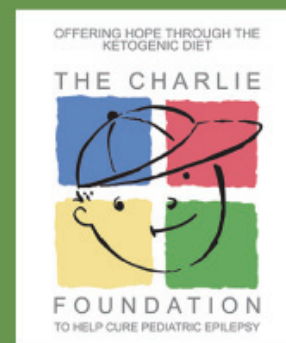


KETONews

A publication for the ketogenic diet from The Charlie Foundation



UPCOMING EVENTS

2012 International Symposium on Diet Therapy for Neurological Disorders

Consecutive conferences for families and professionals near Chicago, Illinois
Professionals' meeting: Sept 19-21 • Family meeting: Sept. 22.

This is the third International meeting organized to gather people from around the world who are invested in the use and advancement of diet therapies for epilepsy. This symposium will provide a forum for extended discussions regarding practical implementation, surveillance and the prevention of adverse effects of ketogenic diet therapies. Scientists will explore novel molecular and metabolic mechanisms that could account for the anticonvulsant and neuroprotective effects of the diet. Attendees will have the opportunity to share information and establish clinical and research collaborations. This spirit of cooperation constitutes the core rationale for this international symposium.

Highlights of meeting sessions:

- Diet and brain health
- Clinical practice; pediatric epilepsy
- Adults experiences with diet therapies
- New applications for diet therapies (other than epilepsy)
- Testimonies from patients
- Basic science exploration of brain metabolism
- Advancing diet therapies into the 21st century
- Keynote Speaker: Gary Taubes, MD, author of Good Calories, Bad Calories
- Celebration event with special guest Meryl Streep, actress extraordinaire and star of *First Do No Harm*, made for TV movie, written & produced by Jim Abrahams, 1997.

Registration information will be posted in the Events link on the charliefoundation.org website in coming weeks.



Beth Zupec-Kania, RD, CD • The Charlie Foundation to Help Cure Epilepsy • www.charliefoundation.org
Volume XI, Issue 1 –Winter 2012 • Complimentary Copy • Email: ketogenicseminars@wi.rr.com

Frequently Asked Questions

Q Is glycerin a carbohydrate?

A Glycerin is an additive that is mixed into processed foods to retain moisture and provide sweetness. It is classified as a 'carbohydrate' and has twenty-seven calories per teaspoon; sugar has twenty calories per teaspoon. Glycerin is also an ingredient in many toothpastes and mouth rinses. It is also an additive in sunscreens and lotions and creams. No one knows the amount that is absorbed into skin but there have been many anecdotal reports of increased seizures after topical use of products containing glycerin.



Support For All

Charlie Foundation Community Forum:

This is a moderated forum for families to share tips and provide support on ketogenic diet therapy. Select the Community Forum link on www.charliefoundation.org

Professional Forum: This is a forum for health care professionals to request support and seek guidance for managing patients on ketogenic diet therapy: www.keto411.org



Charlotte's Story

Dawn Marie Martenz (Mother of Charlotte)

Charlotte was born a healthy, full-term infant. Her first seizure occurred the day after her four-month vaccinations. We called 9-1-1 and were treated at our local emergency department. They stopped her seizure with medications but it lasted 45 minutes. We were sent home a few hours later with the understanding that the seizure was caused by her fever. Three months later, she had another seizure and this time, there seemed to be no cause. We stayed for 3 days in the hospital and had multiple tests. She had two spinal taps, an MRI, an electroencephalogram, electrocardiogram, cardiac ultrasound, kidney ultrasound and a 24-hour urine catheter to analyze her urine. None of these tests indicated a problem and we were sent home with emergency medication along with training to give it in the event that she had another seizure. Charlotte continued to have tonic-clonic seizures periodically throughout the next year. She was started on one medication after another. The second medication, Trileptol, caused an allergic reaction resulting in more seizures and she would stop breathing, requiring resuscitation. Her epilepsy was first classified as "idiopathic" (which means there's no known cause) but her seizures were changing and she started having myoclonic seizures. Finally, we took her to a different neurologist who performed genetic tests that revealed that she had Dravet's syndrome. We received this news while we were in the hospital with our newborn for an emergency surgery for Hirschprung's disease. This was the lowest of all our lows for our family. The neurologist offered us the ketogenic diet but I declined it. (To this day, I regret making this decision.) Charlotte was having thousands

of myoclonic seizures daily. She had regressed in her speech and was not able to function well. After starting Depakote, her beautiful blond, curly hair fell out. In her short life, she had been a total of ten different seizure medications and in multiple combinations. Some days, the only thing she ate was her seizure medication. Slowly, our beautiful daughter was slipping away from us. We trialed an 11th medication (Clobazam) under the care of a new neurologist who we met after we relocated to Washington D.C. for my husband's job. This provided a return and Charlotte began to improve. Two years later, she suddenly lost that seizure control and we were back to daily seizures. We were offered the diet for the second time and by this time we were ready to try it. On the second day of starting the diet in the hospital, her myoclonic seizures stopped completely. She had not had a seizure-free day since she was 18 months old! She adjusted well to the diet and I learned to become creative in making meals that would satisfy her. We placed pictures of Charlotte's meals in a small photo album so she could so she could select what she wanted me to prepare. Although she is not completely seizure-free, there is no medication or combination of medications that has come close to the results of the diet for Charlotte. It is my hope that another parent lost in the relentless fog of epilepsy can see pictures of ketogenic meals and understand the power that "food" can have and be willing to give the diet a chance. I have collaborated with Laura Cramp, our dietitian, in creating a cookbook for families (which includes pictures).

Dawn Marie Martenz and Laura Cramp are the authors of "The Keto Cookbook", Demos Health Publications, 2011.

Visit the Keto Kids link on charliefoundation.org to read about others who have benefitted from ketogenic diet therapy.

Crab Cakes

Entire recipe (cakes + sauce) provides 360 Calories: 8.4gm Protein, 35gm Fat and 3gm Carbohydrate.

Looking for a special meal for the holidays? This is a simple recipe that may be made from canned or fresh crab. Prepare the cakes in advance and microwave just prior to serving with the sauce on the side for dipping. Kids will also eat this cold! Use this recipe as a guide to recreate it for the necessary ratio and protein requirements of your child.

Ingredients

- * 8gm egg yolk
- * 5gm coconut flour
- * 30gm crab meat - flaked
- * Optional: Salt - 1 pinch
- * Optional: Paprika - 1 pinch
- * 15gm butter

Directions

1. Stir egg yolk into cream until mixed.
2. Stir coconut flour into crab meat.
3. Sprinkle salt and paprika over crab meat.
4. Combine both mixtures then form into 6 cakes.
5. Melt butter in small skillet.
6. Brown the cakes for 3-4 minutes on each side.
7. Place on serving plate. Garnish with crab cake sauce.

Crab cake sauce: Mix together the following ingredients and serve over cakes.

- * 9gm sour cream
- * 22gm mayonnaise
- * 10gm lemon juice

Visit the Recipe link on charliefoundation.org to find other tasty ketogenic foods.

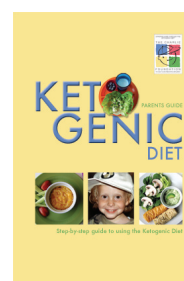


KETOGENIC RESOURCES Credit card orders are now accepted. Request an order form from ketogenicseminars@wi.rr.com



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Includes AC adapter, 4AA batteries, weighing bowl and calibration weights, 5 year warranty.



PARENTS GUIDE TO THE KETOGENIC DIET..... \$10

English or Spanish versions.
Includes recipes, sick-day guidelines and much more.