



**IN THIS ISSUE**

ILAE Dietary Therapy Task Force update

Recent events and dates for your diary

Join us for Purple Day on March 26th



Spring Newsletter 2016 • First Edition

# Ketogenic Therapies

## Newsletter



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**Welcome to the first edition of our new-look Keto Newsletter**

We really hope that you enjoy reading our newsletter, please let us know what you think as your feedback is very important to us. If you would like to include your story for a future edition or have any suggestions on how we can improve our newsletter then please contact me on: [emma@matthewsfriends.org](mailto:emma@matthewsfriends.org).”

– Emma Williams  
MBE, CEO/  
Founder



## A new look but the same quality of information

Over the past few months you may have noticed that Matthew's Friends is looking a little bit different. We have a fabulous new charity website ([www.matthewsfriends.org](http://www.matthewsfriends.org)) featuring more information than ever before, with new ketogenic recipes being added monthly from our ketokitchen. You will also find our introductory films and tutorials readily available on our website and our Youtube channel which everyone can access freely. These tutorials make ketogenic therapies far easier to understand for all concerned when you can actually watch and hear from those professionals that work in this field every day. This is an ongoing project for us and new films are added to our YouTube channel every week.

Our new MF Clinics website ([www.mfclinics.com](http://www.mfclinics.com)) is also currently undergoing a transformation and should be completed in the next couple of months, so if you can't access all the information

please bear with us. Also on our clinic website we will be featuring more information on our new training programme for medical professionals namely 'Matthew's Friends KetoCollege'. We have always been passionate about providing training for professionals in the complexities of managing ketogenic therapies and tailoring these therapies to the needs of the patient first and foremost. Our dedicated team of Mentor's are looking forward to sharing their extensive knowledge and passion for these therapies with those who are looking to start working in this highly rewarding field of dietary therapy, be it for epilepsy, oncology, diabetes or other neurometabolic disorders.

We will keep you regularly updated through our newsletter, Facebook, Twitter, and websites, so don't forget to sign up to our database. It means that you will never miss out on any information and we promise that we never share your data with anyone.

**Matthew's Friends KetoCollege**

June 9th & 10th 2016  
The Felbridge Hotel,  
East Grinstead, UK  
**Visit [mfclinics.com](http://mfclinics.com) for more info**  
[ketocollege@mfclinics.com](mailto:ketocollege@mfclinics.com)

**Keto-friendly recipes**

3 simple recipes  
**Page 5**



# Abigail's Story

It all began with the attack of shingles across my abdomen when I was 12 in 2001. When I was 14 I started getting mild twitching of the abdominal muscles. From 2003 I had a rapid deterioration to episodes of jerking of the abdominal muscles resembling fits. In 2004 I got a diagnosis of propriospinal myoclonus aged 15 by Great Ormond Street professors.

I tried various treatments, lots of drugs often at supra maximal doses and had several long-term hospitalizations. Every summer it seemed I was in hospital trying to control this horrible condition.

I had to dictate my A level exams to a teacher as the drugs had given me such a tremor I was barely able to hold a pen.

I lost out on the normal activities of teenage years – there are many family holidays I don't even remember. Many of the drugs I tried had to be abandoned because of the severe side effects.

I had to leave boarding school in 2006 and missed a school year but was able to catch up at a fantastic local sixth form college

where I was nurtured through A levels by a team of supportive staff. I achieved three good A levels and two AS levels as well as the Duke of Edinburgh award and other achievements. I had to dictate my A level exams to a teacher as the drugs had given me such a tremor I was barely able to hold a pen. However the condition continued to blight my life. At worst I was having two visits to A&E per week on a blue light by ambulance for IV drugs. Visits to A&E twice a day was not unheard of. I had stays in High Dependency Unit and Intensive Care and once stopped breathing because I had had so much medication. Eventually a Portacath had to be inserted in my chest as my veins were in such a terrible condition.

My outlook seem bleak. I was badly affected by the drugs and taking a vast amount of Buccal Midazolam to terminate these frequent attacks. I was not able to learn to drive, university would be almost impossible, I was unable to live alone or even go anywhere alone and I had the prospect of moving into residential care. I had already heard about the diet from a paediatric neurologist in approximately 2005 but I thought it would be impractical at boarding school and anyway it didn't seem to fit as a treatment

for my condition, and had such a bad press for being so difficult to manage.

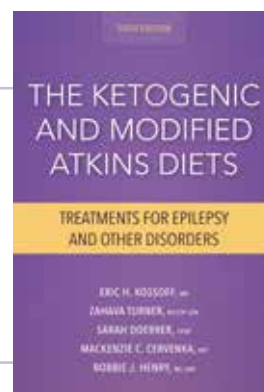
I decided to try it in 2011 with the help of a local dietitian. Matthew's Friends Clinic was not operating at that time but we did get some advice. Unfortunately our "home tried" diet had no real affect but I was able to obtain funding to attend Matthew's Friends from a great GP and was Matthew's Friends Clinic first patient in 2012 I had a proper assessment, the correct prescription and all the relevant tests. Now three years on, on the modified Atkins diet I am living independently albeit with PA support, off at least half of the drugs and reducing my dependence on these and increasing my activities. I have a worthwhile job working with autistic children, have studied with the Open University, I have a boyfriend and I am making big plans for the future. Oh, and the portacath is in a jar in the kitchen!

