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SPRING NEWSLETTER 2017 • FOURTH EDITION

Ketogenic Therapies

Newsletter

EKM THE EASYWAY... with Fay Ripley

Thanks to the generosity of our fundraisers, we are delighted to announce the launch of our new series of free instructional films on how to use the EKM (Electronic Ketogenic Manager) which have been narrated by one of our lovely patrons, BAFTA-nominated actress and cookery writer Fay Ripley.

These films are available to watch via our website and YouTube ketocooking channel enabling ketogenic meals to be easily created by patient, family member or dietitian, no matter what type of ketogenic therapy is being used.



The EKM comes pre-loaded with products from McCance and Widdowson food data tables (7th edition) and will be updated with any new version that is released in the future. Patients and dietitians can also add products to the database that they wish to use so as to personalise the EKM for their specific requirements.

In 2016 we also funded a major re-write of this program so there is now a mobile app available and the EKM can be used on all types of operating systems.



"It wasn't until we started using the EKM that we started to see the seizures reduce by 90%"

"EKM continues to be a lifeline for me"

"It has taken a lot of the hard work out of the ketogenic diet"

"I don't know where we'd have been on our keto journey without EKM"



A distinct advantage of the EKM is that you don't need to be connected to the internet in order to be able to use it, once it is downloaded then you are set to use it wherever in the world you may be. Patients and families also have the capability of completing a weekly monitoring report contained within the program, giving details of glucose and ketone levels, seizure records and any new foods that may have been introduced to the diet, the completed report can then be emailed directly to the managing dietitian, as well as there being the capability of emailing recipes to and from the dietitian.

All this can give peace of mind to both patient and dietitian and ensure that the diet is being managed safely and effectively. These films complement the existing written user guide which again can be freely downloaded from our website or we can send you a free printed copy.

EKM is based on an original idea from our very own Dr. Liz Neal (dietitian) with the software being written and managed by Bruce Carroll. The stipulation of this program is that it would always be freely available to those who need it and that same stipulation still stands today.

For patients wanting to obtain this program you will need to be medically managed for your ketogenic therapy and confirmation will be sought from your managing dietitian before the program is released to you. Details of EKM are available at www.ekmketocalc.com

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[#ketokitchen](https://www.youtube.com/channel/UCqk1k1k1k1k1k1k1k1k1k1k)

TO HELP FUNDRAISING VISIT:

www.matthewsfriends.org/easy-fundraising/

Nominated charity for the 4th Tunbridge Wells Bike Ride



4th September 2016 saw the occasion of the 4th Tunbridge Wells Bike Ride – an exciting event growing year on year, organised by the fabulous team at Wildside Cycles.

Matthew's Friends were delighted to be the nominated charity for the event and our Emma, along with Matthew, plus our Trustee Richard with his son Greg were delighted to attend and help out on the day.

Almost £2,000 was raised in total – an amazing amount! Adam Scriven (pictured) collected an amazing £965 in donations from his supporters and completed the 25 miles Garden Route in 1 hour 59 minutes!

This year our MFGlut1UK Fund is once again the benefiting charity for the 5th Annual Bike Ride, taking place on 3rd September 2017. We really need YOUR help to support this event, please contact us if you can spare a day to volunteer at this fun day in the beautiful area of Tunbridge Wells in Kent.

Please email us at enq@matthewsfriends.org thank you! Huge thanks go to Jessica and her parents Simon and Kate, for nominating and supporting us, which enables us to specifically help families of children with Glut1 Deficiency Syndrome. To find out more about Glut1D, please visit www.matthewsfriends.org/glut1uk/



UK CLINICAL TRIALS - STILL RECRUITING

Please speak to your neurologist or visit www.clinicaltrials.gov for further information.



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.



Ketogenic Diet in Infants with Epilepsy (KIWE)

The investigators are undertaking a prospective multicentre randomised trial to investigate the effectiveness and safety of the ketogenic diet in children with epilepsy under the age of 2 who have failed to respond to 2 or more Anti-Epileptic drugs.

New to Ketogenic therapy? Or needing a refresher course and an opportunity to network with other Ketogenic teams?

MATTHEW'S FRIENDS WILL BE HOSTING THEIR ANNUAL KETOCOLLEGE PROGRAMME

27TH – 29TH JUNE 2017 FELBRIDGE HOTEL, EAST GRINSTEAD, WEST SUSSEX, UK

ADDITIONAL DAY INCLUDED - MEDICAL KETOGENIC MASTERCLASS

TOPICS OVER THE COURSE OF THE PROGRAMME INCLUDE:

Using Ketogenic therapies for Complex Epilepsy

Interactions of medications with ketogenic therapy and when to wean medications whilst on ketogenic therapy

When to use ketogenic therapy and which version is most suitable

Ketogenic therapies in Neuro-Oncology and Metabolic disorders

Ketogenic therapy for infants

Ketogenic therapy for adults

Management of emergency situations

Practical Ketogenic therapy dietetic workshops

LEAD MENTOR & COURSE CHAIR



Professor J. Helen Cross OBE
The Prince of Wales's Chair of Childhood Epilepsy,
UCL-Institute of Child Health,
Great Ormond Street Hospital for Children and Young Epilepsy.

SPECIAL GUEST MENTOR



Eric Kossoff, M.D.
Professor, Neurology and Paediatrics
Johns Hopkins Hospital,
Baltimore.

