was a first step that she never dreamed would turn into a nationwide campaign:

I got involved by accident. When one of the online support groups, POFAK (Parents of Food Allergic Kids, http://health.groups.yahoo.com/group/POFAK/), sent me information on the Food Allergen Labeling & Consumer



Protection Act (FALCPA), I wrote a letter to my members of Congress. Instead of mailing it, I decided to take Ewan downtown with me and deliver it in person to their local offices in Seattle.

It was a pretty amazing experience. At Congressman Jim McDermott's office, the first person I met was Lori Whittaker, MD, his aide for health issues. I was telling her about the bill when the Congressman himself walked down the hall and noticed us. I think my toddler caught his eye. Lori was very helpful and the Congressman was interested in the legislation. The next day, Lori called to tell me that Rep. McDermott had signed on as a co-sponsor of the bill!

Buoyed by her success at Rep. McDermott's (D-WA) office, Anna hand-delivered letters to the offices of her U.S. Senators. She was delighted to learn that Patty Murray (D-WA) had already co-sponsored the bill in the Senate. Soon after, Senator Maria Cantwell (D-WA) signed on, putting all three of Anna's members of Congress behind the effort.

Once I had all three of my members of Congress signed on as co-sponsors, I phoned the other House members from my state. One of Jim McDermott's aides had said it was really attention-grabbing that I was asking for help for my cute little toddler son, so when my parents and several friends

asked if I could help them write letters, I decided to use Ewan's photo to draw attention to our message.

That's how I came up with my postcard! I designed it on the computer, putting Ewan's photo on the front and information on his food allergies and the Food Allergen Labeling Act on the back.

I offered the postcard template to other parents of foodallergic children. Most found it too much of a hassle to do themselves. Once I offered to print them for these families, I had zillions of orders! I think I printed about 3,000 of the cards. One mom called to say that her husband worked at a printer's office and had extra cardstock. That huge box of paper made a big difference – fancy paper is expensive!

Soon all but three of the Washington State Congressional delegation were co-sponsors. My grandfather in Hawaii paid a visit to his Congressman, Rep. Neil Abercrombie (D-HI), and asked his bridge club to send in postcards of Ewan. Almost immediately, Abercrombie signed on as a co-sponsor. As each member of Congress signed on as a co-sponsor, their aides phoned me to let me know they'd done so. I'm sure they do this for everyone, but it made me feel like I was making an impact, like I was accomplishing something.

I was amazed and delighted that many of the aides were so helpful. I had never been "involved" before and didn't know what I was doing. I told folks this, and Congressional staffers

#### The Food Labeling Law

The Food Allergen Labeling & Consumer Protection Act requires labels to state clearly whether a product contains any of the eight major food allergens: milk, eggs, peanuts, tree nuts, fish, shellfish, wheat and soy. It also requires listing these ingredients when they are used as flavoring, additives and spices. Formerly, manufacturers were allowed to say "natural flavorings" for ingredients used in very small amounts.

Beyond labeling, the law also requires the Food and Drug Administration (FDA) to ensure that food manufacturers comply with practices to reduce or eliminate cross-contamination.

The law goes into effect January 1, 2006. The date allows manufacturers time to revamp their labels.

were friendly and helpful. Ken Van Pool, from Congressman George Nethercutt's (R-WA) office, spent a lot of time explaining to me how the system works and giving me wonderful advice. Lori Whittaker, MD, from Congressman Jim McDermott's office and Shakti Hawkins from Senator Maria Cantwell's office both attended our food allergy support group meeting to hear more about the problem.

The bill passed unanimously in both the House and Senate. On August 2, 2004, President Bush signed the Food Allergen Labeling & Consumer Protection Act into law and Anna took the whole family down to Rep. McDermott's office to celebrate - including little Olivia, a baby the McCartneys had recently adopted, after discovering she was a "special needs" child because of her food allergies. According to Anna:

It's all been a tremendously positive experience. The fun part has been watching other people get interested in the political stuff. I think a lot of people (including myself) had the feeling that we're just tiny voices and we won't make any difference – plus we don't know what to do, so we never try. It's fun to explain how it all works and encourage other people, then watch what they do. It's kind of like dominoes - one enthusiastic person can get a bunch more people going, too.

At home with my two children, I generally get the feeling that they have the upper hand. The political stuff has been a neat way for me to feel like a dynamo – I may not be able to convince Ewan to take a nap, but at least I can get the government to listen to me!

You can e-mail Anna McCartney at anna@foodallergyaction. org for more information on her postcard campaign.

Anna's favorite online resources: Food Allergy Action (www.foodallergyaction.org), Charity Lobbying in the Public Interest (www.clpi.org) and AANMA's Farmer's Market (breatherville.org/ farmersmarket).

#### Do you have a story to tell about changing laws in your community?

Is there an issue you're passionate about, but don't know how to get started? Visit AANMA's online Advocacy Center at breatherville.org/cityhall. Find out what you can do to make a difference! We'll help you every step of the way. Contact Sandra Fusco-Walker at 800.729.3804.



### **Making a Difference Award**

We're looking for innovative, top-quality asthma care programs and services that demonstrate best practices in patient care.

#### **Award Categories**

- State or Local Government Medicaid Agencies
- Community Coalitions
- Health Plans
- Individuals

Award winners will receive national recognition and attend AADCH activities, press briefings and Congressional visits May 3-4, 2005.

#### Creative Kids Art Contest

Calling all elementary through high school students!

Use your artistic talent to say "thank you" to President Bush and Congress! They care about schoolchildren with asthma and anaphylaxis. Thanks to them, the Asthmatic Schoolchildren's Treatment & Health Management Act is now law. (See page 33.)

Two winners will be honored during AADCH activities May 3-4, 2005, tour the US Capitol and receive a \$100 US Savings Bond.



Entry forms and rules are available at breatherville.org or by calling 800.878.4403.

Deadline for Entries: March 4, 2005

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