There is nothing to lose from trying this diet and so much to gain. My seizures are so much better controlled I love all my foods and have lots of favourite treats to eat and drink. Don't let the weighing put you off, it comes naturally after a while. My only regret is that I didn't try it sooner.

Abigail aged 27, 2015

## New book release

The Sixth Edition of the popular Ketogenic Diet book is due for release at the end of March 2016 and will be available through Amazon. This book is hugely popular with families and medical professionals, being written by our friends at Johns Hopkins, Baltimore, USA.



# Clinical Trial News

In each future addition of Keto News we will be featuring some information on clinical trials that are currently being carried out in relation to and/or using ketogenic dietary therapies. In this edition we are focusing on 2 trials that are currently underway in the UK and Europe in the treatment of epilepsy. Matthew's Friends are very proud to be helping to support both these clinical trials.

Information currently available on [www.clinicaltrials.gov](http://www.clinicaltrials.gov) is as follows:

## Evaluating Dietary Intervention Before Surgical Treatment for Epilepsy (EDIBLE)



This is a randomised controlled trial to compare seizure remission outcome following resective surgery with or without prior treatment with ketogenic diet in children with epilepsy as a result of focal cortical dysplasia type II.

This is a Europe wide clinical trial and the UK centres taking part are:

Birmingham Children's Hospital  
Bristol Children's Hospital  
Royal Hospital for Sick Children Edinburgh  
Alderhey Children's NHS Trust  
Kings college hospital and Evelina Children's Hospital  
Great Ormond Street Hospital for Children NHS Trust  
Manchester Children's Hospital

The investigators are undertaking the first European Randomised Controlled Trial (RCT) for epilepsy surgery in children with FCD type II, to prospectively evaluate the role of the KD prior to surgery in improving seizure outcome. The investigators will evaluate the role of KD as a disease-modifying treatment to achieve seizure control and improve neurodevelopment and quality of life. Children age 3 - 15 years with pharmacoresistant epilepsy believed to be the result of focal cortical dysplasia type II, considered to be surgically treatable, will be randomised to either receive 6m treatment pre-surgery with a ketogenic diet, or to proceed direct to surgery (no pre-treatment). Primary outcome will be the time to achieve a period of 6 months of seizure freedom from the date of randomisation. Tissue resected at surgery will also be evaluated with regard to the degree of any methylation of DNA.



Edited and approved by:

Professor J. Helen Cross OBE  
MB, ChB, PhD, FRCP, FRCPCH

The Prince of Wales's Chair of Childhood Epilepsy and Honorary Consultant in Paediatric UCL- Institute of Child Health, Great Ormond Street Hospital for Children & Young Epilepsy  
Chair of Matthew's Friends Medical Advisory Board

## Ketogenic Diet in Infants with Epilepsy (KIWE)



Sponsor: University College, London

Collaborators:

Great Ormond Street Hospital for Children NHS Foundation Trust  
Guy's & St Thomas's NHS Foundation Trust  
Cambridge University Hospitals NHS Foundation Trust  
Alder Hey Children's NHS Foundation Trust  
Bristol Royal Hospital for Children  
Birmingham Children's Hospital NHS Foundation Trust  
The Leeds Teaching Hospitals NHS Trust  
Central Manchester University Hospitals NHS Foundation Trust  
UCL Institute of Neurology  
Royal Holloway, University of London  
Young Epilepsy  
Matthew's Friends  
National Institute for Health Research, United Kingdom

Epilepsy, a condition where individuals are prone to recurrent epileptic seizures, is the most common chronic neurological disorder in children. Epilepsy onset is most common in the first two years of life and is associated with poor prognosis for seizure control and neurodevelopmental outcome.

The ketogenic diet (KD) is a medically supervised diet that is high in fat and restricted in carbohydrates and protein. KD therapy has shown to be an effective treatment for seizures in children with epilepsy older than two. Associated benefits include: a reduced requirement for routine and emergency antiepileptic drugs (AED) and fewer seizure related hospital admissions. Although reports suggest that KD therapy improves seizures in younger children there is no high quality trial data that demonstrates effectiveness and safety in this age group. The KD is resource intensive, requiring dietetic and physician time; data is required to justify expansion of services to cater for the apparent need.

The investigators are therefore undertaking a prospective multicentre randomised trial to investigate the effectiveness and safety of the KD in children with epilepsy under the age of 2, who have failed to respond to two or more AEDs. Children will be randomly assigned to either receive the KD or further AEDs. The allocated treatment will be started after a 2 week baseline period, and its effectiveness assessed after 8 weeks. Seizure diaries will be used to record seizures and related events, a questionnaire will be used to assess diet tolerance; also growth and blood biochemistry will be monitored.

The information obtained from this study is necessary to optimise choices in epilepsy treatment, aiming to improve outcomes and thus determine whether and when the KD should be used.



# Keto Cooking



## Ketokitchen answer some of your most frequent questions

'I am finding packed lunches quite difficult, I have exhausted the muffins and quiches option – what else do you suggest?'

