

# KETOGENIC THERAPIES

AUTUMN/WINTER NEWSLETTER 2020 | FOURTEENTH EDITION



Ketogenic Dietary Therapies  
Information • Training • Research • Support

Registered Charity No. 1108016

[MATTHEWSFRIENDS.ORG](http://MATTHEWSFRIENDS.ORG)

## WELCOME TO OUR BUMPER AUTUMN/WINTER KETO NEWSLETTER!

### CORONAVIRUS STAY SAFE, SAVE LIVES

At the time of writing, the UK Government have announced further measures to combat the COVID-19 pandemic that is affecting every single one of us.

This Winter will be challenging for all of us, not least families affected by drug-resistant epilepsy who already cope with so much. Matthew's Friends are here throughout, to support those who are prescribed a Ketogenic Diet to help combat unrelenting seizures. Please join us if you can during November and go **#sugarfreeforepilepsy**, every penny helps.



HANDS



FACE



SPACE

#### SPECIAL FEATURES INSIDE:

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JOIN US & GO  
**#SUGARFREEFOREPILEPSY**  
IN NOVEMBER

[WWW.MATTHEWSFRIENDS.ORG](http://WWW.MATTHEWSFRIENDS.ORG)

[WWW.JUSTGIVING.COM/CAMPAIGN/SUGAR-FREE-FOR-EPILEPSY-NOVEMBER-2020](http://WWW.JUSTGIVING.COM/CAMPAIGN/SUGAR-FREE-FOR-EPILEPSY-NOVEMBER-2020)



**Ketogenic Dietary Therapies**  
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## CONTACT US...

Editor: Emma Williams MBE

NEWSLETTER ARTICLES:

✉ [emma@matthewsfriends.org](mailto:emma@matthewsfriends.org)

FOR RECIPE INFORMATION:

✉ [Ketokitchen@matthewsfriends.org](mailto:Ketokitchen@matthewsfriends.org)

FOR KETOCOLLEGE INFORMATION:

✉ [ketocollege@mfclinics.com](mailto:ketocollege@mfclinics.com)

Matthew's Friends, St. Piers Lane,  
Lingfield, Surrey, RH7 6PW

☎ 01342 836571

🌐 [www.matthewsfriends.org](http://www.matthewsfriends.org)

🌐 [www.mfclinics.com](http://www.mfclinics.com)



**MatthewsFriendsOrg**  
**#ketokitchen**

TO HELP FUNDRAISING VISIT:

[www.matthewsfriends.org/easy-fundraising/](http://www.matthewsfriends.org/easy-fundraising/)

Matthew's Friends are proud to be part of the European Reference Network for Rare and Complex Epilepsies - EpiCARE. For more information then please visit the website at: <http://epi-care.eu/>



**European Reference Network**  
for rare or low prevalence complex diseases  
Network Epilepsies (ERN EpiCARE)



**MATTHEW'S FRIENDS WILL BE HOSTING  
THEIR 5<sup>TH</sup> ANNUAL KETOCOLLEGE PROGRAMME**

**25<sup>TH</sup> – 27<sup>TH</sup> MAY 2021**

**CROWNE PLAZA FELBRIDGE HOTEL, EAST GRINSTEAD, WEST SUSSEX, UK**

**FOR HEALTH PROFESSIONALS: AN ADVANCED CPD  
COURSE FOR NEW AND REFRESHER KETOGENIC THERAPY  
LEARNING AND NETWORKING**



Scientific Committee  
Chair Professor  
J. Helen Cross OBE

### DAY 1 MEDICAL MASTERCLASS

#### NEW FOR 2020: HOW TO SET UP A NEW PAEDIATRIC OR ADULT SERVICE

##### SESSIONS INCLUDE:

- Introduction to Ketogenic Dietary Therapies (KDT) & when to consider these therapeutic options
- Ketogenic Dietary Therapy for Adults
- KDT & AED's
- Management of emergency situations
- Non-epilepsy uses, including Glut1 Deficiency Syndrome, PDHD, Diabetes and Cancer

### DAYS 2 & 3 DIETARY MANAGEMENT

##### SESSIONS INCLUDE:

- How to Prepare the Family for Ketogenic Dietary Therapies
- Considerations of type of KDT to use
- KDT & Infants
- Tube Feeding & Blended Diets
- Monitoring & Side Effects
- Supplementation & Medications
- And more, including workshops on the practical implementation of both traditional and modified ketogenic therapies, supported by cookery demonstrations and case studies

For the full programme and registration details, please visit [www.mfclinics.com/keto-college](http://www.mfclinics.com/keto-college) or to register your interest please email: [ketocollege@mfclinics.com](mailto:ketocollege@mfclinics.com)

Webinars will replace the live event should COVID-19 dictate

CONVENIENTLY LOCATED ONE HOUR TRAIN FROM LONDON AND 20 MINS TAXI FROM LONDON GATWICK

**RCPCH APPROVAL PENDING**



**Adults with drug-resistant epilepsy, who  
have failed TWO or more medications**

**CONSIDER A MEDICAL KETOGENIC  
DIETARY THERAPY**

Contact Matthew's Friends Clinics [info@mfclinics.com](mailto:info@mfclinics.com) for an information pack.  
[www.mfclinics.com](http://www.mfclinics.com)



# We welcome two new members to the Matthew's Friends' Team



## EMILY WHEATLEY NEW REGIONAL CO-ORDINATOR FOR WALES

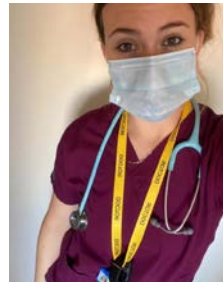
Ella's mum Emily is a very active and supportive member of our Ketogenic Facebook Forum for families and her fantastic pictures of Ella's meals (and the lovely Ella of course) together with the ingredients she uses are really inspirational for others, hence why we now have Ella's Blog on our website, but this is only half the story. Emily has fought tirelessly for Ella's needs and has been through many 'systems, tick box exercises and appeals' which she has won and sadly it is something that many families have to do when they have a child with different needs to others, so Emily is an absolute wealth of knowledge which will be of great help to other families as well as her experience with ketogenic diets.

**Founder/CEO Emma Williams MBE says:** "Emily and Ella are Keto Heros in every sense of the word and I am delighted they have joined the Matthew's Friends Team. Emily has been instrumental in gaining publicity for the diet in Wales resulting in an agreement for the funding of a long overdue Ketogenic dietitian in Wales for children. Our next task will be to get an adult centre in Wales and with Emily as our Regional Co-ordinator for this area, she will be a huge asset in this fight and I am very much looking forward to working with her in this regard."

As you will read from Ella's story on the blog – this is a lifelong treatment for her which also means that for Emily, the Ketogenic Diet is here to stay for her too and I cannot put into words how inspirational this lady is, I just love her passion and drive for the Ketogenic diet and Glut 1 Deficiency."

**Emily Wheatley says:** I am thrilled to be joining the MF team to support and connect with a community. I aim to establish monthly meet and greets as soon as possible to include some keto treats for taste testing! In the short term, I am available via email and direct message on Facebook if you need support with recipe ideas.

I am also going to continue to communicate with the WHSSC regarding the Welsh ketogenic Services and can offer guidance for accessing support within schools where required also. Anything you need help with, anytime you need to let off steam, anytime you need a fresh recipe idea, I am there for you. Much Love Emily.



## WELCOME TO THE MATTHEW'S FRIENDS MEDICAL BOARD.... DR. ALICE WILLIAMS

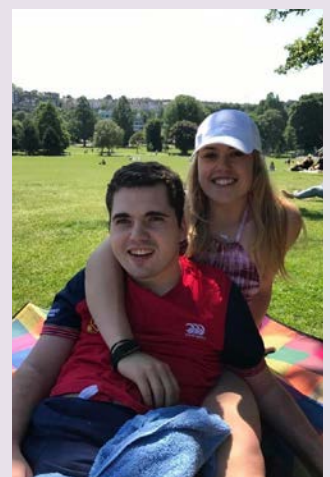
A very special time has come to the Matthew's Friends organization, when we can now welcome Matthew's own sister to our medical board. After studying hard for many years this was the year that Alice qualified and started her career in the middle of a pandemic – she has had somewhat of a 'baptism of fire' to start with! Throughout her studies she has championed the Ketogenic Diet and complex epilepsy within her medical school. She has also been a spokesperson for siblings of a special needs child for many years, speaking very candidly about her experiences. She started presenting at conferences from the age of 12 in this regard and it was around this time that she decided that she was going to become a doctor.

**Founder/CEO – Emma Williams says:** "Obviously I am EXTREMELY proud of her, but I knew she would do it, she has been so dedicated and passionate about this career path that I never had any doubt, although I NEVER want to relive the stress of the A levels and the wait to see if she got into medical school ever again and my heart seriously goes out to all those that go through this! I am delighted that she is joining the medical board and she will be a great asset to families from a professional and personal point of view."

**Dr. Alice Williams says:** "Being part of Matthew's Friends as the sister of Matthew has been an extremely important and special part of my life."

However, to be able to say that I am part of this charity not only from a family perspective but also on the medical board is an honour and a privilege.

An achievement that I cherish the most and I look forward to working with Professor Helen Cross who not only saved my brother's life with her work and vision but also inspired me to become a doctor.



# The Ketogenic Diet – a self-experiment



## Dr Laura Healy (PhD), Senior Dietitian St James's Hospital, Dublin.

Laura qualified with first class honours in Human Nutrition and Dietetics from Trinity College Dublin, completed her PhD in 2011 and has over 15 years' experience in clinical dietetics.

She currently works as a Senior Dietitian in St James's Hospital and with the support of Consultant Neurologist Dr Colin Doherty, the St James's epilepsy team and Matthew's Friends has led the rollout of the first Adult Ketogenic Service in Ireland. This was long an ambition of the epilepsy team and the ketogenic diet is now available as an option for the management of refractory epilepsy in adults and also to those who transition from paediatric service.

