KETOGENIC THERAPIES

ONLINE | SUMMER NEWSLETTER 2023 | EDITION NO. 21

Ketagenic Dietary Therapies

Ketogenic Dietary Therapies
Information • Training • Research • Support

Registered Charity No. 1108016

MATTHEWSFRIENDS.ORG



Ketogenic Dietary Therapies
Information • Training • Research • Support

KETO EDUCATION DAY



PROF J. HELEN CROSS OBE



JEN CARROLL RD



TRACY CAMERON RD



DR ANITA DEVLIN



EMMA
WILLIAMS MBE

The Matthew's Friends Keto Education Day in-person meeting took place 25th May and what a great day it was!

The agenda covered Ketogenic Diets for children and adults; preparing families and patients for Keto; the different types of Ketogenic Diet & supplementations needed; side effects, monitoring and weaning the diet, with plenty of time for Q&A's and visiting the exhibitor stands!

See inside for more from the day...

Matthew's Friends KetoCollege

The first KetoCollege Advance meeting took place 23/24th May, for health professionals supporting families on medical Ketogenic Therapies.

A truly international meeting!

See inside for more from the event.



SPECIAL FEATURES INSIDE:

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GOING ON HOLIDAY - ON KETO! - PAGE 10



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AND MUCH MORE!





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CONTACT US

NEWSLETTER ARTICLES:

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- www.ketocollege.co.uk







MatthewsFriendsOrg #ketokitchen

CLICK HERE TO HELP FUNDRAISE FOR MATTHEW'S FRIENDS ⊕

Matthew's Friends are proud to be founding patrons of the International Neurological Ketogenic Society (INKS) together with our sister organisation in the USA, The Charlie Foundation. This society is bringing Ketogenic experts together from all over the world.







Medical Ketogenic Diet Support Forum



Matthew's Friends Supporting Patients and Families

ONLINE INTRODUCTORY & INFORMATION FILMS

At your leisure, view films made by the Matthew's Friends Team led by the Chair of our medical board, Professor Helen Cross OBE.

Topics include:

- History of the diet
- Different types of diet available
- The need for medical management
- Side Effects of the diet
- Recipe and ingredient demonstrations
- Family Stories

CLICK TO VIEW FILM ③





FACEBOOK FAMILY SUPPORT FORUM

Once you or your loved one is on a medically supervised ketogenic dietary therapy, you can gain access to our Facebook support forum by filling out the request form and sending it to us. You will then be invited to join the forum and get to know other families in the same situation as yourself, where you can discuss any problems or concerns you may have or share your successes, recipes and handy hints and tips that makes things work for you.

This is a safe and confidential forum which is moderated by the Matthew's Friends team of past and present Ketogenic Ambassadors and Regional Co-ordinators all of whom have a wealth of experience. Our Ketochefs will also be on hand to answer any food questions for you and from time to time we will have guest professionals join us for specific question and answer sessions on topics that YOU want addressed.

Click the button below for access to the films and the Facebook support forum.

CLICK FOR ACCESS



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

CONSIDER A MEDICAL KETOGENIC **DIETARY THERAPY**

Contact Matthew's Friends at eng@matthewsfriends.org for an information pack. www.matthewsfriends.org

PURPLE DAY SUPPORT FROM ACROSS THE COUNTRY!

ON PURPLE DAY THIS YEAR OUR FRIENDS AT VITAFLO REALLY **GOT INTO THE SPIRIT OF THINGS.**

To mark the occasion and raise funds and awareness of epilepsy, the Global Vitaflo teams wore purple and had a great time holding a bake sale, pool competition, sponsored purple hair dye and guess the number of purple sweets game. £300 was donated to Matthew's Friends for which we are very grateful. Thank you to all at Vitaflo for your continued support!











LAURA'S GARAGE SALE IN WALES

On Purple Day, Laura Retallick held a garage sale in Presteigne, Wales. She had a stall with cakes together with information on Purple Day and epilepsy. Even though the weather was rainy Laura still raised £40 for Matthew's Friends as well as awareness!

Many thanks Laura – your help is very much appreciated!!



THE BARBERRY BIRMINGHAM AND **SOLIHULL MENTAL HEALTH NHS**

Thank you so much to Jude Munn, Siobhan Keogh, Wendy Rudge and the whole amazing ketogenic team at The Barberry Birmingham and Solihull Mental Health NHS, who manned a Purple Day stand to raise awareness around epilepsy, Matthew's Friends and ketogenic dietary treatments.

They reported that 'the event was a great opportunity to speak to people about the diet, Jude baked some keto cakes for people to sample' and raised £100 for Matthew's Friends selling samosas and cakes!

Just brilliant – we are very grateful to you all for supporting Matthew's Friends and spreading knowledge of ketogenic dietary therapies for epilepsy.







23RD & 24TH MAY 2023

CROWNE PLAZA FELBRIDGE HOTEL • EAST GRINSTEAD • WEST SUSSEX







Following on from the huge successes of our previous KetoCollege Training Meetings, both in person and online, this year saw us launch the first KetoCollege Advance.

We welcomed over 100 delegates from 17 different countries to the Crowne Plaza Hotel, Felbridge in West Sussex for 2 days of practical, in-depth presentations for those currently in ketogenic practice, or those who had already completed the KetoCollege eLearning modules or attended KetoCollege previously and wished to enhance their knowledge.

This meeting covered various topics such as Infants and Neonates. Transition and Adult management, Biochemistry and Dietary management as well as covering Tube feeding, Blended diets, and Parenteral feeds to name but a few.

pictured with Dr. Elizabeth Neal RD from the

Neurologists and Dietitians presented alongside one another to give a 'team' overview of how to manage some of these highly specialised areas. Delegates were also able to submit their own 'most challenging case study' and discuss this with the group and with the expert mentors.

This meeting was led by our Medical Board Chair, Professor Helen Cross OBE, Prince of Wales's Chair of Childhood Epilepsy and Director of **UCL-Great Ormond Street Institute** of Child Health, together with a team of highly experienced international mentors. As always, an abundance of Ketogenic food samples and low-carb lunches were available throughout the meeting and Exhibition stands provided demonstrations and information to the delegates.

Thank you to our expert mentors who take time out of their busy clinics to support this educational meeting.

With our introductory KetoCollege course now available via our eLearning

Matthew's Friends Keto College E-LEARNING **NEW FROM KETO COLLEGE** Six Accessible eLearning

Refresher Learning For health professionals new to Ketogenic
Therapies

O CPD Accredited

Expert Mentors Therapies
Discounts for Low-Income **MODULES INCLUDE:** Introduction to Ketogenic
 4. Modified Ketogenic Diet Therapy Supplementation and Emergency Situations Preparing a Family for Ketogenic Diet Therapy 3. MCT Ketogenic Diet Workshop VISIT WWW.KETO.COLLEGE.CO.UK

platform (www.ketocollege.co.uk) so that high quality, non-biased training is available throughout the year.