If you can make the Flaxseed Bread, then sandwiches can be taken to work or school with the filling of your choice. Salads can be a good option, but if using meat or fish make sure you have access to a fridge. Cubes of cheese, ham/salami and low-carb veggies with a mayonnaise or cream cheese dip could be taken. If you use a food flask then soups can be prepared in advance, however we don't recommend using meat based soups if the meal is going to be stored for a quite a few hours. It would be best to make a vegetable based soup and then perhaps take some cheese or ham to have with it. You can also use lettuce leaves as a wrap if you are on a very low carbohydrate amount and then fill them with tuna mayonnaise or egg mayonnaise. The ketokitchen team are currently working on new recipes for packed lunches, so keep checking in on the website.

'I am currently on chemo and I feel quite sick, I can't stomach any oily textures – how can I get the fat into my diet without the food being really oily?'

Being on Chemo can mean that your tastes can change too, so this can also be a problem for some, so you may need to experiment with ingredients too. Some of the prescription powder products available could be a very useful way of getting more fat into your diet, so have a chat with your dietitian about the products available to you. Look at alternative fat sources to oil and butter such as mascarpone, clotted cream and mayonnaise (if you are able to eat dairy products). Fatty meats can also be useful such as belly pork, duck, salami and bacon and as an additional option there is also avocado which is a very good way of increasing the fat content of a meal.

'My child doesn't like the flavour of coconut, but a lot of recipes seem to use this as an ingredient – what else can I use instead of coconut?'

Sometimes it is the texture of desiccated coconut that people don't like, so using coconut flour (East End or TRS variety) or even ground unsweetened coconut is a better option. However, if it is the flavour that is not acceptable then alternatives can be used. There are the prescription powder products, again speak to your dietitian about what is available to you. You can also think of using ground flaxseed, ground chia seeds, ground almonds (look at all types of ground nuts) and some have found Soya Flour or the addition of some Psyllium husk in recipes useful in reducing the flavour of coconut flour as well.

Please remember to discuss all options with your dietitian before using any new products or making any dietary changes and make sure you adhere to your diet prescription.

#KetoKitchen recipe films and tutorials hit the spot!



Our recent #KetoKitchen project has proved hugely successful, with 1000's of visitors to our MatthewsFriendsOrg YouTube Keto Cooking Channel and on our website. Over 30 films to date have been shared, with more to come during the Spring.

The films cover many aspects of Ketogenic therapy management for families including: Store Cupboard and

Cooking Essentials, Freezing Keto Food, Low Carb Fruits and Vegetables

We are hugely grateful to the Awards for All lottery, Nutricia and Vitaflo for their support of our #KetoKitchen.

We will be fundraising this year for more recipe filming to take place during the Summer of this year. If you can assist with this please, we would be very happy to hear from you!

# Easter Recipes



## AUBERGINES

Although we tend to use them as a vegetable, they are in fact a fruit (a berry to be precise!). There are many different varieties but the one we favour most is the large purple type that is easily available. They are a great ketogenic ingredient because of their ability to soak up a lot of oil. The traditional way of preparing them was to add salt to them to reduce the bitterness, but nowadays this is not necessary and remember if you do add salt to them, it can restrict the amount of oil being absorbed, which is something we DON'T want to happen on the Ketogenic diet, so don't salt your aubergines. They have a mild, fairly bland flavour so using spices and flavourings with them is recommended. The flesh is quite a spongy texture which is why it is so good at soaking up fat, but it is soft when cooked.

They are mostly used in recipes such as a roasted ratatouille or Moussaka (usually a mince based dish, with Aubergine and an egg custard/cheese sauce topping), but they can also replace lasagne sheets, be diced and used in stir fries. They can be used as pizza bases by slicing them and brushing with oil and just frying in a pan, you can then top them with cheese/ham and pop them under the grill. You can also cook them with oil and spices and mix them to a 'dip' consistency. If you add butter to this dip and let it set then it becomes more of an aubergine pate which you could serve with flaxseed bread.



## EASTER CHOCOLATE TREAT SNACK

14g Dark Chocolate (Lindt 90% Cacao Dark Supreme)  
10g Butter

You will also need a few drops of liquid sweetener.



### Method

Melt the chocolate with the butter, stir in a few drops of liquid sweetener.

Pour in to moulds of your choice (I used bunnies and eggs).

Put in fridge to set.

Mo's tip: A few drops of orange extract is lovely added to the chocolate.

This recipe contains **Fat: 16g, Protein: 2g, Carbohydrate: 2g.**

## SIMNEL CAKE WITH MCT

7g Ground almonds (Morrisons)  
18g MCT oil  
17g Eggs and 4g Egg whites  
25g Alpro soya light  
25g Coconut flour (Tiana)  
6g Raisins  
7g Sultanas  
Also a good pinch of Truvia granules, almond essence, some mixed spice and liquid sweetener.



### Method

First make the marzipan: mix the Truvia with the ground almonds. Beat in the egg white and a drop of almond essence to form a stiff paste. Form into small balls, eleven would be traditional. Chop the sultanas and raisins then mix with all the other ingredients, place in a large muffin mould or similar and pop the marzipan balls on top. Bake in a pre heated oven for approximately 25 minutes at 170c/150c fan/gas 4.

This recipe contains **Fat: 9g, Protein: 9g, Carbohydrate: 15g, MCT: 18g.**

## MO'S ICED EASTER BISCUITS

17g Ground almonds (Morrisons)  
3g Medium oatmeal (Mornflake Stoneground)  
14g Butter

You will also need NATVIA sugar free icing mix (available online e.g. Amazon), a few drops of liquid sweetener and almond extract.