### **I would not be writing this article without Matthew's Friends and their dedication to helping patients and professionals (me included) specialise in medical ketogenic dietary therapies (KD).**

Matthew's Friends generously provided support to establish a dedicated National Adult Ketogenic Diet Service for Epilepsy in Ireland, which is now funded by the Irish Health Services Executive (HSE) basically Ireland's NHS! In 2016, I attended KetoCollege organised by Matthew's Friends where I began my journey, and learned from the expert presenters, what was involved in the different ketogenic therapies. Since then, I have been supported every step of the way by all the Matthew's Friends team. I'd like to take this opportunity to sincerely thank each of them for their help and expertise Sue, Val, Mo, Julie and of course Emma! I have also found fantastic support in my Irish and UK dietetic colleagues through dietitian networks set up to support one another and facilitate collaborations. I was delighted to be invited back by Emma, as a presenter and dietetic mentor for KetoCollege 2019.

As much as I learned from Matthew's Friends, I also learnt from every single patient that that has started KD in our service; they each had something unique to teach me. When one particular patient (let's call him John) walked into clinic, with a bruised and cut face, I knew something had gone wrong. As further background to the situation, John had achieved >90% reduction in seizure frequency, was sleeping so much better, mainly had seizures at night, and felt "like a new man" following KD. But he told me that he had 'fallen off the wagon' with his KD and consequently his seizure control had deteriorated. I counselled and encouraged him and we came up with a plan together to enlist greater support from family and made adjustments to his meal plan to help him get back on track.

But it was in that moment, I realised that despite all my professional experience, I didn't really have a personal

sense of the challenge facing patients. Unlike other therapeutic diets there really are no 'days-off', so I decided to embark on my own ketogenic journey, implementing the KD, as I advise my patients to do.

Now I have trialled different ketogenic recipes before, lots from the Matthew's Friends website and the keto cooking channel (each one delicious!) but it's the dedication required to stick with it every meal of every day that's the greater challenge. Ketosis is like a light switch – it's off or it's on – any 'slip' or increase in carbohydrate (CHO) intake can 'kick you' out of ketosis.

I wanted to walk a week in my patients' shoes, gain that first hand insight, develop tools to better support patients and aid problem solving. It also gave me the chance to try new recipes and increase my knowledge of ketogenic foods.

## **My ketogenic journey: Pre Ketogenic Diet planning**

The timing of initiation of KD is important and the time has to be 'right' for patients; ideally not coinciding with planned changes in other treatments for their epilepsy. This is not always possible, but does help both the team and more importantly the patient to judge the effect KD has on their condition and seizure frequency.

I considered trialling the KD on midterm while I was on leave from work, to allow me more time to plan and cook my keto meals. But authenticity was more important to me in the end, I chose a typical working week with all the usual family routines as more representative of what my patients/families face. Pre-diet planning included calculation of nutritional requirements, daily targets for CHO and fat and a meal plan designed to best achieve these that also suited my lifestyle. I chose to follow the modified ketogenic diet (MKD), as this is the type of KD most commonly recommended for adolescents and adults.



My daily targets were 23g CHO and 154g Fat and I used exchanges for fat (10g) and CHO (1g) to build my keto meals.

## Getting started

One consideration before starting the KD was its impact on my family (husband and 2 children age 6yrs and 3yrs). While it is very different to normal meals, the basic ingredients of a typical family meal can be adapted to meet ketogenic needs. However, I chose to have separate meals to my children, as we all know evenings (after a day's work) can be hectic with school work/afterschool activities/social/family activities, so squeezing in time to weigh ingredients and prepare my meals was going to be challenging enough, without 2 'hangry' children having to wait for their dinner!

Food scales were the only essential equipment required for meal preparation along with the usual cooking utensils. Some of the specialist ingredients, e.g. alternative nut based flours, psyllium husk, CHO-free baking powder and sweeteners became the new cupboard staples. Suitable CHO replacements are an integral component to complete a keto meal, some of my favourites included keto granola, keto bread rolls, keto muffins, celeriac chips, and a low CHO tortilla.

I also purchased cauliflower rice and low-CHO slim noodles for a Thai dish I was planning (more on that later). My keto shopping list included extra items outside the norm; some of these items were not widely available so sourcing some of these ingredients proved difficult and could have delayed my start date had I left it too late ... a good lesson to have learned. Also brand matters, there can be large difference in CHO content of 2 similar products.

**It quickly became apparent that being prepared would be fundamental to a successful week, a week that included Valentine's Day and a brunch date! Due to start on Monday, I spent the weekend planning, weighing exact ingredients, and baking muffins/bread rolls that would be easily portable for breakfast/lunch at work.**

I also made a keto "sweet" treat (85% cocoa dark choc, nuts and coconut oil) that would serve as an ideal snack and treat. Batch baking done, I was feeling very pleased and somewhat prepared ... then I realised while I had the base for my meal, I still had to prepare the accompanying filling (e.g. tuna mayo, BLT), and dinner for the next evening, and I still hadn't done the school lunches; honestly it felt like I didn't leave the kitchen all day Sunday!

## Day 1 - Preparation is key

On my first day, I brought 2 keto meals to work: rhubarb, greek yogurt and keto granola, and a savoury keto muffin for lunch. My original keto dinner plan was keto chilli mince and a low carb tortilla for dinner (pictured) but I realised it would taste better slow cooked allowing time for the flavours to develop so Day 2 dinner sorted! At this point I needed a quick and easy keto meal so keto scrambled eggs, with smoked salmon and a spinach side salad it was. On my first day, I had dinner much later than normal but as I wasn't feeling particularly hungry, I managed ok. It highlighted that despite my eagerness to start, I could have been more prepared, and it is easy to overestimate your readiness.



## How do you know if you are in ketosis?

It takes about 3-7 days to go into ketosis. Ketosis can be measured in urinary ketones (dipstick) and blood ketones (finger prick test), as well as other signs of ketosis like acetone (ketone) breath. On day 3 – I felt I was NOT in ketosis and was feeling very disappointed. This was harder than I thought! However examining my intake over the previous few days I realised my error in CHO calculation! Phad Thai is one of my favourite dishes, so I attempted a keto friendly version. I had help (from my hubby) with prep and 'weighing' of ingredients. Unfortunately, a very simple error meant the wrong CHO exchange for beansprouts was used. Using 1g CHO exchange list, 1g CHO = 25g Beansprouts and 1g CHO = 143g bamboo shoots (canned) By using the wrong food exchange, we had inadvertently used 14g CHO rather than the 2g CHO planned. Unsurprisingly, I didn't instinctively recognise what 1g CHO portion size of beansprouts look like on the plate. Even the trained eye of a dietitian can easily get it wrong! It reminded me how incredibly difficult it is, to judge the portion sizes equivalent to 1g CHO of fruit and vegetables without accurately weighing them.

# The Ketogenic Diet – a self-experiment continued...

## Day 2 - 3: An unnatural diet?

We are bombarded with healthy eating messages to encourage intake of fruit and vegetables, without restriction, the emphasis being 'the more the better'. Weighing exact portion of vegetables felt a little unnatural at first, and patients need lots of reassurance to go against these instincts. As the week progressed, my confidence increased and I had to rely less on the scales, for example you learn very quickly that 5 raspberries = 1g CHO, and 2 walnuts = 1g CHO and 5g Fat.



Fibre is not counted in the CHO exchanges used in the MKD. For some adults, certain vegetables that contain very little CHO, can be considered "free" - meaning they do not have to be weighed accurately and can be included as extras, when building a keto meal. I relied on these "free" ingredients for e.g. spinach/mushrooms/celery/cucumber and used them to add bulk and fibre to my keto diet. Watch out for hidden CHO, you always have to read the labels, a spice mix I would normally add for flavour was ruled out, as it contained 10.2g CHO/ half pack, so I used dried herbs and spices instead. This is not a diet of convenience!

## Day 4 - 7: Ketosis and side effects

Day 4 I planned to check my blood ketone level, I was surprised at how excited I was about the result. Unfortunately having the incorrect strips for the ketone/ glucose monitor meant I had to wait. Day 5 (not fasting as I cycle 8km to work and couldn't miss my breakfast!) I was pleased with the blood level of 1.2mmol/L, that evening they were 2.1 mmol/L, just meeting the threshold for therapeutic level of ketosis. Possibly boosted by a late meeting in work and an unplanned walk home with a punctured tyre(!)

I also began to appreciate how you can become fixated on these ketone readings as a measure of success or failure. For patients with epilepsy, the significance of these numbers is even greater as low ketones for some, can increase the worry of seizures occurring. It is important to remember that ketones can be affected by many different factors including hormone changes, activity levels, hydration and illness.

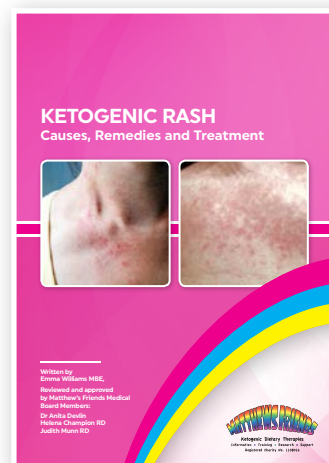
The KD is not without its side effects but with careful dietetic supervision and adjusting the diet most can be easily managed. Some report symptoms of tiredness, nausea, headaches, in the first few days when your body's metabolism is transitioning also known as the "keto flu".

In my experience, this is not commonly reported, but a slow transition to KD, at a pace that suits the individual is always what we advise. The most commonly reported side effect is constipation. I was very proactive in my efforts at prevention, making sure to drink plenty of fluids, bulked up my meals with the 'free' CHO foods, adding flaxseed on yogurts/keto granola and sprinkled over salads. I also included a source of MCT fat in my snack; which all in combination were successful. There are other medium to longer term side effects that we routinely monitor but were not relevant to the time scale I was following.