KetoCollege Advance will now take place annually to discuss the hot ketogenic topics, case studies and future uses as research into ketogenic dietary therapies continues to be pioneered.

inthank you for an amazing Keto Advance! You and your team should be so proud of... what you have created.

Matthews Friends provide the structure and space to network, collaborate with a highly specialist and inspiring network of paediatric and adult neurologists, dietitians, dietetic support workers, patients and families partnering with nutrition companies and charities to innovate and meet the needs of our patients."





THURSDAY 25TH MAY 2023

CROWNE PLAZA FELBRIDGE HOTEL • EAST GRINSTEAD • WEST SUSSEX

After 2 days of very intensive presentations at KetoCollege Advance, it was time for the Matthew's Friends charity to welcome families, patients and other allied health professionals, teachers, and support workers for our Keto Education Day.

Again, led by our Medical Board Chair Professor Helen Cross OBE, presentations took place giving an overview of the diet from infant to adult. A perfect way to find out everything about keto as well as sampling the delights on offer from our Keto Chefs.

Question and Answer time was as lively as ever and new friends were made.

Grateful thanks go to our wonderful Medical Board mentors, promotional supporters and charity exhibitor.



David and family with Val Aldridge.

Look out for conference video insights & interviews on Matthew's Friends social media channels

COMING SOON!



Matthew's Friends



MatthewsFriends



MatthewsFriendsKetogenic



MatthewsFriendsOrg #ketokitchen



"Thanks very much for a well organised & useful educational event!"

"Today has been absolutely wonderful, especially the sausage rolls! The information has been so helpful as we are new to the ketogenic diet"

"A really useful, informative day"



Lovely bites at the Vitaflo stand.





JOIN INKS TODAY

Visit the International Neurological Ketogenic Society (INKS) website www.neuroketo.org for more information on this exciting new society, including exclusive registration discounts for INKS members for the 2023 8th Global Symposium, San Diego.

Scan the QR code to directly access the Membership application form.





REGISTRATION IS NOW OPEN

8TH GLOBAL SYMPOSIUM ON KETOGENIC THERAPIES

About The Event

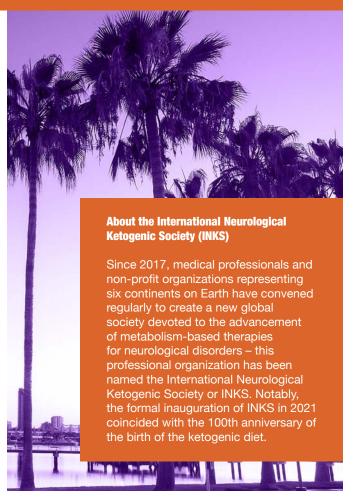
The September 2023 Symposium in San Diego, California will be the first organized by the INKS leadership, and will include many relevant and timely topics - including but not limited to:

- INKS membership and initiatives
- The biochemical interplay between glycolysis and fatty acid oxidation
- Clinical advances and treatment protocols
- Emerging applications of metabolism-based therapies
- The science and practice of flavor perception
- Precision nutrition approaches
- Benefits of dietary and metabolic approaches on overall brain and mental health

Discounted rates will be available at the Loews Coronado before, during, and after the Symposium to make the most of your trip to San Diego. More information coming soon!

WWW.GLOBALKETO.COM

#GLOBALKETO2023









IN PARTNERSHIP WITH











RARE EPILEPSY DAY



Teresa & Val attended the 'Better understanding the Rare Epilepsies' Day held in the Neville centre at YE, where Matthew's Friends offices are based. Our travel arrangements that day could not have been easier! The morning sessions involved Professor Helen Cross and Dr Amy McTague covering the concept of rare disease and the difficulties faced researching rare diseases, where patient numbers are low.

Allison Watson (Co - founder of Ring Chromosome 20 syndrome Research & Support UK) gave an overview about an organisation called 'UK Rare Epilepsies Together Network' (RET) R.E.T aim to bring rare epilepsy charities together to broaden their scope for research, finding collective initiatives to improve the impact on the lives of those with rare epilepsy syndromes. Matthew's Friends is a member charity of R.E.T. The rare epilepsies are often those with difficult to control seizures. Ketogenic Dietary Treatment (KDT) is certainly an area that can be helpful where medication has been ineffective. Elements of how KDT works is an area that we hope could lead to increasing knowledge to enhance treatments in the future!



Group photo YE Rare Epilepsy.

During the breaks delegates were treated to a glimpse of the new MEG scan equipment. Amazing technology (see link below) It would not be out of place in an episode of Star Trek and yet it felt far less scary than I expected. Even toys had been made specially to make having a scan a child friendly experience!

View here: www.youngepilepsy.org.uk/opm-meg

Delegates also had plenty of opportunity to visit the exhibitor stands, including ours!

Stephanie Prince representing curechd2.org gave a very powerful presentation, both she and her husband are doctors, Stephanie works in Oncology, but she spoke as a parent. Her daughter (eldest of 3 children) was diagnosed in January 2021, aged 4 (after presenting with myoclonic seizures) with CHD 2 pathological variant. Stephanie gave a very raw account of dealing with battles every step of the way to gain access to practical help.



So many themes again common to all the rare epilepsies came up, access to speech therapy, education, physio, OT and strategies to deal with behaviour, sibling support.

GLUT 1 DS was represented by Stefanie Watson and her son Adam 19. Both gave an account of life with GLUT1 DS. Their positive attitude shone through, not an easy road, but very much focused on what Adam CAN do and how it is that because of Stefanie's persistence and insistence that something was wrong, that he was diagnosed and then able to access KDT and become such an accomplished young man.

These presentations pre-empted much discussion around support. Early support and then into transition to adult services... Both huge areas where much work is needed!

The day ended with presentations from Lisa O'Brien and Kirsten McHale, both epilepsy specialist nurses (ESN) based at Young Epilepsy. They explained their role as not only in education/care but also in signposting their patients to the different services/resources available.

An example of local resources to Lingfield was represented by a London charity, HOPE, hopeforepilepsylondon.org.uk they offer a wide range of help to families. Your local ESN, if you are lucky enough to have one, will be a link to these types of resources local to you. Delegates came from local health services, interested in developing not only their knowledge around the rare epilepsies and the struggles that families face but also by visiting the exhibitor stands they were able to find out about available support and resources for families. They also had Professor Cross and Lisa O'Brien available to answer any questions & discuss any concerns they may have in dealing with rare epilepsy cases throughout the day!

AMBASSADOR FOR EPILEPSY

STÉPHANE AUVIN, MD, PHD, FAES

PROFESSOR (EPILEPSY & CHILD NEUROLOGY) AT UNIVERSITÉ DE PARIS & ROBERT-DEBRÉ UNIVERSITY HOSPITAL IN PARIS

"I am really honoured to be among the 13 people who will receive the "Ambassador for Epilepsy" award class of 2023. This award is given jointly by the ILAE (International League Against Epilepsy) and the IBE (International Bureau for Epilepsy).