### Method

Pre heat oven to 170c/fan 150c/gas 3-4. Mix the almonds and oatmeal. Soften the butter and mix in to the flour mix with the liquid sweetener and extract. Press into mini muffin moulds to shape. I made 5 biscuits (each biscuit: 4.2g fat / 8g protein / 0.6 CHO). Cook in preheated oven for approximately 10 minutes. When cold mix Natvia with a few drops of cold water and use to decorate the biscuits.

This recipe contains **Fat: 21g, Protein: 4g, Carbohydrate: 3g.**





## Marathon Man

Marathon Man Martin takes on the epic London event for us this year! We wish him the very best of luck, please sponsor him here: [uk.virginmoneygiving.com/martinjukes](http://uk.virginmoneygiving.com/martinjukes)

Huge thanks to him and his colleagues at Avensys Crawley for their continued amazing support.

## Welcome Keto Stars

At Matthew's Friends, we know and understand how vital 'support' is when on a prescribed Ketogenic Dietary Therapy. We want to recognise not only the patients, be they children or adults, but also those around them that contribute so much and can make the difference between success and failure.

This is your opportunity to say 'Thank You' to a special person or family member, group, school, hospice. Perhaps a certain restaurant or hotel has gone that 'extra mile' that has helped your family eat/holiday together happily?

Visit [matthewsfriends.org](http://matthewsfriends.org) and nominate your KETOSTAR!



# COMING SOON... NEW AND IMPROVED FORMULA



**KetoCal 4:1 powder** is a nutritionally complete, very high fat powder that can be used in the dietary management of intractable epilepsy and other conditions where the ketogenic diet is indicated.

- ✓ Upgraded fat profile
- ✓ Now contains the LCPs DHA and AA
- ✓ Now contains multi-fibre 6 (MF6)
- ✓ Upgraded vitamin, mineral and trace elements
- ✓ Aspartame free
- ✓ The new 4:1 powder formulations have a nutritional profile that more closely resembles KetoCal 4:1 LQ

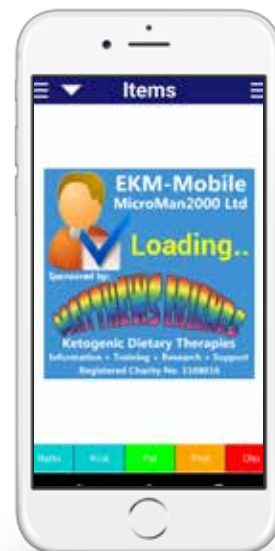
*KetoCal provides a convenient way of administering KDT: as a drink, in meals or as a tube feed*



## Your Handy Keto Calculator

Keep up to date with new developments of the Electronic Ketogenic Manager (EKM) on our website. Not only is there EKM-Mobile for use on Android, iPhone and iPad, there will also be a BRAND NEW VERSION of EKM Desktop, currently in development.

All made possible by funding from Matthew's Friends! EKM allows dietitians and those parents that wish, the ability to fine tune or even create meal plans with accurately calculated ratios and Fat/Protein/Carbohydrate intake.



# Matthew's Friends Down Under



Hi from everyone Down Under at Matthew's Friends NZ.

Last year saw our ketogenic community continue to grow, boosted by the number of children initiated through the newly reinstated Keto Clinic at Starship Hospital in Auckland.

At Matthew's Friends NZ we are persevering with our endeavours to raise awareness of dietary therapy for epilepsy, and to increase access to the treatment on a national basis.

**We are persevering with our endeavours to raise awareness of dietary therapy for epilepsy**

Late last year I had the pleasure of representing Matthew's Friends at the very first combined Australia/New Zealand 'Keto meeting', hosted by Nutricia in Brisbane. This inaugural

professional development event was very well attended by dietitians from both sides of the Tasman, along with guest speakers Professor Helen Cross from Great Ormond St Hospital in London (Chair of the Matthew's Friends Medical Board in the UK), and Dr. Sophie Calvert from Lady Cilento Children's Hospital in Brisbane.

The meeting closed with a lively and enjoyable interactive 'KetoCal Cooking Masterclass' where we were separated into groups to construct our masterpieces. All came away with great meal ideas and recipes to share with our keto families. This coming year we hope to extend our endeavours in the South Pacific to include our Tasman neighbours. We are working with Emma Williams and some fantastic Australian keto parents to formalise support for health professionals and families with the creation of an Australian branch. Watch this space.

– Susan Hill  
President, Matthew's Friends NZ

## Harry's Story

One of our NZ children treated with dietary therapy, 5 year old Harry, was featured at an Epilepsy NZ 'Talk about it' event in New Plymouth in November. Harry's parents Amanda and Bryce spoke of Harry's journey with Myoclonic Astatic Epilepsy and his successful response to dietary therapy. Harry has remained seizure free and recently experienced his first day of school. I was also invited to speak at the event, where I gave an overview of ketogenic dietary therapies and our ongoing work at Matthew's Friends.



**Harry (5) and parents speaking at 'Talk About it'**



## Specialist Chef Neil to join Vitaflo®

Vitaflo® is very excited to announce they have a new employee as part of their team, Neil Palliser-Bosomworth, better known as Chef Neil.