SPECIAL GUEST MENTOR



Mackenzie Cervenka, M.D.
Associate Professor of Neurology
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For further details please visit www.mfclinics.com
or to register your interest please email: ketocollege@mfclinics.com

**REGISTRATION
NOW OPEN**

OUR STORY...

MEET JAMES...

He is seizure free, drug free and so very happy now! This is all because of the amazingly powerful and effective Ketogenic diet.

When he was two, he developed severe, drug resistant epilepsy. He was knocked down so much but he got up again and played on! He wore a scrum cap to take the sting out of the blows which were relentless. His head used to drop to the floor like a bowling ball. It was torture for him and torture for us.

He tried six drugs, none of them worked. After two years we became desperate for a cure.

So he took the dieticians advice and he embarked on a two and a half year feeding plan, with no exceptions and no days off! He took a specific measurement of protein, carbohydrate and fat, three times a day, seven days a week. He did the blood tests, he checked the glucose and ketones twice daily. It took months to get it right, we fine tuned the diet to suit HIS body which took a large amount of observation and record keeping.

Every detail of James was taken into account when tweaking the programme; physical activity, stamina, mood, speech, learning, appetite, interactions and energy levels. It was so very difficult, but the motivation to continue was there, because he just kept getting better!

After six months, he finally became seizure free, on his fifth birthday. What a birthday present! Everyone's hard work had paid off.

He continued the diet for two years as planned. It was such pressure on a young lad, no parties, no break outs! We avoided crowds because where there are people, there is always food! We didn't talk about food. We kept food out of sight and we certainly didn't make toast when he was nearby!

When we started the diet he hardly had the energy to chew and he threw most food back at me. By the end of the diet he would try anything and I actually can't think of a food he doesn't like now!

On his sixth birthday he visited the Munster Rugby team at a training session. They gave him a jersey and a birthday card. Paul, Donnacha, Peter and Simon spent a lot of time talking to James. Was James giving them advice on how to win a battle I wonder?

We were halfway there. He pushed on for another year despite awful tummy pain. Everything was weighed to the gram. He drank the cream, he ate the butter. He did what he had to do to rid himself of those awful seizures. He knew it had to be done. His body told him so.

Now he is seven, he is off the diet and there is absolutely nothing stopping him from living life to the full.

He is a Ketogenic role model.

He is a true inspiration for dietary treatment of epilepsy.

It was so hard, but so worth it!

Thank you to all who have helped us on our journey, especially staff at CUH and Matthew's Friends.

Emma says.....

James, you are certainly a KETOSTAR and a huge thank you for sharing your story with everyone. Your award is on it's way to you!



MEET RHYS...

After a normal pregnancy, Rhys was born two weeks early, in May 2010. It was hard not to notice the large birthmark on his little face but it wasn't a major concern to me as I was just so pleased to meet him. What I was not aware of is that a birthmark, especially one in the position of Rhys's, could be a visual indication of a rare neurological condition called Sturge Weber Syndrome.

Our paediatrician kindly made us aware that he would like to conduct further investigations and so, at 6 weeks old, Rhys had an MRI scan that later confirmed that he did indeed have Sturge Weber Syndrome and so our journey began.

We learnt that the condition, which affects 1:50000 people, had no known cause but could result in abnormal blood vessels on the skin, brain and eyes and could cause onset of seizures and glaucoma.

We tried to continue life as normally as possible as there was the chance that Rhys may not have seizures at all but unfortunately, during a family holiday to Spain when he was 13 weeks old, he had his first seizure, followed by the next, and the next...

Doctors found it incredibly difficult to control his seizures and he stayed for a few weeks in the intensive care unit in Valencia Hospital. With seizures returning every time he moved from I.V. medication to oral, we flew home on a private medical flight and were in our local hospital for another few weeks before he was stable enough to come home.

Over the next year, Rhys was constantly playing catch-up with the dosage of medication to his weight and ended up on a combination of three different anti-epileptic medications. Despite this, he was still having regular seizures so, after careful consideration and investigations, he underwent his first functional hemispherotomy neurosurgery (disconnection of the right hand side of his brain) when he was 14 months old at Great Ormond Street Hospital.

Following the surgery, Rhys's seizures subsided and he went from strength to strength. He learnt to walk, seemed happy and came off two of his medications but sadly, after a year, we saw the tell-tale signs that he was having seizure activity again.

We tried, with the help of Great Ormond Street Hospital, to find the right combination of medicines to relieve him of the worsening seizures but, although he would sometimes go for days without a seizure, he was likely to have one at any given time.

It was out for dinner with friends one night that one of them mentioned that her son was on the Ketogenic Diet to control his seizures. I had heard of the diet before but didn't know much about it. Hearing her talk about it and given that we were failing to manage Rhys's seizures well on medication, I asked the specialist team caring for him for a referral to the dietitians which they were happy to do.



Rhys was weighed, examined and tested for his suitability for the diet and, as he was, we were given his 'prescription' and access to all the supplements he would need. We were also given the Matthew's Friend's website for help, support and advice. I got home and meticulously planned meal after meal for Rhys in anticipation of his start date. I will be honest and say that it did seem incredibly overwhelming at first. This is what reminded me to take a look at the Matthew's Friends website. Here I found lots of inspiration and the opportunity to request a starter box. We found, on its arrival that it was just so thoughtful, containing useful utensils, pots and a set of accurate scales as well as treats that Rhys would still be allowed once the diet commenced. We didn't know at that time, how much we ended up relying on some of those things!