As the week progressed (and my preparation and confidence improved), we did manage to have more family meals together. My husband decided to embark on this ketogenic diet experience with me, as this was more practical for us, in the limited timeframe of 1 week. This is not practical or even recommended for family members, but there are lots of other ways you can encourage and support a family member following a KD, even changing small things like removing the treat press (we all have one) or even how you serve meals by removing the breadbasket or the serving bowl of roast potatoes from the middle of the table, is a good place to start!

## The challenges - An obesogenic environment

As a dietitian, knowing the issues with increasing rate of obesity, I was genuinely surprised by the number of times I encountered high sugar food as convenient snacks. I was much more aware of this, as I had to make a conscious decisions to avoid it.





Some encounters were more occasional ... a school bake sale, a celebration birthday cake, cake in the canteen on Valentine's Day and similar offerings of chocolate coins at my local gym, (spotted by my eagle eyed 6-year-old when attending swimming lessons!). Other examples were more routine, like the chocolates on the hospital wards, every time you shop or purchase a coffee, facing display of sweet food as you wait at the checkout.

Following the KD (specifically), highlighted the potential daily temptations that patients encounter when reducing their CHO intake. I was working so hard to reduce my total CHO intake, counting and weighing every gram of CHO, two squares of milk chocolate (8g CHO) was more than my CHO allowance for one meal (6g CHO) and would undo all that hard work! I did experience some appetite suppression following ketogenic diet and did not feel hungry, thus making it easier to avoid. Also having my 'sweet' keto treat kept me from feeling deprived. Interestingly, by the end of the week, I really began to notice and taste the natural sweetness in fruit and even milk so much more than before.

## Eating Out

I was determined to stick with my keto plan on my brunch date. I chose the restaurant and looked at the menu in advance. There were a few suitable options to meet my keto needs. On request the waiter very kindly provided me with a little jug of cream for my coffee, I ordered the creamed mushroom on toast with rocket pesto, streaky bacon and poached egg. I didn't bring a food scales/or weigh the food, but I was able to accurately judge the food choices, portion size and estimate CHO and fat content of my meal, I just avoided the accompanying sourdough toast!

Eating out can continue to be enjoyed on the KD but maybe best avoided in the first few weeks of diet initiation. As nutrition knowledge improves, with increasing familiarity using CHO and fat exchanges and first-hand experience, you learn to judge the portion sizes, and you can with confidence make appropriate 'keto' choices when eating outside the home.

## Special Occasions

Food is very much a part of how we celebrate special occasions and on Valentine's day I still wanted to cook a special meal (within our keto plan). Dinner was sirloin steak with blue cheese and mushroom cream sauce.

Each meal brought a new learning opportunity and here I realised it is easy to overdo the fat intake at times. As high cholesterol is a potential side effect of the KD, consumption of healthy fats is emphasised from the

start, limiting saturated and trans fat while increasing unsaturated fat sources and making sure to include omega 3 fats.

## Key learning points

**My week on KD was an invaluable learning experience for me. The take home messages which I will bring into my practice are ...**

- The KD is not that controversial.
- Preparation is key. Like all change, the initial weeks are the hardest, but it gets easier (even in a 1 week timeframe) and is totally achievable.
- It is important to address the mixed messages with patients' e.g. healthy eating vs high fat, the magazine version of the KD vs the medical KD!
- At times, I need to manage patient's enthusiasm to prevent them starting on the diet prematurely.
- It's not a natural diet, but it has proved to be effective in epilepsy for over 100 years.
- It's difficult to judge portion sizes without weighing – but I have since developed a new resource to help!
- Side effects are minimal and are easily managed
- It's not all about ketosis, the impact on seizure activity and quality of life is equally important.
- I appreciate it can add pressure to an already busy lifestyles or family life
- Resilience and empathy are required in equal measure.
- It's a wonderful opportunity to empower patients and self-manage some aspect of their lives such as diet, to try to control the uncontrollable, a condition where seizures can strike at any moment.

**Reflecting on my week, I appreciate I only had to deal with the impact of changing my diet, without living with epilepsy and possibly daily seizures, and the impact of taking AEDs that can affect how you think, feel and your ability to cope.**

**Even with this short timeframe, I can acknowledge with empathy the practical, financial, social and emotional difficulties faced by my patients embarking on this diet. As a Dietitian it has enhanced my practice and allowed me to further develop my skills to support, prepare and problem solve with my patients on the KD.**

**Dealing with the KD is not difficult, dealing with seizures is difficult.**

## A DAY IN MY KETO DIET JOURNEY!

### BREAKFAST

Scrambled Eggs, & Smoked Salmon & Spinach



### SNACK

Choc 'n' Nut  
Keto Treat with  
Strawberry



### MID MORNING

Creamy Coffee



### LUNCH TIME

Greek Salad, Feta Cheese & Pine Nuts  
Keto Bread Roll



### DINNER TIME

Keto Chilli Mince, Mixed leaves, avocado,  
cheese, and sour cream on a low carb Tortilla





# JOSH'S KETO STORY

Written by his mum, Kay

**Josh (or 'Spud' as he is affectionally known as), officially started the Ketogenic Diet on December 6th 2014, a Saturday, I know this because after talking to my mam recently she says she remembers the first day he started because the change in him from day 1 was obvious.**

School was the same on the Monday, I hadn't told them he'd started the diet until I went to collect him at home time, his teacher pulled me aside before I had the chance to say anything and told me what a brilliant day he'd had, he was so 'on the ball', attentive and had had a fantastic day the likes of which they'd never seen before. I remember questioning the online group at that point and asking if it was right that we were seeing results this fast and being deeply suspicious it was just another honeymoon period. I was SO scared of getting my hopes up again.

From there we went from strength to strength, there were tweaks along the way and bumps in the road, at the start he'd had 10g of carbs for an evening meal which was causing issues so that had to be reduced. We weren't seeing the seizure reduction we would have liked in the first couple of months, despite the obvious cognitive benefits, so MCT oil was added into his diet, it took time to work out what worked for him but every time the diet was tweaked, we saw an improvement.

One of the best memories I have of him is the first time my son argued back with a 'but you said....' I can't even remember what I'd promised him but the fact he's remembered something I'd said 5 minutes ago and was able to argue for what he wanted had me in tears, he'd never been able to retain any information up until that point and this for me was when I first started to see my son underneath all the seizure activity.



He's 5 years plus on the diet now, I can't put into words how much it's changed his life. The child I have now is NOTHING like the one I first walked into clinic with, the child whose hand I couldn't let go of for even a second for his own safety, the child who talked at you but not to you because he wasn't capable of holding a two way conversation.

I remember them doing a sort of interview at the first appointment before we were given a place on the program, they were making sure my expectations were reasonable and asked me what I wanted from keto, my list was so short, it had 2 things on it, one was toilet training (something he declared he was ready for two weeks after starting the diet!) and the other was seizure reduction.

Keto has given me so much more than what was on that wish list. It's given me conversations and arguments I didn't dare dream of, it's given him progress and adaption, a working memory, the ability to think and reason, it's given him some form of freedom and independence, it's given him a quality of life I wouldn't of dreamed possible at the start of this journey and it's very literally been the making of him. I shall always be grateful for the ketogenic diet.

I have a video of him at an indoor rock climbing center, it's one of my favorite moments in time with him because he's stood at the bottom of that wall trying different footholds, different handholds, working out which way to go, trying different routes, seeing what worked best for him. I can see his brain working in that video, I can see all the progress he'd made up until that point and he continues to make to this day and at the end of that video he made it all the way to the top, he was so proud of himself, and that for me sums up what keto has done for him, it's let him climb over all his obstacles and make it to the top.



Emma says: "We have known Kay and Spud for a good few years now at Matthew's Friends and it is lovely to see the progress Spud has made. The piece of film that Kay refers to is on our website and can be found when you click on the following link and choose 'Spuds story'."

<https://www.matthewsfriends.org/about-us/our-stories/adult/>

# MF Starter Packs continue to be a big hit with families

We send out hundreds of Keto starter packs each year to families all over the UK and Ireland, and it is always lovely to receive your messages and photos. Here is just an example of one we have had recently...

## Message from Corey's mum, Chareen....

"I just wanted to send a thank you for our starter pack for the keto diet. It was a great surprise to receive it and the amount of stuff inside was astonishing my little boy is loving trying the new food in advance and the apron is his favourite addition in helping me cook (I have attached a photo of this).

It is appreciated from the bottom of our hearts thank you for giving us this support and head start and giving Corey a positive look and fun side to it! We loved all the info in the pack we received and Matthew's story was so heart warming and close to home, brought a tear to my eye. My son also started with one type of seizure and the progression through medicine etc meant things got worse, he started having different seizures and side affects so we are hopeful keto works for us too. You guys are a fab charity and we really are blessed to have your support thank you xx"



Starter Packs are free to all families in the UK and Republic of Ireland so long as families are on a medically managed ketogenic diet. You can order them via our website or you can ask your dietitian to send a request to us and we will arrange to get one out to you in the post.

## NEW information sheets available from Matthew's Friends:

### Food Choice booklets

These are lists of protein choices, carbohydrate choices and fat choices with the amounts contained for each food. Your dietitian will give you guidance on how to use these booklets. Your own centre may also give you lists - they can sometimes be referred to as exchange lists as well as food choice lists. These are electronically available so can be emailed to you directly.