Chef Neil, who already works with the Matthew's Friends team, has two decades of experience in creating specialist medical recipes for conditions such as PKU, cancer, ketogenic therapy, dysphasia, weight gain, gluten free, diabetes and many other diets. Neil will be focussing on developing and demonstrating new ideas for ketogenic foods with carbzero®, betaquik® and now also using MCTprocal™ in the UK and internationally. We very much look forward to continuing to work and develop recipes with support from Matthew's Friends.

For those that have not already enjoyed MCTprocal, it is an unflavoured powdered source of MCT that also contains carbohydrate and protein. Although it is suitable as an ingredient for the ketogenic diet the protein and carbohydrate content must be accounted for in any dietary plan. It has been found to be beneficial in adding texture to foods. Recipes developed so far are cookies, pizza, pancakes & waffles, breadsticks, bread, with much more to come. For more information, please contact your dietitian.

**"I am very excited to continue working with Matthew's Friends in my new role at Vitaflo and look forward to continuing to support patients and their carers in this very important area of specialist nutrition- the ketogenic diet."**

– Neil, Vitaflo®



# Ketogenic updates from across the Atlantic



Matthew's Friends Canada (MFC) has made its elegant debut on March 2015 at the Epilepsy Halton Peel Hamilton Gala in Mississauga, Ontario. In 2015 – MFC Directors Jennifer Fabe (President); Cynthia Milburn (Vice President); Nicole Palmieri (Treasurer); and Sarah Mitchell (Secretary) – has been eagerly forging ahead to raise awareness, shape partnerships and network.

In partnership with epilepsy organizations we have supported the publication of the 'Spark Sheet for Ketogenic Diet Therapies' (Epilepsy Ontario); supported family events (Epilepsy Halton Peel Hamilton, Epilepsy Toronto, Epilepsy Durham, McMaster Children's Hospital; Dravet Canada family retreat). To reach out to local communities and businesses MFC held our first Evening of Awareness in June 2015.



MFC is also very proud to be a co-organizer/supporter of the 1st Canadian Ketogenic Registered Dietitian Forum that was held in partnership with McMaster Children's Hospital and Hospital for Sick Children in Toronto, Ontario in October 2015. From coast-to-coast we were proud to see representation from nearly all the ketogenic diet centers in Canada. Facilitating this Forum helped support a network of mutual learning & support as well as identify ketogenic diet issues affecting Canadian families. The experience, knowledge & compassion of the Canadian ketogenic registered dietitians was most impressive!

A committee has also been created amongst the Canadian Ketogenic Registered Dietitians to adapt the Matthew's Friends UK patient education tools into

Canadian context. These patient education tools are nearly completed and will be made accessible to all ketogenic diet centers in Canada very soon.

In addition to this – Matthew's Friends Canada collaborated with Epilepsy Ontario to create the 'Spark Sheet – Ketogenic Diet Therapies for Epilepsy' that is now circulated to all epilepsy organizations throughout the province of Ontario.

Upcoming events in 2016 for Matthew's Friends Canada include raising awareness and supporting the families. We are very honored with the medical advisory board that is being shaped and look forward to working with them on various projects to support MFC and ketogenic families throughout this large country. We are also very pleased to be in partnership with Dr Eduard Bercovici, adult epileptologist whom has established the first Canadian adult ketogenic diet center in Canada at Toronto Western Hospital and look forward to supporting this program.

MFC is also very excited to be invited to discuss ketogenic diet therapies to support groups of the London Epilepsy Support Centre as well as Epilepsy Halton Peel Hamilton. A project on surveying the practices of ketogenic diet centers will also be underway

**We are proud to see representation from nearly all the ketogenic centers in Canada.**

soon to not only support ketogenic dietitian practices but also further identify the ketogenic needs of the country.

We are also very excited to announce the upcoming Matthew's Friends Canada Family Day on September 17, 2016

## Matthew's Friends Canada Family Day

We are also very excited to announce the upcoming Matthew's Friends Canada Family Day on September 17, 2016 where we shall be doing some ketogenic cooking, sharing of ketogenic experiences, fun games and activities! We shall also have honored guests: Emma Williams and Chef Neil Bosomworth & Dr. Eduard Bercovici to join us to share their expertise! Please Save the Date!



**Dr. Bercovici and Jennifer Fabe**

where we shall be doing some ketogenic cooking, sharing of ketogenic experiences, fun games and activities! We shall also have honored guests: Emma Williams and Chef Neil Bosomworth & Dr. Eduard Bercovici to join us to share their expertise! Please Save the Date!