We continued the Ketogenic Diet for around six months and stopped due to it being discovered that Rhys could have his hemispherotomy surgery re-done. Prior to the diet, Rhys was having as many as 10 clusters of drop seizures a day. Once he was achieving good ketone levels regularly, his head seemed clearer and the length of time per day that he was having seizures decreased by a half to three quarters and he was never hungry.

I soon knew all of the weight allowances for the common items in his food choices and challenged myself to match his meals with the rest of the family. When we ate out, I prepared him food to take along and, more often than not, he was not aware that he wasn't eating from the restaurant menu. He did not miss sweets and treats as he was allowed sugar free jelly and I baked him ketogenic cupcakes and biscuits and made ketogenic cocoa truffles and ketogenic chocolate yoghurt.

At the time of going on the diet, Rhys had tried so many medications and this offered an alternative. It is known that Sturge Weber Syndrome is notorious for difficult-to-control epilepsy so we were genuinely grateful to be making some difference for him on a daily basis. We are so thankful and pleased now to say that Rhys is doing fantastically well following his latest operation so long may it continue this time.

Emma says.....

Once again another fantastic and inspirational story. Well done Rhys – your KETOSTAR award and prize is on its way to you.

For those of you who would like to know more about Sturge-Weber Syndrome then please visit www.sturgeweber.org.uk/



CONGRATULATIONS TO OUR LATEST KETOSTARS.....

BOTH NOMINATED BY THE WILDE FAMILY.....

"Vicky Edwards is the school cook at Green Lane Special School in Warrington. When William started school, he was already on the diet (for Glut1) and we were keen for him to have a hot meal at lunchtime. I had a meeting with the school and Vicky 'got' the principles of the diet straight away. From day one she has been brilliant. She asked if there was anything I made especially for him, which there was, chocolate cake, and she asked me to give her the recipe so that she could batch cook it for him. She sends me the menus every term so that I can work out the weights of the foods he can have and we stay in touch by text if his diet prescription changes following reviews. Vicky has made it possible for Will to have the same lunches as his little friends at school and this means so much to us! We think she is very deserving of a Keto Star!!"



OUR SECOND NOMINATION...

Carly Dumican (or 'Mrs. D'), is Williams Teaching Assistant at Green Lane School. Mrs D has known Will since starting school, and although his other TAs have also been brilliant, Mrs D has supported Will at lunchtime even when he was in a different class. We recently hit a period of Will refusing his lunch, and following a meeting with Mrs D, we came up with a plan. One of her suggestions in particular has helped enormously and it has resulted in William eating his lunch again and enjoying it! She is very dedicated and loves Will. Her hard work has ensured that Will stays compliant with the diet (which, as you know, can be a challenge at times!).

Emma Says.....

Wow – what a wonderful school with such dedicated staff to help Will. We agree that both Vicky and Mrs D are thoroughly deserving of a ketostar award. We do hope you liked your bags of goodies!

If you know someone that has gone that extra mile then please nominate them for a ketostar award...

NOMINATE YOUR KETO STAR

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
AND NOMINATE YOUR KETOSTAR!

ADVERTISEMENTS




KETOCAL: MAKING THE KETOGENIC DIET EASIER THAN EVER BEFORE*



KETOCAL PROVIDES:

- ✓ **CONVENIENCE**
Both the powders and liquids are quick and easy to prepare.
- ✓ **FLEXIBILITY**
Suitable as a drink, in food, or as a tube feed.
- ✓ **VARIETY**
Can be incorporated into a range of recipes to increase the variety of ingredients that can be eaten whilst following a ketogenic diet.

SERVICES INCLUDE:



- ✓ Cookery Education Sessions with our Specialist Ketogenic Chefs
- ✓ Free Home Delivery (UK and NI)
- ✓ Ketogenic Recipe Books
- ✓ Ketogenic Diet Management Tool (MyKetoPlanner.co.uk)
- ✓ Sample Packs

If you have an inquiry about our free home delivery service, please call Homeward Metabolics & Specialist: **0800 093 3675**

For further information about our other services, please speak to your managing dietitian.

Kossoff EH, Dorward JL, Turner Z and Pyzik PL (2011). Prospective Study of the Modified Atkins Diet in Combination With a Ketogenic Liquid Supplement During the Initial Month. J Child Neurol. 26(2): 147-51


KetoCal is a food for special medical purposes only to be used under medical supervision. If you would like to find out more about KetoCal, receive a sample, or get further information on any of our ketogenic services then please contact your specialist ketogenic dietitian.

MORE THAN A COMPLETE FOOD...

Keyo, a nutritionally complete, very high in fat, low carbohydrate ready to eat, chocolate flavoured semi solid food in a convenient 100g pot has been available in the UK, Germany and Sweden for a few months now, from VitaFlo®. It has a great chocolate flavour and its texture has been found to be useful for those with feeding difficulties, under specialist supervision. If you are looking for more ideas on how to use Keyo other than as a convenient food to take out and about; why not try the Chocolate Panna Cotta recipe in an Easter egg mould! All you need is 50g keyo, 25g carbzero™ and some gelatine, not forgetting some time to chill and set it in the fridge. A great treat for Easter!

