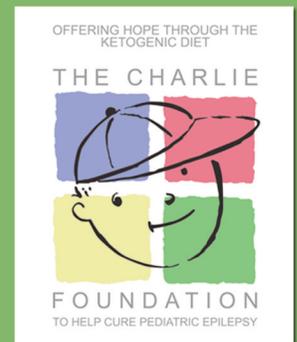


# KETONews

A publication for the ketogenic diet from The Charlie Foundation



## UPCOMING EVENTS

### **Epilepsy Brain Storm Summit November 6, 2010 – Los Angeles, CA**

Epilepsy Foundation of Greater Los Angeles in Partnership with The Charlie Foundation; Dietary Therapies for Epilepsy & More. Held at the Conference Center at Cathedral Plaza. Website: [epilepsyfoundationgla.org](http://epilepsyfoundationgla.org)

## PAST EVENT REVIEW

### **Glut-1 Conference summer 2010**

This 3-day, 2nd annual event was held in Louisville, KY on July 15-17 and was attended by over 150 people. The attendees included families with a child diagnosed with Glucose-1 Transporter Deficiency Syndrome. Dr. Daryl Devivo, the neurologist who described this syndrome in 1991, and his staff spoke about the diagnosis and treatment of this condition. Researchers discussed current and future clinical studies to improve treatment options. Ketogenic recipes from The Charlie Foundation's web-site were sampled by all. To read an in-depth report of this meeting, go to the '2010 Conference' link at [www.glut-1DS.org](http://www.glut-1DS.org). Next year's meeting will be in New Orleans, July 14-16, 2011.

## Macadamia Nut Pancakes

This simple 3 ingredient recipe uses ground macadamia nuts instead of flour yet it tastes like real pancakes. Chopped blueberries, peaches or pecans may be incorporated. Pancakes can be frozen and reheated easily in the toaster oven or microwave. Top pancakes with whipped cream and or butter. Syrup choices include Walden Farms Sugar-free Pancake Syrup (listed in KetoCalculator) or a few drops of Davanci Pancake Syrup Flavoring which may be mixed with butter. This recipe includes gram weights to guide you in creating a recipe and provides 300 calories, 4:1 Ratio. KetoCalculator users will find this recipe in the Standard Meals list under "Pancakes".

## Ingredients

- 30gm Macadamia nuts – roasted
- 28gm Egg, raw – mixed well
- 6gm Oil – Canola, Soybean, Olive or any vegetable oil
- Optional: 3 drops Vanilla Extract

## Directions

- Grind macadamia nuts in a blender until finely chopped.
- Mix egg and oil into chopped macadamia nuts.
- Optional: Add 3 drops Vanilla Extract.
- Spray a nonstick skillet with oil-spray.
- Drop batter into desired size circles into heated pan. Turn over with a spatula when browned.



Visit the Recipe link on [charlifoundation.org](http://charlifoundation.org) to find other tasty ketogenic foods.

## Frequently Asked Questions

*Q* I currently have an account as a health care professional for KetoCalculator. My hospital requires that the username and password are changed annually in all computer programs. Is it possible to do this in this program?

*A* There is a Table Maintenance link within the health care professional's login named "Organization Settings". Within this link you will see your username and password. You may change the existing username and password at any time. Be sure to select SAVE after you have made changes.

## 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.charlifoundation.org](http://www.charlifoundation.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](http://www.keto411.org)

# Julie's Story

Jean McCawley (mother of Julie)

Julie was 10 months old when she was diagnosed with epilepsy. There's nothing more terrifying than watching your child seize, yet we were about to discover something even worse. Julie was prescribed Phenobarbital to control the seizures. I was advised the only side effect was drowsiness. I was unaware that something as simple as a tiny pill would begin a life-time nightmare.

Within 2 weeks of treatment Julie developed blisters and a high fever. Her eyes swelled shut and wouldn't open again for 2 months. She was diagnosed with chicken pox, conjunctivitis, double ear infections and strep throat. She had no exposure to these illnesses. Over the course of the day she continued to worsen. By the next morning I rushed her to an emergency room. Her pediatrician called ahead to notify them a child with chicken pox was arriving.

Her mouth was filled with blisters and she was severely dehydrated. An IV was started and Phenobarbital was added. By now the blisters were breaking and her skin was sliding off. For the next 3 days she continued receiving Phenobarbital intravenously until a nurse said this is Stevens Johnson Syndrome!

I had no idea what that was. At last we could get her better. Little did I know SJS was one of the most severe adverse reactions a person can suffer from. Anti-convulsants are among the top causes. Julie quickly escalated to Toxic Epidermal Necrolysis the most severe form of SJS. After a month, treated in a burn unit with burns over 80% of her body Julie was released. Her eyes, ears and throat suffered extensive damage. At no time were we offered the Ketogenic Diet.

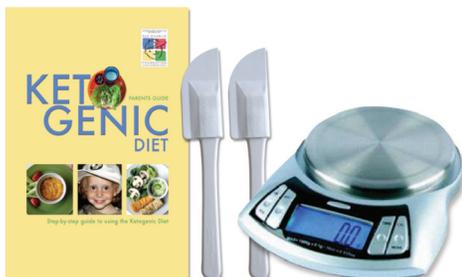
One month later I watched a Dateline story about Charlie Abrahams. His father Jim described a wonderful safe, drug free, treatment for epilepsy. It breaks my heart that this treatment was available for over 70 years but never offered to us. I wonder what life would have been like for Julie if she had been given that choice. They say hind sight is 20/20, that certainly pertains to us. Julie is blind in her right eye and has low vision in her left, she has photophobia, dry eye syndrome, a swallow disorder, scarring in her esophagus and inside her ears and she is one of the lucky ones. Many SJS patients die.

The drug Lamotrigine has such a high incidence of SJS in children that it carries a black box warning, yet neurologists rarely pass this information on to their patients. I can never thank Jim and Charlie enough for appearing on Dateline and giving Julie a second chance. Before the diet Julie suffered life threatening grand-mal seizures and status epilepticus. At 15 months old with the help of Jim Abrahams, Julie started the ketogenic diet. After two and a half years she was weaned off and remains seizure free.

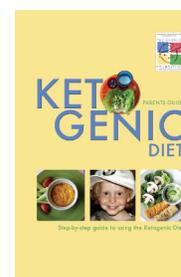


Visit the [Community Forum link on charlifoundation.org](#) to find support for keto families.

## KETOGENIC RESOURCES Credit card orders are now accepted. Request an order form from [ketogenicseminars@wi.rr.com](mailto:ketogenicseminars@wi.rr.com)



**STARTER KIT FOR THE KETOGENIC DIET..... \$68**  
Includes: Parent's Guide to the Ketogenic Diet  
2 Rubber Spatulas  
Digital Mini Scale: 5 Inch Platform  
Weighs up to 1000gm with 0.1gm precision.  
Includes AC adapter, weighing bowl and calibration weight, 2 AA batteries, 5 year warranty.



**PARENTS GUIDE TO THE KETOGENIC DIET..... \$10**  
English or Spanish versions.  
Includes recipes, sick-day guidelines and much more.