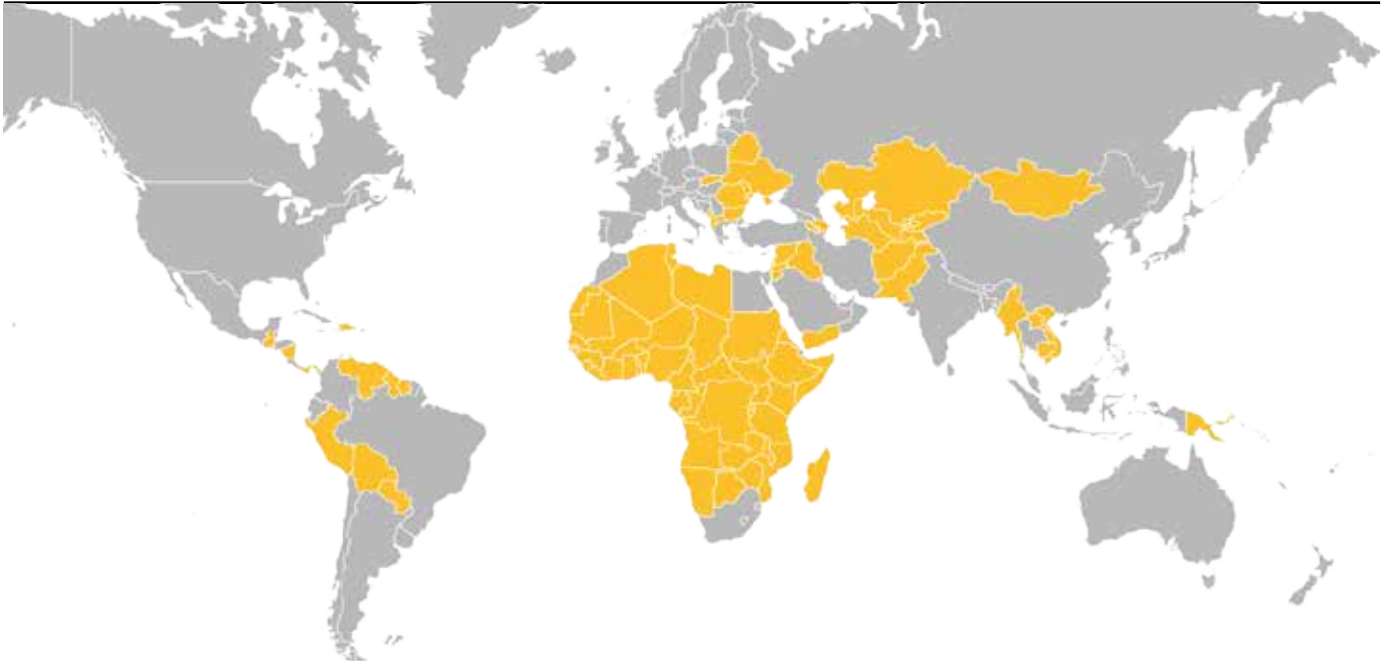
Make sure to visit us at:  
#MF\_Canada  
f Matthews Friends Canada

It truly has been a fantastic first year and we thank all the ketogenic diet families, volunteers, local businesses, physicians, registered dietitians and epilepsy organizations for your support. Special mention to Ankie Werdekker and Melissa Woodworth who are inspiring parents whom have eagerly supported MFC activities and shared their families' ketogenic journey.

We thank our industry partners of Nutricia, Cambrooke Therapeutics, VitaFlo, Nestle, Solace Nutrition for supporting us during this first year.

Jennifer Fabe RD  
President, Matthew's Friends Canada





## The ILAE Dietary Therapy Task Force

The use of dietary therapies around the world has dramatically expanded over the past 2 decades. Every year new centers are starting in areas of the world that need this important treatment for epilepsy. Back in 2005, when I attempted to find every center worldwide (and wrote an article about it), I found centers in 41 countries. Over 10 years later, things are better, and I'd estimate that about 65 countries have ketogenic diet centers.

Unfortunately, there are still major regions of the world that do NOT offer dietary therapy. Many of these are in developing countries with limited resources – the diet is often perceived as expensive, time-intensive, and impossible by local doctors. In this map of the world, areas colored dark are those countries that to my knowledge do NOT have ketogenic diet centers. Many of these are in Central America, Africa, the middle East, South Asia and Southeast Asia.

How do we fix this? In 2014, I was thrilled to hear from the International League Against Epilepsy (ILAE) that they were interested in funding a small 12-person Task Force under the Medical Therapeutics Commission to help advance dietary therapies worldwide. Members of this Task Force are: myself (Dr. Eric Kossoff, USA), Dr. Mackenzie Cervenka (USA), Dr. Janak Nathan (India),

Ms. Emma Williams (of Matthew's Friends UK!), Dr. Liao Xiang (China), Beth Zupec-Kania RD (USA), Kath Megaw RD (South Africa), Rocio Rivera Claros (El Salvador), Dr. Adelheid Wiemer-Kruel (Germany), Dr. Nabil Al-Macki (Oman), Ximena Raimann MD (Chile), Heung Dong Kim MD (Korea).

What have we accomplished so far? Our first task was to create a website. The website is located at [www.ilae.org/Commission/medther/keto-index.cfm](http://www.ilae.org/Commission/medther/keto-index.cfm). It includes free articles, news, lists of books and websites, recipes, supplements, and a maintained list of international ketogenic diet centers.

Our second task was the creation of a consensus document about the "minimum requirements" of a ketogenic diet center. We tried to bring the 2009 ketogenic diet consensus statement "down a notch" in intensity for regions that

Over 10 years later [...] I'd estimate that about 65 countries have ketogenic diet centers.

just can't do the diet to that level. It is listed (the second article) at [www.ilae.org/Commission/medther/keto-articles.cfm](http://www.ilae.org/Commission/medther/keto-articles.cfm)



Task Force meeting at the Global Symposium 2014.

if you wish to read it, with a summary recently published on my Blog at [www.epilepsy.com/article/2015/7/bringing-diet-world-what-does-ilae-minimum-requirement-paper-really-mean](http://www.epilepsy.com/article/2015/7/bringing-diet-world-what-does-ilae-minimum-requirement-paper-really-mean). This is designed to help developing countries realize that dietary therapy doesn't have to be that difficult to do at their hospital.