Keyo can also be used to make lovely chocolate drinks as well! Why not try it as a hot chocolate, or a chocolate milkshake! Simply mix with carbzero and or soya milk to make a delicious chocolate drink. Then serve hot or cold, great any time of the day! For more tasty recipes to try visit www.myketogenicdiet.com or join MyketogenicdietUK&IRE facebook page or subscribe to <https://www.youtube.com/channel/UCdVGPzGa6xeelsk38g31-xg>





At the Natural & Low Carb Kitchen, we understand how difficult and time consuming a ketogenic diet can be. Our aim is to make staying keto a whole lot easier.

All of our snacks, bars, treats and meals can be taken out of the house and need no refrigeration or cooking. Convenience for every day.



We offer a **15% discount** when using the code **Friends15**.
Matthew's Friends receive a percentage of every sale when you use this code.

www.nlcs.co.uk

More adults than ever before are looking at ketogenic therapy to help manage their seizures and improve their quality of life, once again resources are very limited for adults with few centres offering a service. The Birmingham/Midlands area is very fortunate, not only do they have a very good paediatric service available but they can also transition onto an adult centre. They currently accept referrals from the West Midlands and depending on funding can also take referrals from out of area...

The Barberry's Adult Epilepsy Dietary Treatment Service

Although the majority of services and current literature for dietary treatment of epilepsy are based on the paediatric population, here at the Barberry we provide an Adult Epilepsy Dietary Service. Alongside our service we offer suitable candidates the opportunity to participate in our Modified Ketogenic Diet (MKD) trial, which looks at its effects on adults with medically intractable epilepsy (those who have failed to respond to 3 or more antiepileptic medications). Our aim is to provide a tailored dietetic service where we assist each service user with an individualised plan fitting to their taste preferences and lifestyle.

Over time, we have come to learn working with adults brings along a unique set of obstacles to overcome. The biggest challenge we face is the main principle of our diet, which involves restricting carbohydrate intake to 30g per day. This is a significant change to the average adult intake of 250g per day. We advise spreading carbohydrates evenly across the day, aiming for 5-10g per meal and 2-3g per snack. Low carbohydrate fruit and vegetable options are the primary carbohydrate source on this diet. This includes; green leafy vegetables, mushrooms, cauliflower, aubergine and berries. To ensure the diet is as liberal and practicable as possible, we also recommend that meals and snacks should include usual servings of protein foods, such as; fish, eggs, red meat, poultry, nuts and seeds, and generous helpings of foods high in fat such as butter, mayonnaise, double cream and cooking oils such as olive and coconut oil.

Following the initial 3 months, we consider adjusting the diet for service users looking for further improvements. This may involve reducing carbohydrate intake to 20-25g per a day and increasing intake of MCT based fats such as coconut oil. The aim is to further increase ketosis in the body, which seems to be the key factor in improving seizure control in epilepsy patients.

Another difficulty we face with the adult population is that the MKD is often a large change to their long established diet routine and food preferences. By implementing a one month phase-in period, service users are able to take their time and ease their way into the diet. This not only assists with reducing side effects such as dehydration and headaches, it gives users the opportunity to establish a regular eating routine and to build a ketogenic friendly kitchen one meal at a time.

To support our service users we also provide the opportunity for regular contact with a dietitian through email, telephone calls and face-to-face appointments. We additionally offer assistance with sourcing suitable recipes including recipes for those who are time restricted, options for holidays and special occasions and ideas for those who are looking to replace their favourite high carbohydrate meal or snack.



The gradual phase-in period appears to help service users with longer term compliance to the diet. Other factors that appear to be related to higher compliance rates include; motivation level of the service user, an interest in cooking and trying new recipes as well as having supportive family members or carers.

Since our first patient in 2009, we have had over 30 service users involved in our dietary service. Our preliminary results of those who have successfully completed our 3 month trial have shown that over 50% of our patients have had a positive effect on reducing seizures whilst on the MKD diet. As well as reduced seizure frequency, additional benefits include, improved seizure recovery, concentration, clarity of thought and weight loss if desired.

Being involved in a service that has the potential to dramatically improve the quality of our patients' lives has been an extremely rewarding experience. As the evidence base grows, we are hoping the future provides us with the opportunity to expand our services and provide more adult epilepsy patients the opportunity to trial the modified ketogenic diet for themselves.

Emma says.....

"If you would like your service highlighted then please contact us and we would be delighted to feature you in future editions of our newsletter."



GET READY FOR PURPLE DAY!

MARCH 26TH IS PURPLE DAY AROUND THE GLOBE, RAISING AWARENESS OF EPILEPSY

Here at Matthew's Friends we have been Partners of Purpleday.org, since Cassidy Megan created her vision in 2008. If you would like to support us this Purple Day, please visit the Keto Fundraising section of our website.

We have special resources for Purple Day, including downloadable posters and items in our Shop to make your Purple Day event extra special!

If you are raising funds for Matthew's Friends on Purple Day or wish to make a Purple Day Donation then please use our Justgiving page:

www.justgiving.com/fundraising/MFPurpleDay2017



THE KETOGENIC SERVICE AT BRISTOL ROYAL HOSPITAL FOR CHILDREN

IS EXPANDING!!

- We have increased capacity for referrals.
- Waiting times are short!
- We prioritise under 2's.
- Weekly clinics now available in Bristol.
- We accept referrals from the whole of the South West.

Please consider Ketogenic therapy for those patients who have failed to respond to two or more anti-epileptic medications.