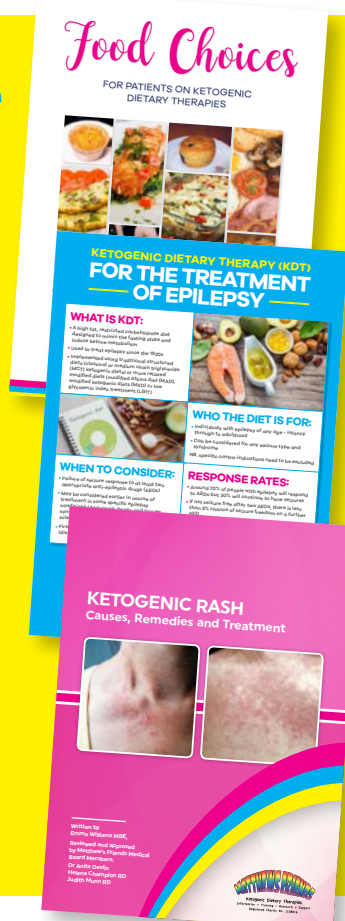
### Doctors Surgery/Hospital Clinic Posters

Please email your address and the number you require to: [enq@matthewsfriends.org](mailto:enq@matthewsfriends.org) and we will send them out to you.

### Keto Rash Information sheets

First in our new series of Information sheets is one focusing on 'Keto Rash' – although very unusual it can still happen and can be extremely worrying for families if it does. We hope the downloadable information sheet will be of some help to you. You can find it on our website at the following link:

[www.matthewsfriends.org/wp-content/uploads/2020/08/WEB\\_Ketogenic\\_rash.pdf](http://www.matthewsfriends.org/wp-content/uploads/2020/08/WEB_Ketogenic_rash.pdf)







# Ask our Dietitian

**Sue Wood RD**

Specialist Ketogenic Dietitian, Adults And Children,  
Matthew's Friends Clinics.

## Question?

Olive oil is now being listed on some labels as containing 91 -92g fat per 100g rather than 100g fat.

Why is this and what does this mean for patients and families when weighing out their oils?

## Sue says...

*It sounds like the nutrition labels on oils are catching up with chemical accuracy ... Vegetable oils are pure 'fat'. The oils are always sold by volume (ie mls) not weight (grams) therefore their nutrition label has to reflect the way they are sold.*

*However ml for ml, oils are lighter than water and this relates to their 'density' and this also alters depending on its temperature i.e. 1g of oil will occupy a different volume ( mls) depending on how warm it is.*

**Olive oil - Density table in function of temperature from**

[www.aceitedelasvaldesas.com/en/faq/propiedades-composicion-aceite-oliva/densidad-del-aceite-de-oliva/](http://www.aceitedelasvaldesas.com/en/faq/propiedades-composicion-aceite-oliva/densidad-del-aceite-de-oliva/)

### DENSITY OF THE OLIVE OIL

Temperature (°C)	Density (kg/ litro)	Temperature (°C)	Density (kg/litro)
6	0,9230	18	0,9150
7	0,9224	19	0,9144
8	0,9217	20	0,9137
9	0,9210	21	0,9130
10	0,9204	22	0,9124
11	0,9197	23	0,9117
12	0,9190	24	0,9110
13	0,9184	25	0,9104
14	0,9177	26	0,9097
15	0,9170	27	0,9090
16	0,9164	28	0,9084
17	0,9157	29	0,9077



*So you can see that 100ml olive oil at 18 °C (according to this table) would weigh  $100 \times 0.915 = 91.5\text{g}$  and that is how it would be declared on a label 'per 100ml'.*

*Put simply, if you are weighing your oil on scales – 1g does mean 1g. It's just that if you are measuring by spoon or measuring jug, 1ml oil does not weigh 1g! The most important thing with the ketogenic*

*diet is to be consistent with your methods. If the oil is always measured in the same way, be it mls or grams consistently, the keto recipe meal will remain constant.*

*Families should talk to their dietitians as to how they should consistently measure their oils and fats.*

# What healthcare outcomes are important to you and your child when using the ketogenic diet?

**Researchers at the University of Plymouth are working with Matthew's Friends, parents and health professionals to really understand what healthcare outcomes are important to measure when using the ketogenic diet.**

Research often uses seizure control and the side effects of a ketogenic diet as the main way of assessing ketogenic diet therapy (these are known as 'outcomes'). However, we also think it is vital to consider outcomes that are important to the children receiving treatment and their parents. Other outcomes may include measurements of physical health, mental health and quality of life, to name a few.

To get involved visit: <https://www.plymouth.ac.uk/core-kdt> and register to take part in the online survey to rate the most important outcomes.

## Progress to date

An extensive review was undertaken to identify the outcomes measured in research studies of ketogenic diet in childhood epilepsy since 2008. The year when the first randomised controlled trial (Neal et al., 2008) and the international consensus statement on optimal clinical management (Kossoff et al., 2008) were both published. A comprehensive list of outcomes were identified, with a sample listed below.

Outcome domain	Example outcomes
Nervous system outcomes	Seizure control, adverse effects
Nutrition outcomes	Fine tuning of KD, dietary intake
Life impact outcomes	Cognition, alertness
Resource Use	Hospital admissions, cost effectiveness

The next phase of our study aimed to identify the outcomes that are important to parents, exploring similarities and differences in the outcomes identified in the earlier review. We received an overwhelming response from interested parents, thanks to Matthews Friends, Young Epilepsy and ketogenic dietitians advertising efforts.

Twenty-one interviews were undertaken and the team extends a huge thank you to those who volunteered and took part. Discussions provided valuable insight to family's



**Jen Carroll MSc FHEA RD**  
Dietitian and PhD Researcher (The CORE-KDT Study)  
University of Plymouth

experiences of epilepsy and ketogenic diet from diagnosis to day to day management of the diet, including successes and challenges along the way.

New outcomes were identified and added to the earlier list of outcomes. Parents shared the importance of participation and independence as key outcomes (among others) for their child. Participation encompassed being able to join in activities with siblings or friends at home, nursery and school such as playing, parties, sleepovers and swimming. Independence for many parents was about regaining lost independence or the potential to gain future independence. Characterised by being able to make decisions, undertake activities of self-care like bathing alone and walking to school.

## Next steps

Help us to achieve consensus on the most important outcomes to measure when monitoring children with epilepsy treated with ketogenic diet

We invite parents, health professionals and researchers who have experience with epilepsy and ketogenic diet to rate the comprehensive list of outcomes using an online survey designed to allow large groups of people to come to an agreement (A Delphi survey). Please register to take part at <https://www.plymouth.ac.uk/core-kdt> or email [core-kdt@plymouth.ac.uk](mailto:core-kdt@plymouth.ac.uk)



# CORE-KDT

Core Outcomes for Refractory Epilepsy with  
Ketogenic Diet Therapy



# INTERNATIONAL CHEF'S DAY

## TUESDAY 20<sup>TH</sup> OCTOBER 2020



**We would like to 'tip our hats' to our wonderful Ketogenic Chefs here in the UK.**

Firstly our wonderful Mo who works in our own Keto Kitchen developing new recipes and adapting patient recipes for our own clinic patients as well as those from other centres all over the UK and Ireland. Mo creates bespoke recipes for families who need inspiration or who are struggling and her keto sausages rolls and bread rolls are legendary!

### **MAUREEN BENN | KETOCOOK – MATTHEW'S FRIENDS CHARITY & CLINICS**



Maureen (Mo) joined the MF team in 2012 bringing with her an extensive background in catering and her love of cooking. Mo is responsible for our recipe development and always welcomes the chance to help families, that may be struggling, to make tasty dishes to their individual prescriptions.

She has enjoyed travelling to several countries demonstrating recipes to both professionals and families and loves meeting the children. You will find her on our cooking channel where she is shown in a series of short films demonstrating some of her popular recipes which she hopes will show newcomers to the Keto diet that it is not as daunting as it may seem.

Next is Chef Neil who donates his charity time to us and has done for many years. He has developed some wonderful recipes over the years, firstly for Nutricia and now for VitaFlo. His Halloumi Fries, tempura prawns and onion rings as well as his keto banoffee pie are quick to disappear whenever we are at meetings together and Neil is fantastic with the families and patients as he tours the country demonstrating his recipes on VitaFlo Cooking days and he is wonderful at increasing the confidence in people to try new things.

### **NEIL PALLISER-BOSOMWORTH | KETO CHEF – VITAFLO**



Neil Palliser-Bosomworth is a consultant chef with 19 years of experience working in various NHS hospitals in the UK, catering for different patient groups and their unique dietary needs. He has also worked as head chef at the Marie Curie Hospice and St Oswald's Hospice. About 12 years ago he was introduced to Matthew's Friends Founder and CEO, Emma Williams. Neil and Emma spent a great deal of time together as she took him through the ketogenic diet and all that it entailed. Neil has since flown with this and ketogenic therapies are now one of his specialities.

Neil regularly travels abroad to demonstrate Keto cooking and can be found at Matthew's Friends meetings and on their ketocooking channel. Neil now works as a medical chef for Nutritional Company, VitaFlo, who make prescription products for Ketogenic Therapies as well as devoting charitable time for Matthew's Friends with their Ketocook Mo, in their recipe development kitchen.

Lastly but by NO means least... the wonderful Chef Derek whose artistry and inspiration as a pastry chef has been a real 'game changer' for the ketogenic diet. Derek is now busy in the Nutricia recipe development kitchen and has been seen on our KetoKitchen YouTube channel demonstrating some of his favourite recipes for Matthew's Friends during lockdown. Thank you for the support of our families Derek and donating your time to Matthew's Friends.

### **DEREK CLARKE | KETO CHEF - NUTRICIA**



Leaving school, Derek studied baking and sugar confectionery. After passing his exams he worked in some of London's biggest 5-star hotels where he decorated cakes for some amazing clients and celebrities. Derek then moved back home and set up his own business making celebration cakes for wedding parties, this is when his godson was born with PKU. He started making and developing recipes suitable for his diet and this where Derek met Sarah from Nutricia.

Throughout Derek's journey with Nutricia he was lucky enough to meet the guys from Matthew's Friends, hearing Emma's story and tasting MO's sausage rolls ("still my fave") he was introduced to the world of Keto.

31 years on and his focus remains the same, to create delicious recipes for the people eating them and make it fun, food does not need to be beige or boring because everyone needs some sparkle in their life.