Our next task will likely be the creation of a PowerPoint teaching file that could include lectures and videos. This teaching file would be available to neurologists and dietitians that want to start a ketogenic diet center at their hospital but may not be able to travel to learn how. The teaching file would be downloadable over the Internet and continuously updated with new slides and material based on new research. This may be our final task – the Task Force is a 3-year project – but stay tuned for more developments on this!

By Eric Kossoff MD  
Medical Director, Ketogenic Diet Center,  
Director – Pediatric Neurology Residency  
Program, Johns Hopkins Hospital,  
Baltimore, USA

## Dates for your diary

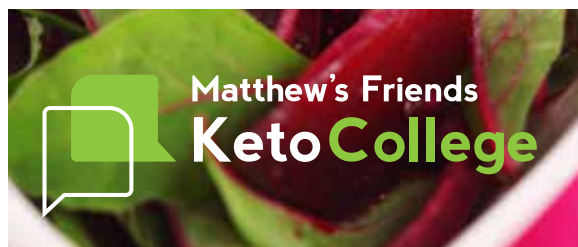
### Matthew's Friends KetoCollege

June 9th & 10th 2016

Led by Ketogenic diet experts, includes presentations, practical workshops and group discussions.

At The Felbridge Hotel, East Grinstead, UK.

Visit [www.mfclinics.com](http://www.mfclinics.com) for more information.



### Banff Global Symposium

20th - 24th September 2016

Four day conference featuring specialists from the world of ketogenic therapy. For more information please visit [www.ketoconnect.org](http://www.ketoconnect.org)



### Conference on GLUT 1 Deficiency

7th - 8th October 2016

The congress website is online and registration form is available at [biomedia.net/Glut2016](http://biomedia.net/Glut2016)



## Recent meetings



### International Congress on Integrated Health – Fulda, Germany, 2015

Matthew's Friends' nutrition experts, dietitian Sue Wood and nutritional therapist Catherine Zabilowicz recently attended the 'International Congress for Integrated Health' in Germany. The emphasis was on cancer and the ketogenic diet (KD) and included interesting and knowledgeable speakers from the world of research and clinical practice.

Visit [www.matthewsfriends.org/keto-news](http://www.matthewsfriends.org/keto-news) for more information on the Congress.



### Conference on Nutritional Ketosis and Metabolic Therapeutics – Tampa, January 2016

Mounting evidence about the central role of metabolism in the pathophysiology of varied disease states has sparked a revival of interest in the development of metabolic-targeted therapies. Therapeutic ketosis is one of many promising such treatments, and animal and clinical data has demonstrated its significant and widespread efficacy. Matthew's Friends dietitian Sue Wood attended this meeting where a range of international experts presented on the science and application of low-carbohydrate nutrition, ketogenic diets, ketogenic supplementation, metabolic supplements, and metabolic drugs for treatment and prevention of cancer and neurological diseases, as well as for optimizing wellness and extending human performance and resilience. Sue has prepared a synopsis of the meeting and if you wish to read it please visit [www.matthewsfriends.org/keto-news](http://www.matthewsfriends.org/keto-news).



### British Paediatric Neurologist's Meeting (BPNA) – Sheffield, January 2016

Emma Williams MBE and Julie Edwards attended the above conference, whilst also having an MF stand and catching up with neurologists and medical professionals from all over the UK and abroad. Glut 1 Medical Board Advisor Dr. Archana Desurkar did a wonderful talk on the mis/missed diagnosis of Glut 1 Deficiency and the importance of being able to diagnose this condition and implement the ketogenic diet rapidly. Dr. Desurkar also gave an overview of other possible therapies that are being trialled at the moment. Dr. Desurkar will be preparing a write up on her talk for our summer newsletter.

# Hadley's Story



My son Hadley has an as yet undiagnosed severe form of drug resistant epilepsy. It started about 8 years ago and he spent months as an in-patient in Great Ormond Street where he was treated with a huge variety of powerful drugs. If you are reading this you probably know only too well the agony of watching your child suffer the constant side effects of the drugs used and the horror of the weans to remove them when they fail. Matthews Friend's made the Ketogenic diet available for Hadley. They held our hands, educated us, stood with us when things were really bad – and we all know that's the vast majority of the time with kids like ours. They acted as an advocate for Hadley when we were unable to. Emma answered my calls in the middle of the night, listened to me rant, advised me, counselled me, redirected my energy from

Emma answered my calls in the middle of the night, listened to me rant, advised me, counselled me

hopeless anger to productive processes and generally stood firm and allowed me and my family to lean on her and her organisation. When I had nowhere else to turn Matthew's Friends were there for me, and more importantly for my wife, my son and his siblings.

I've been asked to write a brief article on why I am rowing the Pacific and fundraising for Matthew's Friends and most would think that the above paragraph

would probably cover it, but whilst the above would be reason enough alone it isn't the reason for me. It means I owe Matthew's Friends and it means I admire the staff and respect the work they do, but it isn't the reason I'm fundraising for them.