Please contact the ketogenic dietetic team:

Victoria Bittle, Lucy Pope or Chloe Elliott via

Email: ubh-tr.ketodietitians@nhs.net or Phone: 0117 342 8802



PROFESSIONAL & FAMILY CONFERENCE 2017
17th-18th NOVEMBER HILTON LIVERPOOL

Have you heard of Dravet Syndrome?

Join us to learn more about this rare and catastrophic condition

DRAVET SYNDROME UK BIENNIAL CONFERENCE 2017

HILTON LIVERPOOL, LIVERPOOL ONE, 3 THOMAS STEERS WAY, LIVERPOOL L1 8LW
FRIDAY 17TH NOV (PROFESSIONAL DAY) & SATURDAY 18TH NOV (FAMILY DAY)

Join us for a packed agenda, with talks covering many significant topics given by some of the world's leading experts in Dravet Syndrome including **Professor Helen Cross OBE, Professor Ingrid Scheffer, Professor Lagae, Professor Sanjay Sisodiya, Professor Sameer Zuberi and Dr Elaine Hughes.**

We shall also be discussing the latest updates on Dravet syndrome, the latest data on current and emerging treatment along with sharing best practice approaches and more!

RCPCH has approved this activity for CPD in accordance with the current RCPCH CPD Guidelines - for further information please contact teresa.f@dravet.org.uk or call 07874 866937

www.dravet.org.uk/
www.facebook.com/dravetsyndromeuk
@DravetUK

SEASONAL RECIPES

No sooner do we navigate our way through the 'festive' season that it seems we have the next big food obstacle to deal with... Easter! You can't move in the shops for Easter Eggs and you really don't want to see how many ways to enjoy a certain brand of cream egg every time you switch on the TV!

Once again Mo has worked her magic and we have selected a few recipes that will hopefully help you during the Easter holidays. Don't forget to visit our website for loads more recipes and our ketokitchen Youtube page for further ideas.

To 'ASK MO' then please email: ketokitchen@matthewsfriends.org

Visit Matthew's Friends **#KetoKitchen** YouTube channel for Ketogenic recipe demonstrations and tutorials!



HOT CROSS BUNS

INGREDIENTS

- 80g Almond flour flurry - HOLLAND AND BARRETT
- 52g Eggs
- 12g Psyllium husk - TELEPHONE BRAND SAT-ISABGOL
- 9g Sultanas
- 2g Orange zest
- 4g Butter

You will also need a pinch of salt, 1 teaspoon BARKAT baking powder, 7g white wine vinegar, 85g boiling water, 1 teaspoon mixed spice or cinnamon and 10g STEVIA granules or sweetener of choice.

METHOD

- Pre heat oven to 180c / fan 160c / gas 4.
- Chop the sultanas and finely grate the orange zest then weigh it!
- In a heatproof bowl mix together the almond flour, husk, sweetener, baking powder, salt, mixed spice, sultanas and orange zest.
- In to this stir the beaten egg, vinegar and butter cut in to pieces, mix well.
- Pour in the boiling water then stir until a stiff dough forms.
- Divide in to three equal sized buns, mark each with a cross and place on a lined baking tray, cook in a pre-heated oven for approximately 25 - 30 minutes.

Each bun if divided in to 3 will have: 17.6g fat / 7.8g protein / 4g CHO

MKD: 12.07g CHO

FAT: 52.80g

PROTEIN: 23.64g

KCAL: 618

This recipe will need to be adapted to EACH INDIVIDUALS prescription. Please take this recipe to your dietitian and he / she will help you to do this.

PLEASE DO NOT ATTEMPT ANY TYPE OF KETOGENIC DIET WITHOUT MEDICAL SUPERVISION.



MO'S TIPS

They can be eaten as they are or split and spread with butter. You could divide in to 4 smaller buns which would make them an ideal snack, they would only need approximately 15 - 20 minutes cooking.

When they had cooled, I glazed them with a little JOSEPH'S sugar free maple syrup, this is optional.

CAULIFLOWER CHEESE

INGREDIENTS

- 114g Cauliflower - boiled in unsalted water
- 50g Cheddar cheese
- 50g Double cream - MORRISONS
- 2g Smooth mustard

Grate the cheese and then weigh it! Reserve 10g.

Place remaining 40g of the cheese in a small saucepan with the cream and mustard.

Heat until the cheese has melted, pour over the cauliflower and serve sprinkled with the reserved cheese.

METHOD

- Grate the cheese and then weigh it! Reserve 10g.
- Place remaining 40g of the cheese in a small saucepan with the cream and mustard.
- Heat until the cheese has melted, pour over the cauliflower and serve sprinkled with the reserved cheese.

MKD: 5.03 g CHO

FAT: 43.89g

PROTEIN: 15.76g

KCAL: 478

This recipe will need to be adapted to EACH INDIVIDUALS prescription. Please take this recipe to your dietitian and he / she will help you to do this.

PLEASE DO NOT ATTEMPT ANY TYPE OF KETOGENIC DIET WITHOUT MEDICAL SUPERVISION.



MO'S TIPS

Make sure the cauliflower is well drained before weighing (I left mine on a piece of kitchen paper for a few minutes).

This sauce goes well with other vegetables, or on top of a leek lasagne.

CHOCOLATE COVERED COCONUT ICE

INGREDIENTS

- 120g Desiccated coconut - unsweetened
- 110g Coconut milk - BLUE DRAGON
- 30g Coconut oil
- 75g Cacao - LINDT 90% dark supreme
- 28g Granulated sweetener - e.g. NATVIA

You will also need a few drops of vanilla extract and ¼ teaspoon of liquid sweetener.