# SEASONAL RECIPES

## FROM OUR KETOKITCHEN



**Worrying about how to do a keto advent calendar?  
Think inside the box..... By MF Ketocook Mo.**

For my idea of an Advent Lucky Dip Box, I suggest a balance of food treats and little toys. My suggestions for food treats are Mini Muffins, Festive Fat bombs, Spicy Biscuits and/or Butter Biscuits as Christmas Biscuits as they are Tree shaped, a little bag of Savoury Puffs, a little bag of Cheesy Nibbles, Parsnip & Celeriac Crisps, and maybe for the last dip maybe a toy or cuddly Santa could be in place. This could be held back until the last dip to ensure it is found on the right day.

Chocolate items will have to be kept cold in between dips, but this idea gives plenty of scope for families to control what is actually found and it doesn't have to be chocolate every day.

It may seem like a lot of baking but hopefully some of these things will be in use over the Christmas period and all of them keep well so can be made in advance; muffins freeze, Fat Bombs keep in the fridge and the remainder are all good cupboard keepers in poly boxes.

I have attached a photo as an example and I have used what I have to hand but it is just to give the idea. You can make the box as big as you want, decorate it how you want

or even use a Christmas bag or sack instead of a box and you can fill it with things that is suitable for your loved one that they can look forward to their 'dip' every day.



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

**PLEASE ENSURE YOU CHECK PRODUCT LABELS FOR VALUES.**

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

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



## FAMILY SIZE CHRISTMAS CAKE

### INGREDIENTS

- 150g Almond flour flurry – HOLLAND & BARRETT
- 300g Egg
- 25g Raisins
- 25g Sultanas
- 19g Coconut flour - TIANA
- 180g Butter
- 1g Orange zest
- 44g Prunes – canned in juice
- 10g Psyllium husk
- 100g SUKRIN GOLD
- 100g SUKRIN or NATVIA icing
- You will also need 1 teaspoon of mixed spice, 1 teaspoon of BARKAT baking powder and a few drops of orange extract.

### METHOD

- Pre heat oven to 170c / fan 150c / gas 4
- Start by chopping the sultanas, prunes and raisins, a bit fiddly but you get a better distribution through the cake, then soak them in 30mls of the prune juice for at least ½ hour to plump them up.
- Mix together the almond flour, coconut flour with the Barkat and mixed spice.
- Soften the butter, beat in the Sukrin Gold and then the flour mixture.
- Whisk the egg until light and frothy, stir in to the mixture and combine well.
- Stir in the soaked fruit and orange zest. Place in a greased and lined 7 inch cake tin or silicone mould.
- Cook for approximately 40 minutes until cooked through. When it is cold, make icing by mixing the Natvia / Sukrin icing with just enough water and a few drops of orange extract to make a stiffish icing.



**MKD 5G CHO PER PORTION**  
**CHO: 60.54G**      **FAT: 262.12G**  
**PROTEIN: 75.20G**      **KCAL: 2902**

**TRIED & TESTED**  
 MATTHEW'S FRIENDS

### MO'S TIPS

Decorate how you like; there are lots of lovely items available that make it Christmassy without adding to the ratio. not really fruity cake but just enough to make it a bit different!! If you cut in to 12 portions, this will give you 5g CHO per portion.

## SPICY BISCUITS

### INGREDIENTS

- 36g Butter
- 54g Almond flour flurry – HOLLAND & BARRETT
- 6g Ultra fine fiber flour – LONJEVITY FOODS
- 24g SUKRIN GOLD

You will also need 4g ground ginger or mixed spice.

### METHOD

- Pre heat oven to 170c / fan 150c / gas 4.
- Mix the dry ingredients together.
- Soften the butter then add to the dry mix and stir well until a sticky dough forms.
- I use a cookie shaper which makes life easy but if you don't have on just divide into equal size balls and make whatever shape you like by flattening out.
- I found that you can roll it out between parchment paper and use a cookie cutter.
- It does take some careful handling but if you slide a palette knife under them, they will lift off and onto the baking tray quite easily.
- Place on a non-stick baking tray, a silicone liner or baking parchment is great for this.
- Cook for approximately 10 minutes. Remove from the oven and leave to cool, they crisp up!



**CLASSICAL 3.32:1 RATIO**  
**CHO: 5.26G**      **FAT: 59.95G**  
**PROTEIN: 12.82G**      **KCAL: 612**

**TRIED & TESTED**  
 MATTHEW'S FRIENDS

### MO'S TIPS

Before cooking you can make a hole in them if you are planning to thread a ribbon through to hang on the Christmas tree. Leave plain or decorate with edible spray glitter. I made 16 cookies, each one gives: FAT: 3.75g PRO: 0.8G CHO: 0.33g



## HALLOWEEN COOKIES

### INGREDIENTS

- 18g Butter
- 17g Coconut powder - TRS or EAST END
- 10g Ultra fine fiber flour - LONJEVITY FOODS
- 3g Cocoa butter - SEVENHILLS ORGANICS
- 8g Cocoa dark supreme - LINDT 90%
- You will also need 12g SUKRIN or NATVIA sweetener, a few drops of liquid sweetener and some extract - I used orange.

### METHOD

- Pre heat oven to 190c / fan 170c / gas 5.
- Reserve the Lindt and cacao.
- Mix the fiber flour and coconut powder together. Soften the butter and beat in the sweetener, mix dry ingredients into the butter to form a dough, it will, don't add any liquid!!
- If you roll it into a sausage shape you will find it easy to cut into round cookies, or you can simply use the dough in a cookie shaper if you have one, or simply place a small amount into mini moulds.
- You don't want them too thick or thin, they need to be similar to a normal shortcake biscuit (not chunky shortbread).
- Bake for 10 - 12 minutes. They will crisp as they cool.
- Melt the Lindt and cacao together over hot water and add a few drops of liquid sweetener and extract of your choice.
- Use the chocolate to decorate the cookies, the easiest way is to let the chocolate set then do face painting using edible ink pens (available online). Or just use what you have to hand. I used a few cake decorations which you can buy in all supermarkets, they are so tiny and light they will not add anything to the ratio.
- I had just enough chocolate left over (after scraping the bowl well) to make a BAT!! Then I melted 9g of cocoa butter, added some extract / liquid sweetener and made a ghost and skull. 9g gives 9g fat so use it like a fat bomb!



### CLASSICAL 4.19:1 RATIO

CHO: 3.91G

FAT: 32.94G

PROTEIN: 3.96G

KCAL: 328



### MO'S TIPS

I made 8 mini cookies, this makes it easier to use as treats and has 0.48g carbs per cookie.

## TRICK OR TREAT FAT BOMBS

### INGREDIENTS

- 15g Cocoa butter - SEVENHILLS ORGANICS
- 10g White chocolate - LINDT LINDOR
- You will also need some flavouring of your choice - orange extract is nice, and some natural food colouring.

### METHOD

- Melt the cacao and Lindt over hot water.
- Add flavouring. Divide the chocolate into how many colours you want to make and add food colouring.
- Set in silicone moulds and freeze.

### MO'S TIPS

Best kept in the fridge, but they are OK at room temperature for an hour or so. All chocolate melts when it gets warm but with these being small pieces they need a little more care. I made 5 pieces but it will depend on the size of course! Mine are quite big.

Portion values: FAT: 4.02g PRO: 0.10g CHO: 0.84g



### KETOGENIC RATIO: 4.27:1

FAT: 20.10G

PRO: 0.51G

CHO: 4.20G

KCAL: 200



**PLEASE ENSURE YOU CHECK PRODUCT LABELS FOR VALUES.**

**These recipes will need to be adapted to EACH INDIVIDUALS prescription. Please take these recipes 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 favourite flour

Fiberflour is one of Mo's favourite keto baking ingredients and Lonjevity Foods have kindly given us a discount code 'MF20%' typed into the coupon code space will get you 20% off your order. Here's a link to the product:

[www.lonjevity-foods.com/product-page/fiberflour](http://www.lonjevity-foods.com/product-page/fiberflour) it's well worth a try.

Thanks to Lonjevity Foods for their generosity.

*Mo says... "Ultrafine Fiberflour values are per 100g, FAT: 2.00g PRO: 21.00g CHO: 15.90g making it a good ingredient for MKD & MCT recipes. If it is combined with either ground almonds or coconut powder it adds a lightness to the texture."*



## NEW T-Shirts and Aprons coming to the MF Shop!

Look out for our new T-shirts and adult aprons with our NEW KetoHero Logo on them. Ideal presents for people and you are raising money for us at the same time.

At the time of writing, we are waiting for our orders to come in and then you can order via our website shop (the link is below). Don't forget that we have our new Travel Mugs and matching notepads as well as our free samples and starter packs that are available. So keep checking and we will also put on our social media page when stock has arrived.

Visit: [www.matthewsfriends.org/matthews-friends-shop/](http://www.matthewsfriends.org/matthews-friends-shop/)



## CHRISTMAS CARDS AVAILABLE NOW!

Designed exclusively for us by Oxted Artist and Matthew's Friends supporter Melanie Barren, our Christmas cards are now available through our online shop or you can ring the office to place your order.

Packs of 10 cards are priced at £4.50 per pack (plus P&P) with all profits going to help us continue with our work.



visit: [www.matthewsfriends.org/matthews-friends-shop](http://www.matthewsfriends.org/matthews-friends-shop)

# Epilepsy Resources

Epilepsy Action has launched a new resource. It's been created by young people for young people aged 16-25, to help them manage their epilepsy.

The **Epilepsy Space** is a mobile friendly website and all the content has been reviewed by epilepsy specialist nurses and young people. It's full of information, epilepsy facts, tips, and stories from young people with epilepsy sharing their experience.

It's the place for young people with epilepsy to learn more about their condition, share with others, and grow their confidence to live well with epilepsy.