In addition to the recognition by my peers of the ILAE and the French epilepsy chapter, I am very touched by the fact that this distinction also comes from patient associations. I am very grateful to the executive boards of both the ILAE and the IBE.

The name of the award 'Ambassador for Epilepsy' obliges me to continue my activities and to move forward, but all this would not be possible without a great team that surrounds me in the Pediatric Neurology department of the Robert-Debré University Hospital in Paris and at the Université Paris-Cité."

The official award ceremony will take place during the International Epilepsy Congress in Dublin in September 2023.

The 'Ambassador for Epilepsy' awards are given every 2 years during the International Epilepsy Congress to 12 personalities (caregivers, researchers or members of patient associations).



Nominations are submitted by the national chapters, patient associations or member of the executives committee. A selection is done by vote by the executive board of the ILAE (International League Against Epilepsy) and the executive board of the IBE (International Bureau for Epilepsy).

The team at Matthew's Friends extend their warmest congratulations to Professor Auvin, whom we have had the pleasure of working with for many years through Glut1DS community support, various ketogenic diet projects, Global Symposia organisation and more recently, the formation of the International Neurological Ketogenic Society (INKS). Professor Auvin is a true Ambassador for Epilepsy, and this award is richly deserved.





Following KDT is something that is managed easier with preplanning. Travelling and going on holiday take that planning to another level!

It may be a good idea to start by staying somewhere in UK with family/friends for a few days, before planning a bigger trip to build your confidence. Even when you feel happy to go further afield, it's great to have supportive family/friends alongside!

SEIZURE TRIGGERS

Aside from KDT think about triggers for seizures that may be accentuated around travel. You cannot always manage everything but being aware helps with preplanning!

Constipation – A change in foods/water/routine may cause constipation. Even if constipation is not usually a problem it would be a good idea to talk to your team. Possibly take some 'just in case' laxative option with you.

DOWNLOAD INFO SHEET

Dehydration - Particularly in hot climates, extra fluids will be essential.

Excitement/anxiety – Some children do better when they are told about a holiday nearer the time as it gives less time for the excitement to build up. For others, it's the opposite to allow time for processing, otherwise anxiety can be a problem. For some, emotional stress/excitement may mean extra calories are needed to cope with the drain on energy requirements.

Illness – Beyond taking an adequate supply of your regular and emergency prescription medications, it's worth packing your normal over-the-counter remedies too as you may find sugar free versions hard to find or labels may prove confusing if in a different language! Best to cover the basics for pain relief (e.g. sugar free paracetamol), tummy bugs (e.g. Dioralyte sachets, probiotics) and hay fever/allergy if this is an issue.

In case you are flying - How to Take Prescription Drugs through Airport Security (tripsavvy.com)



CLICK HERE TO VIEW WEBSITE →

Travel sickness - be it car/air/ sea can really ruin your journey or outing and upset your planned keto meals, so maybe ask your pharmacist about tablets, or if you prefer try Sea Bands.



Tiredness – Think about the journey. Will it mean an early start? Will there be time to rest? Is there a time difference? Can you stop over somewhere or would a direct journey work better?

Temperature - Is your destination going to mean a big temperature change? Will you need to arrange for heating or air conditioning. Hand fans, cool water sprays and neck coolers may be helpful.

Written by Val Aldridge, **Ketogenic Family Support.**

OF COURSE, IF CONCERNED ALWAYS GET MEDICAL ADVICE!

AVOID SUNBURN/SUNSTROKE

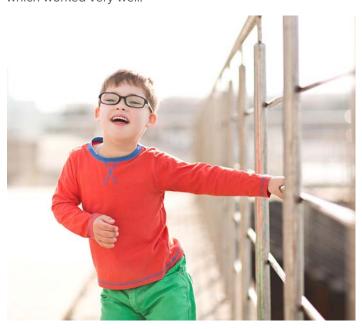
Suncream - There are many all-day suncreams available nowadays. When Greg was on KDT, Ultrasun was the only one I knew of, and it certainly worked well for us. I can't be the only parent who battles to get the sun cream on?! We had a rule that the suncream went on or we couldn't go out and once done it really did last all day, even with going in and out of the water.

It is sometimes said that suncream can cause a drop in ketosis. Our medical board have assured us that suncream is not likely to be the problem, much more likely that heat/dehydration are the culprits. Of course, our very special children do have a habit of reacting to products when they aren't supposed to! Keeping covered up and in the shade or indoors when the sun is at its strongest may then be the best option. It may also be worth trying a suncream at home on a small area of skin, to check for hypersensitivity.



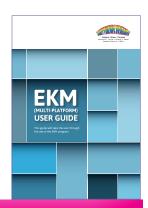
Hats - Another battle in our house! Superglue required! I was pleased recently to help my niece out by buying her son a Titanic captain's hat (he is Titanic mad) he wouldn't take it off for the whole holiday!

Activity Levels - Speak with your team before you go. Think about the holiday activities. For example, Greg went on a skiing trip with school, although he was a pretty active boy, we felt that he would likely need more calories on the days that he skied so we added in an extra snack option which worked very well.



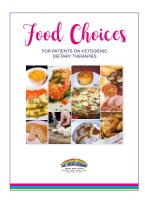
WHAT ELSE TO TAKE:

- A letter from your medical team outlining your/your child/dependant's condition with contact details.
- Copies of your prescriptions both medications and dietary
- · Your meal planner. There are now many available, so go with whatever you are most comfortable. The Electronic Ketogenic manager (EKM) does have the advantage of not needing internet connection which may be important if you plan to 'go bush'!



CLICK HERE TO VIEW WEBSITE →

- Exchange/food choice sheets. If it is easier to use exchange/ food choice sheets when you are out and about then make sure you have some spare copies with you.
- Scales + spare batteries.
- · Basic easy recipes you know work, are enjoyed and will travel well, like Mo's bread rolls or sausage rolls.



- All in one shakes/muffins/Keto meal replacements for any delays or to fall back on should something go wrong.
- If possible/practical batch up meals before you go to take
- Prescription feed /plastics and spares for any tube feeding equipment.
- Check with your feed delivery companies as they may be able to deliver to your holiday destination in the UK particularly if you're staying there for a few weeks.
- Fats/oils! Take any foods that may be helpful to add fat to meals whilst eating out.





Written by Val Aldridge, Ketogenic Family Support.

CHOOSING A DESTINATION

When choosing a destination, find out as much as you can about the area before you go.

Obviously 'curly' behaviour is not a problem for all but when it is, it can be a big factor in choice of destination and accommodation. Think about having space for time-out for everyone. My family always went to the same place for our holiday, so it became routine causing less anxiety.

Self-catering or staying with supportive family/friends may be easiest, but you will need to know what cooking and storage facilities are available. Look up where the nearest supermarkets are and local restaurants. Look at the restaurant menus online before you go if possible, so that you can pick out appropriate meals ahead and avoid the stress of realising its not so keto friendly.