METHOD

- Reserve the chocolate, liquid sweetener and 10g of the coconut oil.
- Put all remaining ingredients in a pan and heat until sweetener has dissolved, stir well.
- Place in a lined small tin / mould (6 inch x 3 inch is good) and leave in the fridge to set for as long as possible.
- When set, melt the chocolate in a basin over hot water, remove from heat then stir in the 10g of coconut oil and the liquid sweetener.
- Turn out the coconut ice and cut in to portions, it is up to you what size you want but do make sure you divide equally. Coat each piece with the melted chocolate and leave to set.
- Weigh each one and you will know how much chocolate and oil you have added. I made 12 pieces.

12 pieces will give: 13.5g fat / 1.3g protein / 1.8g CHO

CLASSICAL: 4.3:1 RATIO
FAT: 162.12g
PROTEIN: 15.76g
CHO: 21.92g
KCAL: 1610

This recipe will need to be adapted to EACH INDIVIDUALS prescription. Please take this recipe to your dietitian and he / she will help you to do this.

PLEASE DO NOT ATTEMPT ANY TYPE OF KETOGENIC DIET WITHOUT MEDICAL SUPERVISION.



MO'S TIPS

You will need to scrape any chocolate residue out of the bowl and add it to each piece as equally as you can.

You must use UNSWEETENED desiccated coconut and you need to tip the coconut milk in to a jug and make sure the solids are well mixed in to a liquid before weighing.

Keep in the fridge.

NUT FREE EASTER CAKE

INGREDIENTS

- 19g FiberFlour - www.lowcarbmegastore.com
- 26g Eggs
- 3g Cocoa - BOURNVILLE
- 19g Butter
- 9g Cacao butter - SEVENHILLS organic
- 6g Cacao - LINDT 90% dark supreme

You will also need 12g granulated sweetener, 2g BARKAT baking powder, a few drops of vanilla extract, ½ teaspoon of liquid sweetener and a few drops of orange extract.

METHOD

- Pre heat oven to 180c / fan 160c / gas 5.
- Reserve the cacao and Lindt chocolate.
- Mix together the fibre flour, cocoa, baking powder and sweetener granules.
- Soften the butter.
- Beat in the fibre flour mix with the beaten egg and vanilla extract.
- Place in two small silicone moulds of your choice.
- Bake in pre heated oven for approximately 12 minutes until risen and firm.
- When they are cold, melt the cacao and Lindt chocolate with the liquid sweetener and orange extract. Use this to decorate the cup cake.



MO'S TIPS

I made egg and chicks with the chocolate mix, or you could just spread it. I cooked the cakes in two small ring moulds to make a nest shape.

These make two good snacks.



MKD: 5.26 g CHO
FAT: 32.81g
PROTEIN: 8.48g
KCAL: 350

This recipe will need to be adapted to EACH INDIVIDUALS prescription. Please take this recipe to your dietitian and he / she will help you to do this.

PLEASE DO NOT ATTEMPT ANY TYPE OF KETOGENIC DIET WITHOUT MEDICAL SUPERVISION.

WELCOME TO THE TEAM...

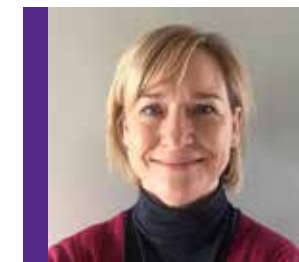
Medical Board member - Helena Champion RD

Helena graduated from the University of Sheffield with a BSc in Biochemistry before qualifying as a Dietitian after a further post graduate study. She has worked at Cambridge University Hospital for the past 14 years, and is currently the dietetic lead for the provision of the ketogenic diet for children with epilepsy with in the East of England; a service she helped establish in 2009.



She has worked with the inherited disease metabolic service; both for children and adults as well as in gastroenterology and paediatric cystic fibrosis. Helena has contributed to a weaning booklet for infants on a ketogenic diet released in 2015 and has published an observational case study of an infant who was breast fed while following a ketogenic diet.

We are delighted that Helena agreed to join our team and already she has been set to work helping to review and write the Ketocollege training course and as well as being a Mentor for that course. Her wealth of experience and knowledge is always greatly valued and she will now be part of the team that will review and monitor both our printed information guides and our website information.



Glut 1 Ambassador and Regional Co-ordinator - Helen Wilde

We are delighted to also welcome to our voluntary team, Helen Wilde, who has joined existing Regional Co-ordinator Gail Hall, to cover the Northern area. We are extremely grateful for the time they spend volunteering for us and for making people more aware of ketogenic therapy and providing support and information for the local area.

HELEN SAYS.....

"First and foremost, I am mum to William who is 9 years old. William was diagnosed with Glut-1 Deficiency Syndrome at the age of 3 and a half and has been on the MCT Ketogenic diet since then, Will has 'classical' Glut 1 and started having signs of Glut 1 deficiency in infancy. At 9 weeks old, he started having prolonged apnoeas (blue episodes) and also started with episodic eye movements, both of which we now know to be early signs of Glut 1.

As William progressed through his first year, it was apparent that he had developmental delay and his head circumference was falling off on the centile chart. William had a normal brain on MRI scan and had lots of blood tests, all of which showed no cause for the developmental delay.