I have sat helplessly and watched my son have tens of thousands of seizures. Each one hurt me in ways I can't even begin to explain. The seizures took my son away, piece by piece, day by day. His speech, his ability to walk, his fine motor control and his future. With it went my hopes and dreams for him and for the future I'd planned for my little family. We became increasingly isolated due to the restrictions his condition placed on us collectively. As time passed our world shrank little by little, we saw more of hospitals than we did of pubs and restaurants. Our late nights were spent nursing, and lying awake waiting for the next seizure whilst worrying how we would pay our mortgage now my wife was unable to work because she had become a 24/7 carer, doctor, nurse and maid. During the days we spent in hospitals we saw the new cases coming in. One of them may have been you. We knew what the future held and we smiled and tried to be helpful. I pointed numerous families towards Matthew's Friends with a silent prayer that their story would turn out differently than mine. I recognised the punch drunk exhausted look that the mums and dads were wearing and I hated that I knew what was coming for them without some sort of miracle. Most of all I hated that their beautiful innocent perfect little children were going to suffer.

So if you have a son or daughter that's been affected by severe

epilepsy in the last 8 years, you're the reason I'm fundraising for Matthew's Friends. It's too late to save my son or my family from the pain but for you, it might not be. I don't have a magic wand, or the skills to be a top neurologist. I have a big heart and I'm stubborn. Boy am I stubborn. I also have a big sense of adventure and the compulsion to try to help in the only way I can. Sadly I'm never going to invent the cure for your child but I can perhaps, raise enough money for Matthew's Friends to make the Ketogenic diet available to everyone early enough to give them a chance. Maybe to give your children a chance. Maybe to give your family a chance.

That's why I'm rowing the Pacific and fundraising for Matthew's Friends. I'm doing it for you, and if not for you directly, for the ordinary innocent people like my son and my wife and I were, the ones that have a major problem coming and don't even know it yet. If not you, then I'm doing it for them.

Support Endurance Limits Ocean Rowing Team in the Great Pacific Race in order to raise funds for Matthews Friends. o donate by text and support the Endurance Limits team please text 70070 with the message ELMF99, followed by the amount you wish to donate, ie. £1, £3, £5 or £10. You can stay up to date with their Pacific Campaign progress:

[@EnduranceLimits](https://twitter.com/EnduranceLimits) [f /endurancelimits](https://www.facebook.com/endurancelimits)  
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Hadley pictured with his sister Bethany, 2015



# Fundraise for Matthew's Friends

## Thank You

Matthew's Friends rely solely on donations and fundraising for the work we do - we would like to thank all our supporters for their amazing work in helping us to do this. More information can be found the fundraising and events pages of our website. If you are planning an activity for us, then please contact us by phoning the office or via our website and we will do all we can to support you.

## A Walk for Tiger

*"We are doing the Hadrians Wall Coast to Coast Walk for Matthew's Friends because they have helped Amelie to get her life back.*



*Amelie was diagnosed with epilepsy at 3 months old. Her seizures (we called 'Polly' to try and make light of the severity of her condition) have nearly stolen her from us a few times. The medication she was given sometimes didn't work and the ones that helped calm 'Polly' have had awful side effects. At 5 years old Amelie was introduced to the Ketogenic Diet and is supported by Matthew's Friends on this.*

*Amelie is now off one of the medications and is reduced in the last one. She is a different little girl. She has found a belly laugh we have never heard before and smiles daily now instead of fighting 'Polly' day and night. Without this diet I dread to think of what Amelie's future would be like. Without Matthews Friends I do not think my daughter would have much of a future or enjoyment that she has now and I owe Matthew's Friends my world.*

*We are walking for Tiger (Amelie) to help raise money for this charity so others can benefit as we have. We would be entirely grateful if you could donate.*

*Thank you so much! Mum x (Kayley)"*

A fantastic event on 25th March 2016, please support Amelie and her family! Visit [www.justgiving.com/Amelie-Burns](http://www.justgiving.com/Amelie-Burns) to donate.

## Contact

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y [matthewsfriends](https://www.youtube.com/matthewsfriends)

If you would like to submit an article for publishing in Ketogenic therapies News then please send it to [emma@matthewsfriends.org](mailto:emma@matthewsfriends.org).

## Friends Family Food

Visit our Friends, Family Food fundraising campaign page on our website and host your own 'low carbohydrate' social event for friends and family. Show them that low carb is delicious!



## Purple Day

Purple Day 26th March 2016!

As always, here at Matthew's Friends we support Purple Day for epilepsy awareness and the founding organisation in the USA, The Anita Kaufman Foundation. This year we have resources available on our website shop for those wishing to fundraise for us and in Matthew's hometown of Oxted, Surrey we are going to be dancing the night away with classic rock covers band, One-Eyed Jack! Please visit the Fundraising section of our website for further information and help us to raise funds and awareness for PURPLE DAY!



**PARTY ON FOR  
PURPLE DAY**

WITH  
**ONE EYED JACK**

AT THE ROYAL BRITISH LEGION,  
42 CHURCH LANE, OXTED,  
SURREY RH8 9LB

TICKET PRICE £4 VIA PAYPAL  
FOR PRE-ORDERED 'TICKETS' VISIT  
[matthewsfriends.org](http://matthewsfriends.org)  
OR £5 ON THE DOOR.

TICKETLESS, BRING PAYPAL RECEIPT  
NON-REFUNDABLE

Raising funds for

To be held on PURPLE DAY  
at 7.30pm on SATURDAY 26th MARCH 2016