If staying in a hotel, a fridge or some dedicated space in the kitchen fridge (label your food clearly), will make life a lot easier. Contact the hotel before you go or if booking via an agent, get them to liaise with the hotel. Chefs can be very interested and helpful!





READ THIS ARTICLE IN OUR SUMMER 2019 NEWSLETTER A simple letter from your dietitian to the hotel may be helpful too. Example (MKD) below (thank you Sue Wood).

Jen is on a special diet to treat a medical condition. The diet is called The Ketogenic Diet and it is key that her meals are low in carbohydrate (e.g. very limited intake of sweet / starchy foods) and include generous amounts of fat. The diet also includes protein-based foods to appetite.

The ketogenic diet can make it difficult to choose directly from restaurant menus as there is often insufficient information about how the item has been cooked or what additional ingredients may be present. Therefore, Jen will need to ask questions about the food on the menu and may need items to be cooked and served more simply in separate bowls (vegetables / fruits etc) so that she can then weigh the appropriate portion onto her plate (she will have her own set of gram scales). She may even need to bring some special food items of her own. We ask you to please help by understanding that this is not her being exceedingly awkward but an essential part of this recognised medical treatment!

Meal ideas (W = she would need to measure)

MEAL	FOOD TYPE	PREP NOTES
Breakfast	Bacon, egg, tomatoes (W), mushrooms, baked beans (W), sausage (W), kippers, butter	Notes: If possible all fried in oil / butter. Carbohydrate content of sausage (per sausage) would be useful.
Lunches/ Dinners	Any meats/ fish / shellfish / eggs Vegetables (W) + / salads (W) fruit (W) e.g. strawberries, blueberries, raspberries + double cream (W)	Plain cooked + butter / oil (Please check addition of herbs spices with Jen). Plain cooked + serve separately so can be measured. Please provide butter / full fat mayonnaise in addition). Serve fruit separately to double cream so can be weighed



Written by Val Aldridge, Ketogenic Family Support.

TRAVELLING WITH FOOD

One of the hardest things when travelling with food is keeping it cold. So much of KDT food needs refrigeration!

The last thing you need is to end up with food poisoning, so think about the best way to keep things cool.

LINK TO ARTICLE: HOW TO TRANSPORT FOOD SAFELY | BBC GOOD FOOD (-)

Maybe take the fridge with you. Plug in cool boxes are great for long car journey's - Best Electric Cool Boxes UK Comparison - April 2023.

LINK TO TOPCHOICE.CO.UK →

Consider using dry ice to keep food frozen for long car/ coach journeys. When Greg went on his skiing trip the coach journey was 24 hours. I batched all the meals, froze them and then added dry ice to keep them frozen. There are safety rules around using dry ice so it's worth contacting the suppliers to get things right for your journey!

LINK TO BUYDRYICE.CO.UK **⊙**

It's also important to find containers to suit your journey. I was able to use foil containers for the ski trip, writing on top the name of the meal and if anything needed adding, usually mayonnaise for Greg! Liquids definitely need to be in leak proof containers!

LINK TO ARTICLE: BEST FOOD STORAGE **CONTAINERS 2023 | BBC GOOD FOOD ⊙**





EATING ON THE JOURNEY

You may feel happiest packing your own meals for the journey, just like making a school/work packed lunch.

To avoid leaks and spills aim for either carton products like KetoCal, KetoVie, K.Yo, or dry fats contained in foods, for example Mo's keto rolls or sausage rolls, keto muffins, low carbohydrate breads with plenty of butter and cheese/ mayonnaise etc.

- Hide Calogen/Liquigen/cream in sugar free jelly.
- Cooked sausages, hard boiled eggs, nuts, olives, bacon strips, avocado, pork scratchings/crunch may also be useful.
- If you are stopping off on road or by rail, look out for Marks & Spencer 'Simply Food' outlets as they have simple keto-friendly snack options as mentioned above, along with ready-made salads like Greek or Caesar that may suit you. They also supply napkins and wooden cutlery to take away.
- If you plan to stop at a pub/restaurant on the way, check their menu online before you set off. You can quickly see if it's the right option. Nothing worse than arriving hungry to find there is nothing suitable! If you do find yourself unprepared go for a protein and fat meal.
- Plain fish or meat (no coating or batter).
- Cheese and eggs (omelette is a good option and most places can rustle up an omelette!).
- Add butter and/or oil to the meal.
- Look for low carb veggies...Salad leaves/cucumber and/ or mushrooms.



Written by Val Aldridge, Ketogenic Family Support.

DISCUSS A POSSIBLE EMERGENCY PLAN WITH YOUR DIETITIAN BEFORE YOU TRAVEL.

TRAVELLING FURTHER AFIELD

If you are planning to stay outside the UK research food availability in the area, especially supermarkets. Will the foods adapt well to KDT? Think about what foods you may need to take with you from home.

Ask other keto families on the forum, someone may have already visited the country you are going to!

- · Make sure you take your meal planner with you. Food values can differ in countries – YOU MUST READ LABELS and enter them in your meal planner to get correct values.
- Food labelling is the same in the UK, Europe, Australia and New Zealand. USA food labelling is different.

UK/EUROPE/AUSTRALIA	USA
All products labelled per 100g	Products labelled per portion size
Example:	Example:
Label per 100g contains 50g CHO	Label - 30g portion contains 3g CHO
100 divided by 50 = 2	3 divided by 30 x 100 = $10g$
2g product = 1g CHO	10g CHO per 100g product 10g product = 1g CHO

Net carbohydrate is the amount of carbohydrate once fibre has been removed.

UK/EUROPE/AUSTRALIA FIBRE	USA FIBRE
Always use figure for total carbohydrate Fibre has already been taken off	Fibre is included in the total CHO. Fibre is not absorbed and therefore will need to be subtracted from the total CHO amount.

TRAVELLING BY AIR

Check out the airport restaurants re keto friendly food online, if you can eat at the airport that saves an extra meal to bring with you! You will usually find somewhere open doing 'all day breakfast' fry ups! Check opening times!

Carrying food in your hand luggage may attract 'sniffer dog' attention. I remember looking down to see a dog sniffing Greg's cooler bag, when I automatically stretched my hand out to stroke the dog I was told very sternly 'Don't touch the dog' That was one time I was very glad I had my letter of explanation!

- Check country information to see if you can take any food/prescription foods through customs.
- USA/Australia are particularly strict with this.
- Advise your airline accordingly, before you get to the airport. Especially if taking liquid supplements with you or you may have to open them all!
- You can also request priority boarding if queuing is problematic.
- Request to take a cool box on the flight, remember though that ice bricks contain fluid so they must be declared, but should be allowed as the food/ products are your medication!
- Check re allergens like nuts/sesame etc.
- Weigh liquids and meals pre-journey, it's not easy on a 'wobbly' flight table!
- Get your keto team to supply a letter for the flight (see example below) including contact details.

John is on a medically prescribed ketogenic diet to treat his epilepsy.

Each meal is made to his individual dietary prescription, with all fat, carbohydrate and protein needing to be weighed.

