

KETO NEWS

Medical University of South Carolina

Winter Edition 2017

Ketogenic Diet Resources

While the ketogenic diet can have amazing benefits for individuals suffering from epilepsy, it also carries a large caregiver and patient burden. In other words, I think we can all agree that it's not the easiest diet to follow! Whether you have meal plans provided by your dietitian or you are doing your own meal planning, surrounding yourself with a good support system can be key. It never hurts to bounce ideas off other ketogenic diet patients or caregivers when it comes to variety, social situations and holiday ideas. Pinterest, Facebook and other social media outlets are great options but always be sure to check credibility and only use recipes approved by your dietitian.

Check out these resources to help you achieve long-term success on the ketogenic diet.

- [KetoConnect Blog](#): A support blog for patients and caregivers.
- [Keto Friends](#): An initiative that connects new ketogenic diet families to a network of experienced parents for educational and emotional support.
- [Keto Cooking Channel](#): Matthew's Friends is a UK based charity that has a cooking channel with fabulous meal ideas.
- [The Charlie Foundation](#): This organization was founded in 1994 to provide information about diet therapies and has recipes, videos, low carbohydrate product lists.
- [My Ketogenic Diet](#): Recipes, information and tips from VitaFlo®.
- [KetoVie Blog](#): An on-line place to share tips, hints and family stories. KetoVie™ also has [CAMBROOKEcare™](#) which can assist with formula reimbursement.
- [Nutricia Navigator Program](#): Assists families with finding coverage for KetoCal products.
- [National Organization for Rare Disorders](#): NORD may be able to assist with financial burdens of doctors' appointments, travel and other expenses.

February 13 is
International
Epilepsy Day!
Be sure to wear
purple and
share your
story!



International
Epilepsy Day

#epilepsyday

In This Issue

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- New Products
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Wear purple and celebrate International Epilepsy Day on Monday, February 13th.



KetoVie Café Kwik Mix

A quick mix baking blend that can be used to create a variety of delicious recipes. Bake your favorite baked goods, like muffins, cookies and quick breads. Sold in a 1.5 pound resealable pouch.

[Check out these recipes.](#)



Featured Recipe: Keto Waffle

Ingredients:

28 grams or 1/4 cup [KetoVie Café Kwik Mix](#)
30 grams or 2 Tbs heavy cream (36%)
37 grams or 2 Tbs +1 tsp egg, beaten well
10 grams or 2 tsp canola oil
7 grams or 2 tsp water

Directions

Heat waffle iron and grease with oil. Whisk all ingredients until blended and pour in greased waffle iron. Bake waffles until toasty golden brown.

Tips: Complement recipe with a serving of butter and/or whipped cream to enhance flavor as well as the ketogenic ratio, which will allow for a portion of fresh berries. Replace canola oil for equal amount of bacon fat for great flavor. Increase recipe three-fold or more and stack cooled waffles between sheets of waxed paper. Bag and store in freezer for a quick heat & serve breakfast. Reheat in toaster or oven.

Nutrition Facts

Servings 1: 4:1 ratio; Calories 364; Net Carbs 2.2 grams; Protein 6.9 grams; Fat 36.5 grams

Valentine's Tips

Like any holiday, Valentine's Day can be tricky on a ketogenic diet. Try adding sugar-free, carb-free strawberry flavoring to KetoCal® and/or heavy cream for a festive treat. Another great idea is to make all of your keto foods heart shaped by using a cookie cutter. Check out the [KetoConnect blog](#) for more tips.



Celebrate Valentine's Day Keto Style

Lab Reminder

Most patients need ketogenic diet labs done every 3 months in order to prevent or treat any side effects and to make sure you are obtaining the full benefit of the diet.

If you have not done your labs in more than 3 months, please contact us at 843-792-3307 to see what labs are needed at this time.

A Story of Hope

Check out this beautiful story about Charity, an infant born with Alobar Holoprosencephaly (HPE), and her journey on the ketogenic diet that was highlighted in [The Edmarc Visitor](#).



The 5th Global Keto Symposium was held September 20-24th in Banff, Alberta, Canada.

Keto Symposium

The 5th Global Keto Symposium is the biennial event that brings together hundreds of medical professionals, scientists, trainees and industry professionals to discuss the state of ketogenic therapy research and innovations. The 2016 event was the largest to date with over 500 attendees. The symposium is dedicated to improving the lives of people with neurological disorders and is organized by The Charlie Foundation. As John Freeman, MD once stated, “The idea of food as medicine has been a controversial topic in this country for many years. But the statistics don’t lie, nor do the thousands of people who will tell you how their lives were changed because of it.”