William started with seizures aged 2 and a half and was started on anticonvulsants. Six months later, his epilepsy was getting worse and it was only when a professional colleague suggested Glut 1 deficiency that I looked the condition up. William had all the signs, and when I saw a video of a baby on YouTube having an episode of the abnormal eye movements that I knew that William had Glut 1.

William had the lumbar puncture and the genetic test both of which were positive for Glut1. We had our answer! William has now been on the Ketogenic Diet for 5 and a half years and he is doing very well. We have had seizure freedom for 3 years and we have seen great improvements in all areas of his development, especially speech and mobility.

As well as being wife to Mike and Mum to William, I have been a qualified nurse for 23 years, specializing in adult and Paediatric Neurosurgery. The majority of my experience (20 years) has been in paediatrics and I have worked at two big centres- Great Ormond Street Hospital in London and Alder Hey Children's Hospital in Liverpool. I moved into Clinical Research Nursing in 2007, becoming a Neuroscience Research Nurse in Liverpool in 2009. However, it became more difficult to work and meet Williams needs so I chose to give up my job in 2012. I still work part time as a nurse, but fit this in around William's needs. The Ketogenic Diet saved our son. He wouldn't be the little boy he is today if we hadn't been diagnosed when he was. Matthews Friends has been fantastic, providing a huge amount of information on Glut 1 Deficiency, and bringing the families of children with Glut1 together, both here in the UK and around the world."

If you are interested in becoming a Matthew's Friends Regional Co-ordinator or an Ambassador for us, then please contact emma@matthewsfriends.org for more information. We will be featuring further members of the Matthew's Friends team in forthcoming issues of our newsletter.

Matthew's Friends Canada Building support

With only a few months into 2017 – Matthew's Friends Canada team is carefully building its understanding & support for its country. Continuing on the global mission of raising awareness & support for ketogenic families & health care professionals. Keeping us inspired are Canadian experiences such as the one by our Avery as you see in this video: <https://goo.gl/q5DTXO>

Here is a great overview of what we have planned for 2017:

- Various awareness events with Dr. Eduard Bercovici, Ketogenic RD Jennifer Fabe in partnership with surrounding ketogenic diet programs, epilepsy organizations and Dravet Canada (Guelph, London, Toronto, Hamilton, Vancouver).
- Cooking Demonstrations for ketogenic families by Chef Wiese and Ketogenic RDs
- Co-supporting the Canadian Ketogenic Diet Conference in partnership with Hospital for Sick Children and McMaster Children's Hospital in Toronto, ON.
- National Survey of Ketogenic Diet Programs is a project that is in partnership between McMaster Children's Hospital, University of Toronto & Matthew's Friends Canada that is soon to be launched with the goal to gain an understanding of current clinic practice, program structure and challenges. While at the Global Symposium in Banff – a Canadian submeeting was hosted by Matthew's Friends Canada that invited Canadian ketogenic RDs, physicians, social workers, nurse practitioners, and nurses to contribute to the questions included in this survey.
- Challenges of Initiating the Ketogenic Diet (Phase 1) – a Caregiver Perspective is another research project coordinated by McMaster Children's Hospital & University of Toronto that MFC proudly supports
- Matthew's Friends Canada 'Spring Fling with a Twist' catered by our Chef Patron Patrick Wiese in April 2017
- Golf Tournament Fundraiser in June 2017

Make sure to visit us on Facebook and Twitter

 Matthews Friends Canada  MF_Canada

or email us at info.canada@matthewsfriends.org



Canadian Sub-Meeting Group during Global Symposium 2016 in Banff

Canada goes keto!

Written by: Helen Lowe RD – Hospital for Sick Children
& Alex Ferguson RD – BC Children's Hospital

It all started in September with a couple of keto professionals chatting over a carb-loaded pasta dinner. We were discussing how hard it must be for patients to follow such a strict diet. Imagine having to do something that looks so hard while knowing there are few alternatives for seizure control?

It was then that we decided we should all try following a ketogenic diet. We hoped to experience all its touted benefits, and to truly understand what our kids and families manage on a daily basis with meal planning and unpleasant side-effects. How can we truly understand what it's like if we've never done it ourselves?

That was the beginning of what became a coast-to-coast initiative including 10 centres across Canada. Dietitians, physicians and nurses all joined together to experience what it's like to manage our own ketogenic diet.

How did it go down? We all started together on November 21, 2016. Each person chose their own diet modification: low ratio classic, MCT, LGI or MAD. Everyone had their own reason for choosing their own diet. We had an email 'support group'. As we progressed in our diets, we shared our experiences, provided suggestions for each other and plenty of support (and diet tips) were exchanged. It was motivating and helpful to know others were doing it with us. The ketogenic diets were continued for one to two weeks, depending on individual tolerance and commitments.

Helen's perspective: Personally, I chose the MAD to better understand it, because it's not a common diet choice at The Hospital for Sick Children. In testing urine ketones, I found it easy to go into ketosis, but initially, I didn't feel well! This was a shared experience amongst others from within our group: headaches or initial feeling of nausea when getting used to the high fat content of these diets. It didn't take long to adjust and I was feeling well by the end of the week. The biggest benefit I experienced was that I slept much better! It was fantastic.

I was happy to have planned my menus and prepared my food in advance. This helped when adding something so time consuming to an already busy schedule. I was less prepared during my second week, and I noticed that it was a little harder to have enough food to eat and still stick to my 20 g net carbs a day. If I'd planned my second week better, I wouldn't have been so hungry.