## A Huge Thank You... from Hope Charity

**"A huge thank you to Emma Williams founder of Matthew's Friends, for hosting a presentation on the Ketogenic-Diet for HOPE for Paediatric Epilepsy London families on the 5th July 2020. We know how busy Emma is, as a full time MUM and charity CEO, so we really appreciated her giving up her spare time for free to help our families.**

Emma who was awarded an MBE for her service to children with epilepsy, is one of the world's leading names in the world of Ketogenic Dietary Therapies, so our families were excited to hear her insights into how the diet could help their children. They were not disappointed. Emma's presentation was educational and informative and her enthusiasm for the diet was infectious. Many of our families were at a crossroads in terms of their children's health and they didn't know which way to turn.

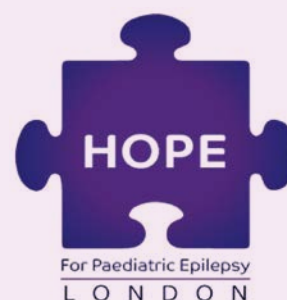
Emma showed our families that the Ketogenic Diet is a possible solution and her presentation made such a significant impact on some of the families that they want to plan to start their children on the dietary therapy as soon as it is possible. Once again thank you Emma from all at HOPE - we really appreciate you sharing your knowledge and expertise with us. Thank you also for your kindness and empathy towards others struggling with similar issues that you have had to face. You are an inspiration!"

**Dr Nadine Gurr Chair:**

**HOPE for Paediatric Epilepsy – London**

## About the Hope Charity....

HOPE for Paediatric Epilepsy - London, (winner of the 'Young Epilepsy Champions Award' 2014 Best Community Support Group), is a charity run by a team of volunteers for children with epilepsy and their families. It was set up in 2012 by Scott Little, a parent who identified that there were no support services for children with epilepsy in the area of North London where he lived. He found caring for a child with complex epilepsy an isolating experience, as it is for many families, so he decided to set up a charity to support those in a similar situation.



Over the past 8 years the charity has grown and now supports many more families through free, monthly clubs based in Whetstone. These are open to anyone that can travel to the venue and provide a chance for children with epilepsy and their siblings to play games, do arts and crafts, use the adapted soft-play room and playground and take part in hosted activities (such as entertainers) every month.

The parents also have the chance to talk, exchange information and relax in an informal setting with others who are in a similar situation and understand the difficulties of caring for a child with epilepsy. They can even get a manicure if they choose! The charity also provides free days out and a Christmas party.

The HOPE volunteers are available both at the clubs and online to provide support and information. HOPE also invites epilepsy professionals to give talks to the parents and children at the clubs and provides a dedicated information table containing the latest literature on paediatric epilepsy.

Aside from the clubs, HOPE have always provided anti-suffocation pillows to the children that attend. In 2017 HOPE extended this by starting an Anti-Suffocation Pillow Project - funding pillows for any child with nocturnal convulsive seizures living in London.

HOPE relies on fundraising and donations from the general public despite the great need for support for families with children affected by epilepsy.

HOPE exists to provide this support. For more information, visit our website at: <http://www.hopeforepilepsylondon.org.uk/> or our Facebook: [@HopePaediatricEpilepsyLondon](https://www.facebook.com/HopePaediatricEpilepsyLondon) and Twitter: [@HopeEpilepsy](https://twitter.com/HopeEpilepsy)

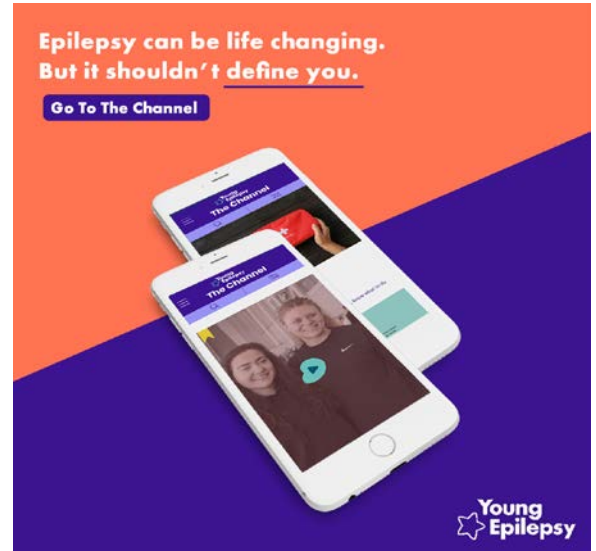


## Young Epilepsy launches The Channel [thechannel.org.uk](https://thechannel.org.uk)

Young Epilepsy exists to create a society where children and young people with epilepsy are able to thrive and fulfil their potential. As part of our mission, to equip young people with epilepsy with knowledge and relevant support, they have just launched [thechannel.org.uk]The Channel

The Channel has been co-created with our Young Reps and is a place where young people with epilepsy can get information, advice and guidance when they want it, where they want it and written in a language that they can relate to.

Designed in a similar style to a social media platform The Channel provides information on lifestyle, health and epilepsy related subjects through video, animation and blog posts. Young people feel part of a community, leave us comments, ask us questions directly and, importantly, contact Young Epilepsy for further support.



# Congratulations!

**Congratulations to the Chair of our medical board, Professor J. Helen Cross, as she is elected as President of the International League Against Epilepsy (ILAE).**

We are absolutely delighted for Professor Cross that she has been elected as President of the International League Against Epilepsy (ILAE), the preeminent association of healthcare professionals and scientists working in epilepsy across the globe.

Professor Cross is The Prince of Wales's Chair of Childhood Epilepsy, Head of Developmental Neurosciences Programme and Honorary Consultant in Paediatric Neurology at UCL Institute of Child Health, Great Ormond Street Hospital. Helen's research has primarily focused on optimising outcomes in the early onset epilepsies and is a leader in the field on initiatives including the ketogenic diet and epilepsy surgery in children.

CEO/Founder, Emma Williams says "Helen's commitment to the field of Complex and Refractory Epilepsy is inspirational and motivational, quite frankly I don't know how she does SO much. She is revered by her fellow professionals and of course, for charities like us, she always goes the extra mile. For the families, she is literally an outstanding neurologist, I wish I could clone her!"

Certainly for our family and obviously Matthew most of all, her work changed our lives for ever and I know many other families that say the same. We are currently working together for several projects and it is always a pleasure. We are so pleased for Helen and we know that she will bring so much to the role of ILAE President and to have an ILAE President that is SO positive about Ketogenic Dietary Therapies is wonderful too."



Matthew pictured at one of his fund raising balls with Professor Cross, his mum Emma and Sister Alice and his Keto dietitian, Liz Neal.

# 7<sup>TH</sup> GLOBAL SYMPOSIUM ON MEDICAL KETOGENIC DIETARY THERAPIES

**19TH-23RD OCTOBER 2021**  
**BRIGHTON HILTON METROPOLE | UK**  
**COLLABORATIVE SCIENCE AND CLINICAL CARE**



#### KEY DATES:

Poster Opening Submissions  
**1st February 2021**

Poster Closing Submissions  
**30th April 2021**

Early-bird Registration Closes  
**30th April 2021**

**REGISTER INTEREST AT: [GLOBALKETO2021@MATTHEWSFRIENDS.ORG](mailto:GLOBALKETO2021@MATTHEWSFRIENDS.ORG)**

**#KETO2021**  
**[WWW.GLOBALKETO.COM](http://WWW.GLOBALKETO.COM)**



**FIRST ANNOUNCEMENT:  
STARTING NOVEMBER 2020**



**A webinar and podcast series** for healthcare professionals **covering the latest insights into the Medical Ketogenic Dietary Therapies.**

Brought to you by the organisers **Matthew's Friends** and the **International Neurological Ketogenic Society (INKS)** supported by **Nutricia Ketogenics**, the Platinum Sponsor of the 7<sup>TH</sup> GLOBAL SYMPOSIUM ON MEDICAL KETOGENIC DIETARY THERAPIES.

For more information visit: [WWW.GLOBALKETO.COM](http://WWW.GLOBALKETO.COM)



**INTERNATIONAL  
NEUROLOGICAL  
KETOGENIC SOCIETY**



**KETOGENICS**





## KetoVie 4:1

**ACBS approved and available on prescription**

**With 5 years of supporting families in North America with ketogenic diet therapy, we are thrilled to do the same in the UK.**

KetoVie 4:1 is a ready-to-use nutritionally complete ketogenic formula for both oral and tube feeding for the dietary management of intractable epilepsy and other conditions that require a ketogenic diet.



### Summary of KetoVie Features:

- ✓ For ages 3 years+
- ✓ Contains MCT, 25% of total calories (12g/250 mL)
- ✓ 100% Whey-based protein
- ✓ Contains Carnitine 50mg per 250 mL
- ✓ Available in ready-to-use liquids: Vanilla and Chocolate

Please read our 'Everyday is Everything Blog' to learn more about how KetoVie can help:  
<https://www.ketovie.com/blog/2016/02/the-ketovie-mission-explained/>

**Further information is available at: [www.ketovie.co.uk](http://www.ketovie.co.uk)**

**For samples, please email: [UKinfo@cambrooke.com](mailto:UKinfo@cambrooke.com)**

**CAMBROOKE™**

Eat Well. Live Well.  
  
 AJINOMOTO

smile.amazon.co.uk

**Between 1 April and 30 June 2020  
Amazon donated £40.87  
to Matthews Friends as a result  
of the AmazonSmile programme**

As you know every penny raised means such a lot to us especially in these strange and difficult times. Please sign up to Amazon Smile to raise funds for Matthew's Friends us each time you shop.

Every time you Shop on AmazonSmile at [smile.amazon.co.uk/ch/1108016-0](https://smile.amazon.co.uk/ch/1108016-0) Amazon donates to Matthews Friends, and it doesn't cost you a thing!

*Thank you.*



## EUROPEAN GLUT1 CONFERENCE POSTPONED TO 2021

As the Covid 19 situation in Europe is still critical and imposes severe restrictions on medical meetings, the organisers have decided to postpone the European Glut1 conference until 11th and 12th June 2021.