As we know today, the ketogenic diet is an evidence based therapy mainly used for difficult to control seizures. The question today is how many diagnoses can be treated by ketogenic diet therapy? After attending the symposium it is overwhelmingly obvious that the diet can be used to treat many diagnoses—Cancer, Autism, Parkinson’s, Alzheimer’s, and even fatal brain tumors. Scientific data regarding these new uses of dietary therapy is accumulating rapidly. To conclude, it is safe to say the ketogenic diet is providing hope to once incurable diagnoses, and it is up to us as families and medical professionals to advocate the use of ketogenic diet therapy.

To learn more about the research and information presented at the 5th Global Keto Symposium including interviews from speakers and summaries of research check out the www.ketoconnect.org website.



SAFE is an epilepsy support group and advocacy group in SC with several chapters throughout the state.

South Carolina Advocates for Epilepsy (SAFE) Updates

- February 11th—Monthly meeting:** Jill Swing, founder of SC Compassion group, will be on hand to share current information about the SC Compassionate Care Act and show us how to become active advocates in educating our legislators, residents of SC and more! Meeting begins promptly at 11am at the Cathedral Church (3790 Ashley Phosphate Road, North Charleston). Bldg. A, Room 103.
- February 21** will be the first group meeting for "The Heart of the Caregiver" support group. This is a 10 week series with a cost of \$15 and is being offered to caregivers of epilepsy patients. Childcare is not available for this event. Group size is limited to 10 and a few spaces are still available. If you would like to join this group, please contact SAFE at karen@scepilepsy.org no later than February 17.
- March 11 - Stroll for Seizure Control:** The [registration form](#) is located on the [SAFE website](#) or you can e-mail SAFE at karen@scepilepsy.org. Early registration is due by February 27th. A lot of fun activities are planned again this year and [Heather's Ride Organization](#) will be joining the stroll! If you have never considered a bike ride due to your child's seizures, come try out this Tandem Trike and enjoy cycling with your child. The rides will take place on the outside trail of the park. Helmets will be available for the children/parent riding the Tandem Trike.



- March 26 - Purple Day!** Let's head out to the [Stingrays'](#) game all decked out in PURPLE! Discounted tickets will be available. More information to come soon so stay updated by checking the SAFE website frequently and subscribing to their e-mail updates.

Quest Keto

[Quest Keto](#) is part of Quest Nutrition which is best known for their delicious line of low carbohydrate protein bars. The company has now expanded into frozen ketogenic diet foods. Each meal contains 250-500 calories and is a 2:1 ketogenic diet ratio. In today's fast paced world, this line of keto products offers an easy, convenient and tasty meal option.

Featured Meals:

Sausage Flatbread:

470 calories; 42 grams fat, 3 grams net carbohydrates; 16 grams protein



Sausage, Egg, & Cheese Biscuit:

510 calories, 47 grams fat, 3 grams net carbohydrates, 19 grams protein



www.questketo.com

Study of Neonatal Infants on Ketogenic Diet

Authored by: Erik Kossoff MD/Ketogenic Diet Editor on 1/2017

The last few years have seen a trend towards considering the ketogenic diet for the “extremes” of age. Some research points to safety and benefits for elderly people with epilepsy (and possibly dementia), and other studies suggest that infants may in fact do better than older children. Using the diet in people outside the typical school-aged childhood range has changed our way of thinking about this therapy. Adding to this trend, an interesting article was just published in January 2017 in the journal of *Epilepsia* from Lindsey Thompson RD, the ketogenic dietitian at Children’s Mercy Comprehensive Epilepsy Center in Kansas City, and her excellent team. Entitled “Use of the ketogenic diet in the neonatal intensive unit—safety and tolerability,” this was a short case series of four infants with very severe epilepsy who had failed to respond to 3 or 4 drugs to control their seizures in the ICU. Their ages ranged from 6 to 10 weeks when the ketogenic diet was started, which is amongst the youngest ever reported. All were started gradually without a fast over a 1 – to 2– week period, which is a bit slower than typically done for older children.

Study highlights:

- All four achieved ketosis with side effects of constipation in two and hypoglycemia in just one (interestingly, the oldest the infant).
- Three of four had subjective improvement in seizures, including two infants who had periods of seizure freedom.
- However, the EEG improved in only one child, fitting with research suggesting the EEG does not always correlate with clinical improvement.
- Even more remarkably, all four are still on the ketogenic diet at this time, including three children with over 2 years of continued dietary treatment.

Thompson L, Fecsk E, Salim M, Hall A. Use of the ketogenic diet in the neonatal intensive care unit —safety and tolerability. *Epilepsia* 2016; doi:10.1111/epi.13650 (online).

Patient Spotlight

We are looking for patient stories for upcoming newsletters. If you or your child is on a ketogenic diet and would like to be featured in our next newsletter, please let us know.

E-mail Reminder

As a reminder, personal e-mails are not monitored on a regular basis.

Please never send urgent information in a personal e-mail. Please utilize My Chart or the phone system for any questions or concerns so that a member of our team can get back with you quickly. If you need help setting up your My Chart, please ask at your next visit.

Contact Us

Give us a call with any questions or concerns about ketogenic diet therapy.

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