John will be unable to eat the foods supplied. It is therefore necessary for all meals to be brought with him for the flight, together with a few meal items for the first couple of days away. He also needs to take special prescription products or foods difficult to obtain whilst away.

Some will be liquids including medications:

- Buccal midazolam
- KetoCal liquid
- Liquigen
- Calogen
- Sweetener

Please help by allowing extra baggage allowance for the products and extra cabin allowance for a cool bag (with cool bricks) containing meals and products for the journey.

John also needs regular blood monitoring to test ketone and glucose levels; this involves a finger prick test (much like diabetic tests). Please allow that the monitoring kit includes small sharps for testing.

Thank you for your support in John's treatment.

Now you have your lorry loaded....Happy holidays!!!

It would be great to add information on our website about your experience of holidays/trips out/restaurants, tips about local foods, good places to eat out!

Email us at ketokitchen@matthewsfriends.org

ENABLED ADULTS CLUB

Introducing Enabled Adults Club - a labour of love that's close to my heart. My name is Ben, and my older brother Aaron has been disabled since birth.

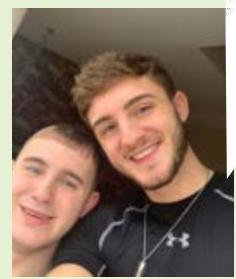
Growing up together, I realised that as Aaron got older, the opportunities for him seemed to diminish. When I turned 18, I had a world of possibilities ahead of me, but I couldn't say the same for Aaron.

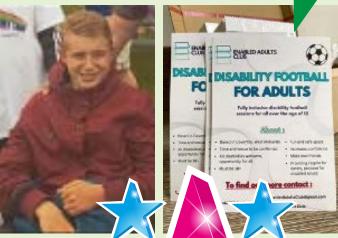
Seeing the struggles my parents faced as caregivers, especially after Aaron finished school, broke my heart. They had to shoulder immense stress while providing round-the-clock care, and it was even harder with funding cuts from the government. I knew I had to do something to help both disabled adults like Aaron and their incredible caregivers.

That's why I started Enabled Adults Club. Our mission is to provide more opportunities for disabled adults who often feel left out, while also giving caregivers the well-deserved respite they need. We currently run football sessions because I know there aren't many places where disabled adults can come together and enjoy the world's best sport. Plus, Aaron is absolutely obsessed with it!

I'm determined to make a positive impact in the lives of disabled adults and their families, and I invite you to join us on this journey. Let's create a community where everyone feels valued, included, and supported. Thank you for your ongoing support as we continue to grow and expand our offerings. Together, we can make a difference!

 $\mathfrak L$ 1 from every person who attends each session (when up and running) will be donated to Matthews Friends x





MATTHEW'S FRIENDS:

"When Andrea let us know about Ben's amazing plans, we were blown away. Aaron & his family have been a part of our Keto-family community for many years as Aaron has Glut1 Deficiency Syndrome, which requires him to follow a life-long ketogenic diet. Thank you Ben – you are our Keto-Star!"





We have nominated the ketogenic diet team at the Birmingham and Solihull Mental Health Nhs Foundation Trust for a Keto-Star award!

They do an amazing job in supporting adults with drug-resistant epilepsy with medical ketogenic diets and raising awareness! THANK YOU!

If you know of anyone you think deserves the recognition of a KetoStar Award please do let us know by nominating them using our form.

DOWNLOAD OUR KETOSTAR NOMINATION FORM HERE (9)



CELEBRATING THE FIRST EVER CHARITY FUN(D)RAISING KAKEFEST!

As the saying goes "A picture paints a thousand words", and so here are several pictures taken during the recent Tonbridge Teafest, which was on Saturday 29th April 2023.















While the main reasons for Neil Bindemann, the organiser of TeaFest, was to raise awareness of, and funds for, the Lifestyle Health Foundation, Brainstrust and Matthew's Friends, an equally important objective, for him, was for people to enjoy a charity fundraiser, with cakes that were baked with next to no sugar... ie kakes. He wished to do this to showcase to other health-related charities, a possible alternative approach to running a cake sale using a lot less sugar.





And that, as the pictures help to show, was achieved, thanks to kakes supplied by Matthew's Friends, and those, baked by Neil and friends using Qetomix from his Ketobakery.co.uk (see our Qetomix Keto Recipes in this issue!), along with low carb snacks from the likes of Go Low Baking and Raw Gorilla. Teafest couldn't be a Teafest without Tea, so a big thank you also need to go to Kib Herbal Tea, Pukka Herbs and Nutratea.

The atmosphere during the morning, all around Tonbridge, helped by the glorious sunshine, was fabulous. A variety of music groups could be heard from various venues

around the town, thanks to the wonderful youngsters from the Tonbridge Scouts Band, who played outside Nancy's Tearooms, Café Society Jazz who were inside the Tonbridge Old Firestation, Saxonymous at Verdigris, overlooking the river, with Hilden Brass on the Riverwalk and Grenadillas inside the Tonbridge Parish Church.

The highlight of the day, just before the Sevenoaks and Tonbridge Concert Band performed their main concert in the afternoon, was the amazing Albert (Pip) Parson's, who is to be 100 years young in Nov, playing the drums with the Roarin 20s, and being presented with a gift from the Mayor of Tonbridge and Malling, Councillor Sue Bell.



The Sevenoaks and Tonbridge Concert Band ended a memorable day performing music by the Beatles music from popular musicals such as Mary Poppins.

We are delighted to announce that over £3500 has now been raised with over £2500 coming via Neil's Justgiving page.

VISIT NEIL'S JUSTGIVING PAGE HERE →

To purchase Qetomix visit www.ketobakery.co.uk for quick and simple keto baking

QETOMIX SPECIAL FEATURE

Following the recent wonderful Tonbridge TeaFest event, our Mo was inspired to create some of her most popular keto favourites, using Qetomix - a unique blend of just 4 ingredients - Golden flaxseed, almond flour, chia seeds & desiccated coconut.

Qetomix is available to purchase online at Ketobakery.co.uk, at a currently discounted price of £5.25/525g bag. Enjoy!



QETOMIX DAIRY FREE CHOCOLATE MINI LOAF

INGREDIENTS

- 40g Qetomix
- 42g Egg
- · 20g Plant butter FLORA
- 12g TRUVIA granules or your choice of granular sweetener

METHOD

- Pre heat oven to 180c / fan 160c / gas 5.
- · Lightly grease 2 mini loaf tins 8cm x 4 cm.
- · Mix the cocoa and vanilla extract with 2 teaspoons of hot water to make a paste.
- · Mix together the Qetomix and Barkat.

- · 4g Cocoa powder
- You will also need 1g BARKAT baking powder, and 1/4 teaspoon vanilla extract.
- Beat together the Flora plant butter with the Truvia granules until light and creamy.
- Gradually beat in the egg, then stir in the cocoa paste followed by the Qetomix.
- Mix well then divide between the mini loaf tins and cook for approximately 15 minutes.