The current plan is to keep the original program and venue in Lille, but more details will be announced in the future.

This is sad news, but we hope that it will ultimately mean that as many people as possible will be able to attend the conference and at least it gives us something to look forward to!

GLUT1





We are extremely proud to introduce two new Family Blogs to our website, which are being written, filmed and prepared by two VERY inspirational families.

We have Ella's Keto Blog and Lucy's Cookery Corner. We have no doubt that their efforts will be of great help to others along their journeys and we want to say thank you to the families for doing this.

Make sure you visit their blogs regularly for updates and watch out for notifications from us when new posts have been made. You can sign up to be kept informed of all our latest keto news and events at the following link:

[www.matthewsfriends.org/contact-us/keep-in-touch/](http://www.matthewsfriends.org/contact-us/keep-in-touch/)

We do not share your details with anyone outside of Matthew's Friends.

## Ella's Keto Blog

[www.matthewsfriends.org/2020/08/06/ellas-keto-blog/](http://www.matthewsfriends.org/2020/08/06/ellas-keto-blog/)

Be ready to be 'wowed' with the creations that Emily comes up with for Ella.

This is Ella..... Ella loves craft time, mini beast hunts and jumping on her trampoline.

I am Ella's Mum, Emily.... I love helping others, live music and drinking my body weight in tea!



Ella has GLUT1 Deficiency which means her brain is unable to use glucose for power. Ella therefore is powered by ketones through a classic ketogenic diet.

Ella has sensory food aversions and is a grazer which means her poor Mum (yes, that's me!) is forced to work extra hard to 'normalise' her ketogenic meals. Ella is a true slave driver and also eats less if the food doesn't look 'pretty'. This all means I am, in my mind at least, creating culinary masterpieces which I hope will prove useful to you and many other families. Please note, if your ketogenic superstar is anything like mine, ketogenic masterpieces are still likely to be rejected often. If that happens, you are not alone!

Ella and I will be sharing our adventures with you all through our blog. I hope our adventures and ketogenic 'masterpieces' inspire you and make you laugh!

**Until next time.... Emily and Ella**

## Lucy's Cookery Corner

[www.matthewsfriends.org/2020/07/23/lucys-cookery-corner/](http://www.matthewsfriends.org/2020/07/23/lucys-cookery-corner/)



Watch Lucy in her own kitchen preparing and cooking some of her favourite Keto recipes, she is a natural and we think Mo had better watch out – she has some serious competition!

Lucy has Dravets syndrome (SCN1A gene) – it is a catastrophic epilepsy condition that is extremely resistant to treatment. She is also diagnosed with an intellectual disability and co-morbid ASC and ADHD.

Lucy was 9 years old when she first tried the diet.... the result was almost immediate. After a month on the diet she was a totally different child being able to participate more in life.

When she was transferring to secondary school (special school) at 11 years old, we decided to stop the diet as it 'might be easier' for them to manage! Her medication had to be increased significantly to control her seizures resulting in toxicity. Her hair started falling out, she could barely lift her head and she was like a zombie.

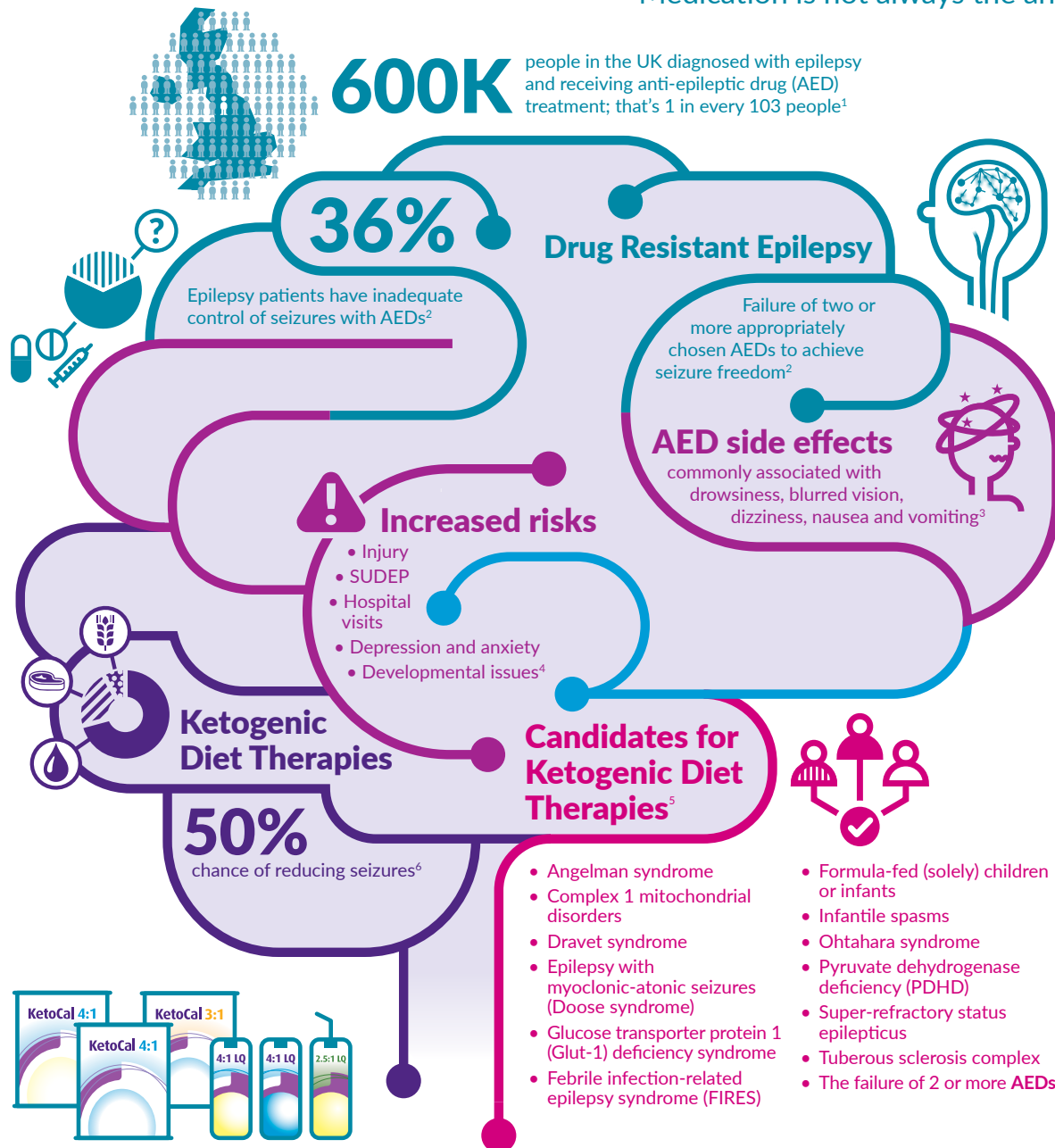
We took the step to re-start the diet – her medication was halved and she has been on the MAD ever since. Over the years we have experimented and refined various recipes. Lucy now enjoys a wide and varied diet and is able to prepare many of the keto meals herself. Friends and family have also joined in the process and often have 'Lucy friendly' food prepared for her when visiting. Initially, it is hard work but the rewards are significant.

She is now 20 years old and is moving into supported independent living.