Alex's perspective: I chose to follow a 1.5:1 ratio classic KD because, as a vegetarian, I was concerned about getting adequate protein without overshooting my carbohydrate goal. I created recipes to ensure I reached my protein target while staying within ratio. Let me tell you, within a couple of days I was feeling pretty sick of eggs and cheese. On a positive note, I was encouraged to come up with unique combinations for recipes that I have now been able to share with my vegetarian patients (such as palak paneer – an Indian dish of paneer in a creamy spinach curry).

Jennifer's perspective: I gradually progressed my way to up to about a 2:1 ratio with a small amount of MCT. I began with label reading, recipe planning & mindful shopping for foods. I then attempted bulk keto cooking (Keto Chili), creative salads with nuts & avocados and even some formula meal replacements. I experienced mild nausea when gradually titrating up my diet prescription. Interestingly – during a busy weekend, I accidentally overestimated my fat intake for a lunch meal. Shortly after, I experienced significant abdominal upset and nausea – that I hoped would pass but lingered instead. It was so significant that I did not think I could leave my house for my family gathering! So anxious to relieve the symptoms, I gave myself 2 – 3 Tbsp correction doses of juice and this discomfort alleviated within minutes – a valuable lesson learned!

Overall, it was a very useful experience. We have developed a greater understanding of what it feels like to be in ketosis, how easily the level of ketosis can change and the importance of having foods prepared well in advance.

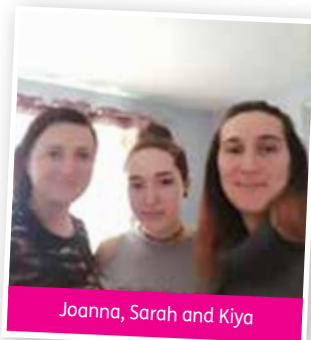
Participating Centers: BC Children's Hospital, Alberta Health Sciences, Children's Hospital Winnipeg, Royal University Hospital, McMaster Children's Hospital, Toronto Western, The Hospital for Sick Children, Toronto East General (Oncology), London Health Sciences, Janeway Children's Health and Rehab Centre.

Matthew's Friends are inviting dietitians across the UK and Ireland to take part in a similar experiment as our Canadian friends – if you would be interested in taking part then please email emma@matthewsfriends.org

Fundraising for Matthew's Friends

There are so many people to thank that we can't always do this individually in our newsletter, but please visit our website to read about all the fantastic activities and mad cap ideas our supporters do to raise money for us. A HUGE thank you to all of you. Please know that we are so grateful and it is YOU that make all the work we do possible. Please like and follow us on  Matthew's Friends and Twitter  @matthewsfriends for up to date news on all our events. Please support us and request an MF fundraising pack today from enq@matthewsfriends.org

Craig's Mum Joanna, along with Sarah and Kiya (pictured) are taking part in the exciting Glow in the Park event on 29th April! Visit their Justgiving page below to read all about it and sponsor them. They are raising funds for the MFGlut1UK fund, supporting families of children with Glut1 Deficiency Syndrome.



Joanna, Sarah and Kiya

<http://www.justgiving.com/Joanna-Wallis>



Bruce's daughter Beth

Bruce Calder and his fabulous team mates Alan Calder, Bryn Turnbull, Jamie Smith, Kevin Madill, Neil McLean and Russell Paton are taking part in the Run Garioch event on Purple Day, the 26th March! They are raising funds for Matthew's Friends as Bruce's daughter Beth (pictured), has been helped tremendously by the Ketogenic Diet for her epilepsy and by our charity.

Read Bruce's message on his Team Justgiving page and support them if you can – every penny really does help. Thank you. <https://www.justgiving.com/fundraising/Bruce-Calder>

Alan Wells (pictured) ran the Original Hampton Court half marathon for Matthew's Friends on 19th February, raising £255 plus Gift Aid for our charity! Thank you Alan! Please visit his Justgiving page here <https://www.justgiving.com/fundraising/Alan-Wells2>



Alan on his run!

The Directors and Staff of HJP Chartered Financial Planners based in Dorking, Surrey decided to donate their Secret Santa funds to Matthew's Friends instead of buying each other gifts. We're delighted to have their support, thank you everyone at HJP!



Centre is Selena from HJP, Julie (left) and Sam (right) from Matthew's Friends



Martin Jukes

Martin Jukes is taking on the London Marathon! Martin is our only runner this year – please support him here...

<http://uk.virginmoneygiving.com/fundraiser-web/fundraiser/showFundraiserPageaction?serUrl=MartinJukes&faId=807065&isTeam=false>

He and his colleagues from Avensys in Crawley have been long time supporters of our charity, we are so grateful for their ongoing support.



Ketogenic Dietary Therapies
Information • Training • Research • Support
Registered Charity No. 1108016

13TH ANNIVERSARY

Rainbow Ball

Saturday 30th September 2017

LINGFIELD PARK RACECOURSE

SAVE THE DATE

TICKETS £65 • WELCOME DRINK • 3 COURSE DINNER • RAFFLE & AUCTION

To book tickets: www.matthewsfriends.org
julie@matthewsfriends.org ☎ 01342 836571

If you would like to get involved and help us in any way, please contact the Matthew's Friends office on **01342 836571**, or email enq@matthewsfriends.org. Every penny helps us to make the difference to the many families and Ketogenic centres we support. Please help us to continue our work and extend our services through 2017 and beyond, thank you.