EACH LOAF WILL HAVE: 16.26G FAT / 8.40G PROTEIN / 1.30G CHO **ALLERGENS: NUTS, EGG**

MKD 2.60G CHO TOTAL | 1.30 G CHO PER LOAF

CHO: 2.60G **FAT: 32.53G PROTEIN: 16.81G KCAL: 370**

VISIT MATTHEW'S FRIENDS #KetoKitchen YouTube channel

FOR KETOGENIC RECIPE DEMONSTRATIONS AND TUTORIALS!

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

QETOMIX BLUEBERRY MINI LOAF

INGREDIENTS

- 18g Qetomix
- 22g Egg
- · 23g Butter
- 2g Cornflour

- 7g Blueberries
- You will also need 1g BARKAT baking powder and 1-2teaspoons of liquid sweetener.

METHOD

- Pre heat oven to 180c / fan 160c / gas 5.
- · Soften the butter and mix in all the dry ingredients.
- · Add beaten egg and sweetener, beat until it thickens.
- · Place in a mini loaf tin, then push the blueberries into the top evenly.
- · Cook for 15 minutes.
- · Leave in the tin for a few minutes to absorb the fat.



PROTEIN: 7.79G

MO'S TIP

A little vanilla extract gives a nice flavour. They are easily batched up, just ensure you get the correct weight of blueberries into each

QETOMIX CHEESE BISCUITS

INGREDIENTS

- · 30g Qetomix
- 10g Egg
- 20g Butter
- 3g Parmesan cheese FRESH
- 10g Mature cheddar cheese -CATHEDRAL CITY
- · You will also need a pinch of salt.

METHOD

- Pre heat oven to 170c / fan 150c / gas 4.
- Finely grate the cheeses.
- · Melt the butter and stir in the Qetomix with a pinch of salt.
- · Add both cheeses and beaten egg, stir until it forms a soft dough.
- · Divide into equal portions and place on a lined baking tray, flatten to shape.
- Cook for approximately 12 minutes until crisp and golden.
- Leave to cool.

MKD 1.69G CHO TOTAL CHO: 1.69G **FAT: 30.78G PROTEIN: 13.02G KCAL: 336**

MO'S TIP

I made 12 mini biscuits, but you can make larger ones, they will take another 2 or 3 minutes to cook. They are nice served buttered or served with a dip.

> **VISIT MATTHEW'S FRIENDS KetoKitchen YouTube channe** FOR KETOGENIC RECIPE DEMONSTRATIONS AND TUTORIALS!

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

QETOMIX MINI SULTANA LOAF

INGREDIENTS

- 45g Qetomix
- 50g Egg
- · 30g Butter
- 13g TRUVIA granules or sweetener of your choice
- 7g Sultanas
- You will also need 2g BARKAT baking powder and a good pinch of cinnamon or mixed spice.

METHOD

- Pre heat oven to 180c / fan 160c / gas 5.
- · Chop the sultanas, this helps to give a better distribution.
- Lightly grease mini loaf tins, I used 8cm x 4cm and made 3 small loaves
- · Soften the butter then mix all the ingredients together.
- Divide equally between the mini
- · Cook for approximately 15 minutes.



FAT: 42.78G CHO: 7.33G **PROTEIN: 18.68G KCAL: 489**

MO'S TIP

I find using scissors easier to cut the sultanas into small pieces. I made 3 mini loaves, each giving: 14.25G FAT / 6.22G PROTEIN / 2.44G CHO

LOW CARB BAKING POWDER

As you are no doubt aware, there is currently a severe supply issue with Barkat baking powder; the preferred brand used by Mo in our online Keto Recipes and the brand we regularly provide to new Ketogenic Diet patients as part of our free Starter Packs (UK).

We know that many of you use this product, so we have been looking at alternatives.

Dr Oetker Gluten Free Baking powder is an option, at 19g of carb per 100g, a teaspoon in a recipe will add approx. 0.80g carb to an average recipe.

*Ingredient Declaration

Raising agents (E 450 (diphosphates), E 500 (sodium carbonates)), starch.

* Many of our products are made from natural resources, the composition of which may vary in some case of modifications teh attached mentioned information will not be updated automatically.

Nutrional Information	As sold per 100g
Energy	331 kj 78 kcal
Fat Of which saturates	0 g 0 g
Carbohydrates Of which sugars	19 g 0 g
Protien	0.1 g
Salt	45.7 g



Another option is to make up your own by mixing 2 parts of Cream of Tartar to 1 part Bicarbonate of Soda, both of which are carb free, then use as you would baking powder.

MO'S TIP

up. Sieving the two together would mix it well.

A CORE OUTCOME SET FOR CHILDREN WITH EPILEPSY TREATED WITH KDT

What outcomes are important to measure?



We are delighted to share that the Core **Outcomes for Refractory childhood Epilepsy treated with Ketogenic Diet** Therapy (CORE-KDT) project has recently concluded with the identification of a core set of 14 outcomes.

The project was led by Jen Carroll (ketogenic dietitian and PhD researcher) in collaboration with Dr Avril Collinson, Professor Mary Hickson (University of Plymouth), Professor Helen Cross (UCL Great Ormond Street Institute of Child Health) and Emma Williams and Val Aldridge (Matthew's Friends).

WHAT IS A CORE OUTCOME SET?

A core outcome set defines the minimum outcomes that should be consistently measured and reported in a particular health area. A core outcome set developed together with parents, health professionals and researchers would identify the most important clinically relevant outcomes to measure for childhood drug resistant epilepsy treated with KDT and ensure outcomes relevant to all are considered.

Parents were consulted during the early planning stages of CORE-KDT and invited to participate in each phase of the study to ensure that their views were considered.

KDT OUTCOMES

Ketogenic diet therapy (KDT) can result in both seizure and non-seizure related benefits for children with drug resistant epilepsy. Yet there was no consensus among health professionals, researchers and parents regarding the outcomes to be measured and reported in clinical trials or keto clinics. When we reviewed the outcomes measured in past studies, we found considerable variation and inconsistency in the outcomes, their definitions, and measurement approaches. Clinical outcomes like seizure control and adverse effects dominated, while functional and quality of life outcomes were rarely considered.

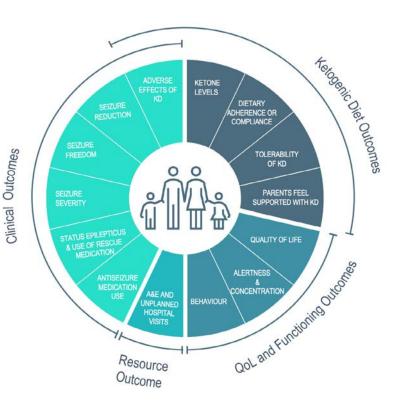
When we interviewed 21 parents to understand their view on outcomes and their families' experiences of KDT, it became clear that the outcomes traditionally used in research do not adequately reflect their priority outcomes. (read here). These issues hamper the evidence base in KDT, limit comparison between clinical studies, risk duplication of research efforts and exclude parents' perspectives.