# NUTRICIA Ketogenics

## DRUG RESISTANT EPILEPSY

Medication is not always the answer

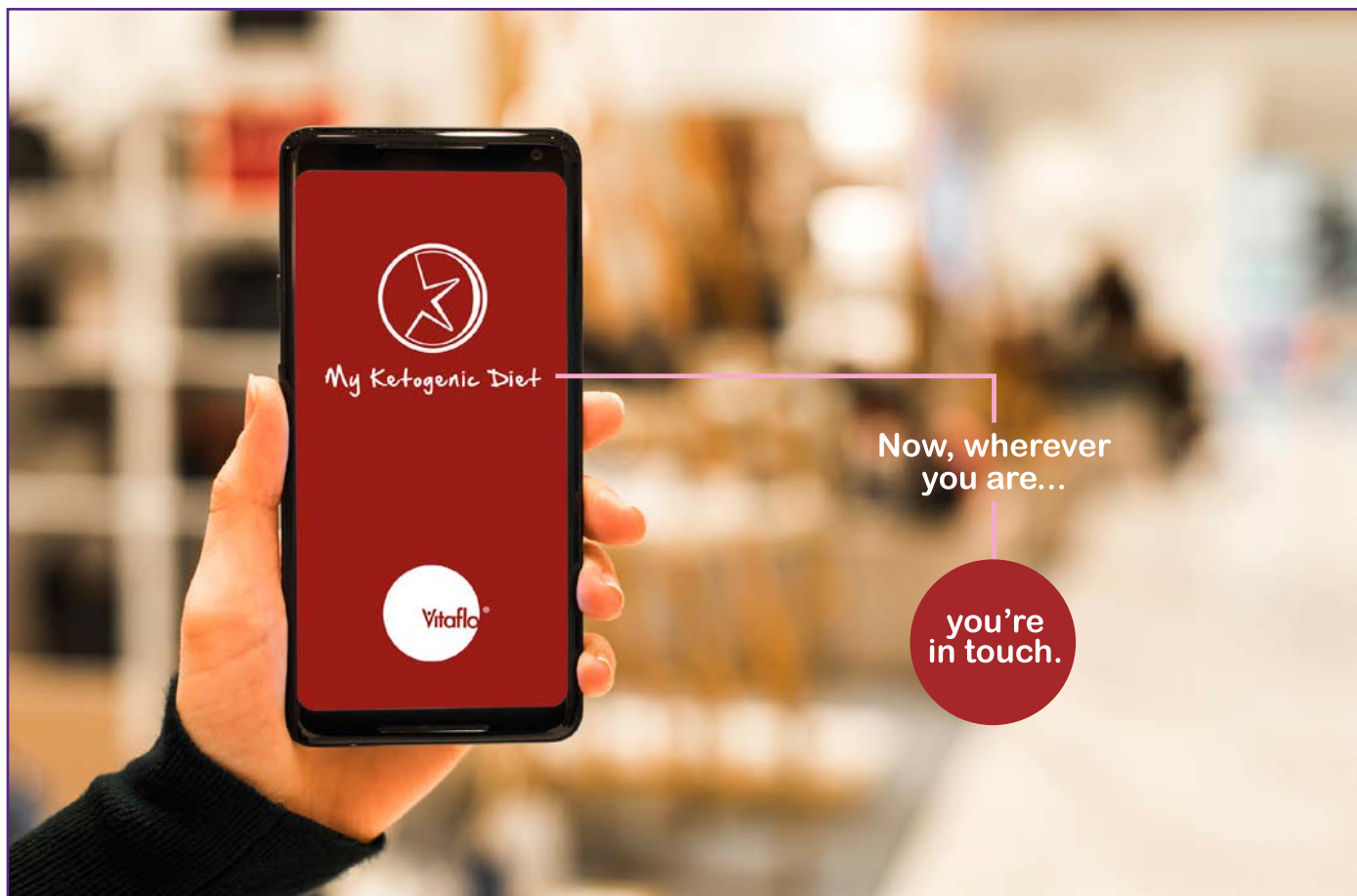


This information is intended for healthcare professionals only

The Ketocal range are Foods for Special Medical Purposes for the dietary management of drug resistant epilepsy or other conditions where the ketogenic diet is indicated and must be used under medical supervision.

1. Joint Epilepsy Council (2011) 'Epilepsy Prevalence, Incidence and Other Statistics', Available at: <http://www.jointepilepsycouncil.org.uk/> (Accessed: 16th April 2018)
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3. Epilepsy Foundation (2018) 'Risks with Epilepsy', Available at: <https://www.epilepsysociety.org.uk/risks-epilepsy#.W6DyWehKJIU> (Accessed: 18th September 2018)
4. Epilepsy Society (2018) 'Risks with Epilepsy', Available at: <https://www.epilepsysociety.org.uk/risks-epilepsy#.W6DyWehKJIU> (Accessed: 18th September 2018)
5. Kossoff, E. et al., 2018 'Optimal Clinical Management of Children Receiving Dietary Therapies for Epilepsy: Updated Recommendations of the International Ketogenic Diet Study Group'. *Epilepsia Open*: 1-18
6. Martin K et al. Cochrane Database of Systematic Reviews 2016:CD001903.pub3





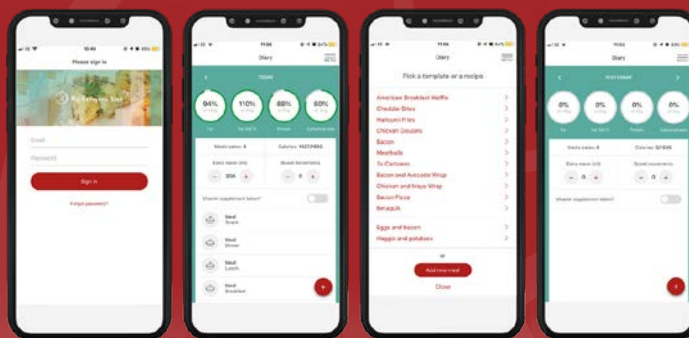
## The new My Ketogenic Diet App, from VitaFlo®.

*Informed & In touch. It's made for you.*

The brand new **My Ketogenic Diet App** from VitaFlo has been created for patients who are already following, - or who are thinking about following - a ketogenic diet.

### The App allows you to log and record:

- The foods you eat
- Your ketone and glucose levels
- Your seizures
- And much more



Via the App you can share this information **directly with your Dietitian**, allowing them to track your daily progress and help you reach your fat, carbs and protein targets.

So, no more spreadsheets and diaries to take to the clinic.

**To find out more about the My Ketogenic Diet App, contact your Healthcare Professional.**



VitaFlo® International Ltd, Suite 1.11, South Harrington Building, 182 Sefton Street, Brunswick Business Park, Liverpool L3 4BQ, UK.  
Tel: +44 (0)151 709 9020 E: [vitaflo@vitaflo.co.uk](mailto:vitaflo@vitaflo.co.uk) W: [www.vitafloweb.com](http://www.vitafloweb.com)

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# FACEBOOK FORUM FAMILY FOOD!

**You would be forgiven for thinking these fabulous Keto food pictures are from a glossy marketing brochure and can't possibly be 'real' Keto - but they are just that!**

These are REAL Keto meals, shared by our fabulous Keto families in our Facebook Forum. Never let it be said that a Ketogenic Diet is unpalatable or unappetising!



**We love our FB forum and the fantastic group of people that are on there. We have members that are on medically managed diets from all over the world which enriches our group tremendously as we all learn from one another.**

The message below came in from the very lovely Tebatso in South Africa. She is an adult following the Ketogenic Diet for her epilepsy and is a regular on our Monday night Zoom Virtual 'Cuppa and Chat' sessions. We would also like to thank the wonderful group of medical professionals that make guest appearances and help to support our families, so far we have welcomed Professors Helen Cross, Eric Kossoff, Joerg Klepper and Associate Professor Mackenzie Cervenka as well as other members of our medical board including our Dietitian Sue Wood and Epilepsy Nurse Lisa O'Brien, with more planned for the future.



Tebatso said...."I want to send this shout out to you my Matthews's Friends family..."

A few weeks ago when we started the Virtual Cuppa chats, they were a way to connect during lockdown ...and of course get invaluable information from the different professionals..! In my humble

opinion these sessions have become a lot more! They have become a safe place to meet with people that are travelling a similar journey that I'm travelling...people that get 'it'!

Now 'it' can be a lot of things... can be exchanging recipes about Brussel sprouts for breakfast, laughing & giggling about the many escapades we've encountered along this incredible journey! 'It' can be encouraging a fellow forum member/parent who is feeling anxious on that day or who has had a rough time for whatever reason. Whatever 'it' is, I'm grateful there is a family that one can holler to through the airwaves or 'meet' virtually every Monday!!

Monday's will never be the same again! So thank you fam...I just wanted to let you know that you rock!!

And to the team taking the time & making the effort to organize everything & keep things moving...thank you.. thank you!!"

Apply to join our forum here [www.matthewsfriends.org/ketotraining-family-access/](http://www.matthewsfriends.org/ketotraining-family-access/) and find us on Facebook here [www.facebook.com/groups/MFKetoForum](https://www.facebook.com/groups/MFKetoForum)



**MEDICAL KETOGENIC DIET  
PATIENTS AND FAMILIES**



**WE ARE HERE TO SUPPORT YOU, WHENEVER YOU NEED US.**

**@MATTHEWSFRIENDS ENQ@MATTHEWSFRIENDS.ORG**

**JOIN OUR FACEBOOK PRIVATE FORUM**



# Fundraising for Matthew's Friends

COVID-19 has hit our charity hard, like so many others. We are so grateful in these difficult times for the kind support and generosity of you all. Please like and follow us on [Facebook](#) **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](mailto:enq@matthewsfriends.org)

## Run for Matthew's Friends in 2021!

If, like many of us, you have gained a bit extra during lock down and are looking for ways to step up your fitness and get out and about a bit more how about a challenge?!

We have a space available for the Royal Parks Half Marathon which is now on 11th April 2021

It is a spectacular Half Marathon in central London – the first and only one of its kind. The stunning 13.1-mile route takes in the capital's world-famous landmarks on closed roads, and four of London's eight Royal Parks – Hyde Park, The Green Park, St James's Park and Kensington Gardens.



In addition to that, we have been lucky enough to be granted a place in The Virgin Money London Marathon 2021 which is now being held on 03 October 2021.

As we are sure you are aware, the Covid pandemic has made it extremely difficult for small charities such as ourselves to fundraise, so if you would like to help us by taking part in either of these iconic events, to raise much needed funds, please email in to us on [enq@matthewsfriends.org](mailto:enq@matthewsfriends.org) and tell us a bit about yourself.



**CONTRIBUTE. SUPPORT. SUSTAIN.**

**DONATE MONTHLY**

MEDICAL KETOGENIC DIETARY THERAPIES

[WWW.JUSTGIVING.COM/MATTHEWSFRIENDS](http://WWW.JUSTGIVING.COM/MATTHEWSFRIENDS)

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**Please remember to use easyfundraising every time you shop online!**

Over 4,000 shops and sites will donate, so you can raise FREE donations for us no matter what you're buying. These donations really help us out, so please sign up if you haven't yet.

It's easy and FREE! You can get started at [www.easyfundraising.org.uk/causes/matthewsfriends/?utm\\_campaign=raise-more&utm\\_content=en-n2](http://www.easyfundraising.org.uk/causes/matthewsfriends/?utm_campaign=raise-more&utm_content=en-n2)

**Raise FREE donations for us every time you shop online.**

Over **4,000** shops and sites will donate!



## East Surrey District Scouts Donation!

Thank you to Rob Holyoake and the East Surrey District Scouts for the kind donation of £36.02 from their St. George's Day parade.

Your support is very much appreciated.



## BIG THANK YOU TO GRACIE FOR SELLING RAINBOWS!

**We received a lovely photo and the following message from her mum which said**

"Hi, I have just donated £100 to your charity on behalf of a young lady who you are helping and supporting .. her mum is a colleague of mine and praises your amazing work ... my daughter who is 11 raised this money throughout the pandemic by making and selling rainbows , doing raffles etc .. her name is Gracie.

The Rainbow symbol has always been very close to our hearts as you can tell from our own logo and to receive this message, donation and the lovely photo was a lovely surprise for us in the office. WELL DONE Gracie and thank you for thinking of us.

### Rainbows help raise NHS funds



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 2020 and beyond, thank you.