THE CORE OUTCOME SET

We identified a long list of 77 outcomes and asked parents, health professionals and researchers to rate the importance of these in an online survey that was repeated twice. Participants were then invited to attend an online consensus meeting where undecided outcomes were discussed and voted upon and the core outcome set agreed.

Fig 1. Illustrates the first international consensus on outcomes for children with epilepsy treated with KDT. It has been developed encompassing the views of parents, health professionals, researchers, charity and industry representatives from 34 countries.

FIGURE 1: THE CORE OUTCOMES



The core outcome set includes commonly reported outcomes including seizure reduction, seizure freedom and quality of life in line with existing guidelines for children with epilepsy. With the inclusion of six physiological outcomes (four prioritised by interviewed parents) and three functional outcomes (all prioritised by interviewed parents), the core outcome set now better reflects the priorities of all stakeholders.

A CORE OUTCOME SET FOR CHILDREN WITH **EPILEPSY TREATED WITH KDT CONTINUED...**

Furthermore, three of the seven new outcomes identified during the parent interviews are represented: parental confidence with KDT, rescue medication use for status epilepticus, and seizure duration was merged with seizure severity. Read the full paper here.

FUTURE WORK

We have convened an international group of experts to review the appropriateness of existing tools to measure these outcomes. We may have to develop a bespoke tool which meets the needs of children using the KDT. Future work will also explore the potential to adapt the core outcome set for other settings where KDT is utilised, including paediatric metabolic disorders and adult drug resistant epilepsy.

Thank you!

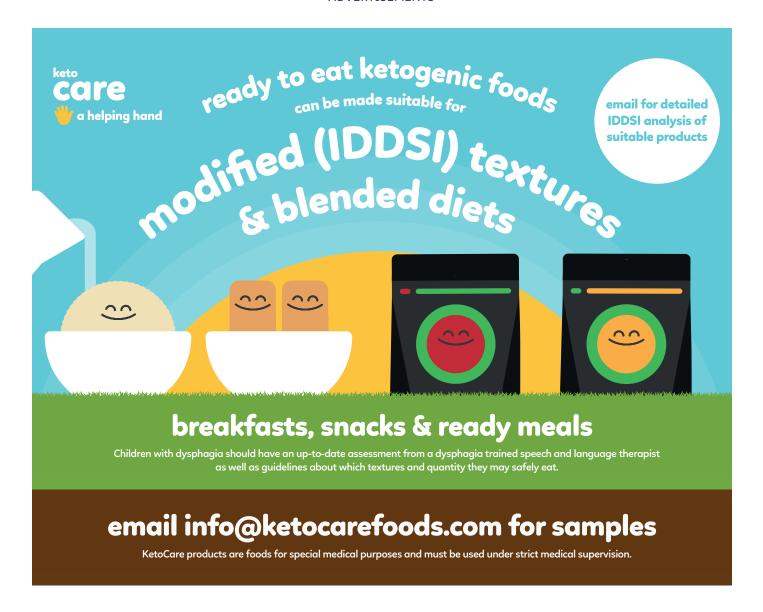
We are incredibly grateful to the parents and professionals who participated and shared their views in the interviews, online international Delphi survey and consensus meeting. We also wish to thank Matthew's Friends, Young Epilepsy, Epilepsy Action and participating keto centres for their support with recruitment to this project and our funders the University of Plymouth, the British Dietetic Association and Nutricia.

If you would like to find out more or to share any feedback please contact Jen at core-kdt@plymouth.ac.uk



Core Outcomes for Refractory Epilepsy with Ketogenic Diet Therapy

ADVERTISEMENTS



DID SOMEONE SAY PARTIES?

WRITTEN BY EMILY WHEATLEY -

Wow! What a few months it has been. We have had the Keto Food Festival, Easter AND we witnessed the Coronation of King Charles. Don't know about you all, but I am actually longing for some relaxation!

I was thrilled to kick-start the adventures with the Keto Festival, in Bristol, as it gave us an opportunity to taste test products Ella hadn't tried before, many of which we purchased whilst at the festival and again since which shows how incredible the emerging Keto market is in the UK. We also got to chat to the owners and representatives of the companies which led to some incredible support for the Matthews Friends community with some special discount codes for us to make use of, which definitely helps during the cost of living crisis.





The support from these companies, who will also be facing

some challenges with costs I'm sure, means a great deal and so if you're in the forum and try the foods, please do give them a shout out and a share to raise their profile. They deserve it!

Next up was Easter....

did someone sav CHOCOLATE?! I love making some chocolate treats for Ella but this year, I outsourced our Easter chocolate as Deliciously Guilt Free made some amazing eggs. The oozy insides made Ella smile from ear to ear and were well worth the purchase.



Last time I looked, they had created some other egg flavours to try so may be worth a taste test ahead of next Easter. Eggs all year round could catch on in our home. In fact, I'm sure Ella would insist upon it if asked!







The EPIC Coronation Tea Party was last on our list before I took a well earned rest from baking and we made use of the incredible white loaf from Heylo. If you haven't tried it, you're truly missing out. You could easily confuse it with the "real" thing! It was truly delightful offering Ella some finger sandwiches that looked the same as everyone else's.

These little things make the diet enjoyable for many of our children and indeed adults who are following strict ketogenic diets. The tea party also featured sausage rolls from Ketorona Bakery, which are again so so yummy, blue cream with red berries and a white meringue nest (Ella had the keto version from the recipes section of the Matthew's Friends website: **click here for Jubilee Meringues recipe**) and some union jack decorated biscuits to really embrace the theme!

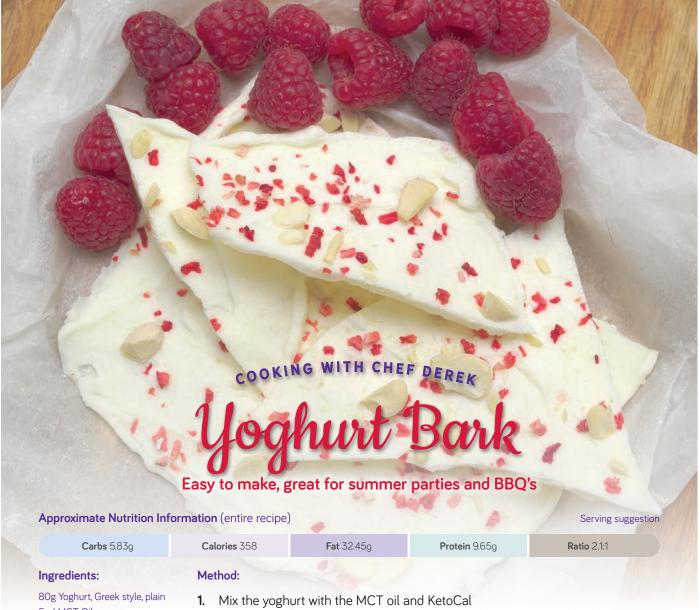
By the time this post is published, I will probably be back on the party train as we prepare to celebrate the birth of my nephew (auntie for the 4th time for me!), my birthday and then Ella will be a bridesmaid in August as my partner and I tie the knot! Phew. I'm tired out just thinking about it!



Time to get in the garden and soak up some vitamin D with my feet up whilst I get the chance!

Until next time,

One partied out Emily.



5ml MCT Oil 20g KetoCal 4:1 powder (Vanilla) 1g Morrisons Freeze Dried Raspberry Pieces (HCP added*) 10g Almonds, toasted

- 2. Line a baking tray with baking paper and spread over the yoghurt mixture so it is the thickness of a pound coin
- 3. Sprinkle over the chopped almonds and Freeze Dried Raspberries
- 4. Place in the freezer until fully frozen
- 5. Break into pieces



Connect on Instagram and keep up to date











These recipes are intended for patients who have been prescribed a Ketocal product by a healthcare professional, KetoCal is a Food 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.

Always consult your managing healthcare professional before making dietary changes.

Allergens may be present, please check individual product and ingredient labels. If concerned about allergens please contact your healthcare professional.



This recipe was created on MYKETOPLANNER:

The dietary planning tool that provides flexibility and variety for the ketogenic community. MyKetoPLanner.co.uk

Check meals on the go

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Daily meal plans

NEWS FROM MATTHEW'S FRIENDS NETHERLANDS-FLAUNDERS



Written by Dr. Elles van der Louw RD **President of Matthew's Friends Netherlands-Flaunders**



On Wednesday 30th April Matthew's Friends Netherlands-Flaunders organised a hybrid educational meeting for professionals in the ketogenic field. This was organised in close co-operation with Nutricia.

More than 400 people from 24 countries attended this meeting virtually and more than 40 people were live attending at the venue in Utrecht, the Netherlands to meet and greet with our foreign guests Prof Dr Jong Rho and prof dr Eric Kossoff and experience their lectures.



Prof Jong Rho



Prof Eric Kossoff

Prof Dr Jong Rho updated us about possible predicting models of Ketogenic diet therapy and Prof dr Eric Kossoff gave an overview of anti-epileptic drug use during KDT.





Dr Jong Rho, Dr Elles van der Louw and **Prof Eric Kossoff**



Prof Jong Rho speaking during the Q&A session

Lively discussions followed during Q & A session. During the second part of the meeting attendees present at the venue were invited to present cases from their clinical practice for discussion and advice from colleague experts and the invited speakers.

This educational meeting has delivered much food for thought and tastes for more!

Matthew's Friends Board - Netherlands-Flaunders

NEW BOOKLET FREELY AVAILAB

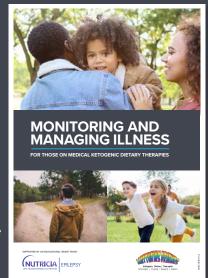
We are delighted to launch our new Family Monitoring and Managing Illness booklet. Written and approved by members of the Matthew's Friends medical board and international medical advisors and supported by an educational grant from Nutricia.

This booklet is aimed as general background recommendations and is broken down into three useful sections:

- Home Monitoring
- Managing illness at home whilst on a ketogenic dietary therapy.
- The Ketogenic diet in Hospital.

We hope to have these recommendations translated into various European languages in due course, with the English version being freely available to families and professionals alike now. If you would like copies for your clinic or you are a family of someone on the diet and would like a copy for yourselves, please email enq@matthewsfriends.org and we can arrange to get these sent out to you.

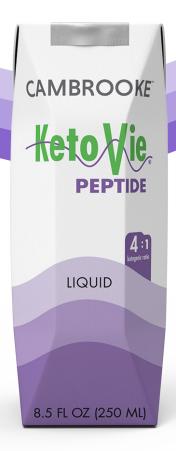
This booklet is not to replace the quidance given from your own ketogenic centre, and please consult your team should you have any concerns regarding your diet.



Many thanks to all those involved with this booklet and to Nutricia for providing the grant.



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

The 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
- <u>And much more</u>









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.

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FUNDRAISING FOR MATTHEW'S FRIENDS

We are so grateful in these difficult times for the kind support and generosity of you all. Please like and follow us on f 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

WE'D LIKE TO THANK THESE FABULOUS FUNDRAISERS!

LEWIS AND SHAUN'S



FOR MATTHEW'S FRIENDS

Our Val's great nephew, Lewis Whatley, and his friend, Shaun Sheffield, took part in the Southampton Marathon on Sunday 2nd April to raise funds for Matthew's friends.

Both young men did incredibly well. Lewis ran through shin splints which he said afterwards were, 'amazingly, the only bit of him that didn't ache!'

We are very aware that when someone takes on a challenge such as a marathon, mountain climb, trek etc., for Matthew's Friends, it's not just the day or weekend of the event itself but the months of training beforehand that take so much time and dedication. We are so very grateful to Lewis and Shaun for taking on the Southampton Marathon and send them our heartfelt thanks and appreciation for the effort they put into their training and fundraising.

Between them they have raised well over £1000 for Matthew's Friends to date. If you would like to add to their amazing total click the link below to their JustGiving page:

VISIT LEWIS & SHAUN'S JUSTGIVING PAGE

Every penny raised will be put to exceptionally good use helping those suffering with intractable epilepsy using ketogenic dietary therapies and also in supporting their families with advice and information.

THANK YOU, LEWIS AND SHAUN.





ANDY'S NATIONAL 3 PEAKS CHALLENGE

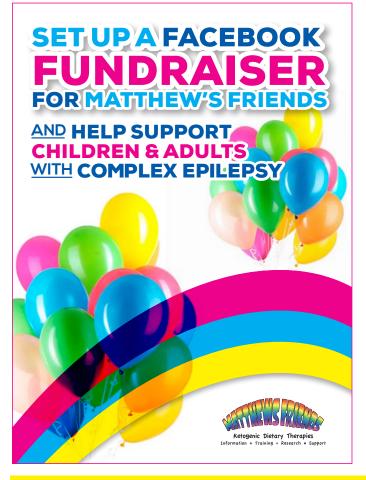
Our designer Andy is taking on the National Three Peaks 24hr Challenge in September to help raise funds for Matthew's Friends. If you would like to help Andy you can visit his page by clicking the link below!

VISIT ANDY'S JUSTGIVING PAGE



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SUMMER SALE! - LIMITED TIME OFFER! WE'RE HAVING A SUMMER SALE



MATTHEW'S FRIENDS GREEN APRON £5.00

(Mo is not included!)



KETOCOOKING BOOK £5.00 PLUS £1.50 P&P.



TRAVEL MUG NOTE PAD & PEN*

CLICK HERE TO GRAB A BARGAIN!

ALL OFFERS AVAILABLE IN UK MAINLAND ONLY

*1 Strawberry or Avocado travel mug together with a Strawberry or Avocado note pad and a Matthew's Friends pen.