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SPRING NEWSLETTER 2018 • SEVENTH EDITION

Ketogenic Therapies

Newsletter



European Reference Network for Rare and Complex Epilepsies (EpiCARE) – Annual General Meeting.

On the 9th and 10th March, Emma attended the EpiCARE annual general meeting in her capacity as member of the European patient association group (EPAG) and a work package leader for Ketogenic Dietary Therapies (KDT), giving a presentation on the work of the KDT group.

This group is made up of 33 professionals from all over Europe and their aim is to make sure that KDT expertise is available to all those patients who need it, whichever country they may be in, as well as make sure that the standard of care within this treatment field is of a high and consistent level.

This is a 5 year project which will include producing guidelines for various patient groups, training programmes

and support networks for families and patients and this is consistent with our own mission statement to bring Ketogenic Dietary Therapy to all those who need them, where ever they may be.

We are extremely proud to be part of the EpiCARE group and if you would like to know more about EpiCARE and all the work they are currently carrying out, then please visit their website at: <https://epi-care.eu/>



From Seizures and the Ketogenic Diet to Running the London Marathon!

Read the amazing story of Greg Aldridge, son of our Trustees, Val and Richard Aldridge, who is taking on the challenge of the London Marathon for us this year. We are immensely proud of him. Read more on Page 4.



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

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#ketokitchen

TO HELP FUNDRAISING VISIT:

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/>



In Honour of Norman...

It is with a heavy heart that we have had to say goodbye to one of our Matthew's Friends original Keto Stars of the past, the gorgeous Norman and the following message came from his family:

"My cousin's name was Norman Scorer - an exceptional young man who despite his many challenges showed much courage and endurance earning a very special place in all our hearts. With the support of Matthew's Friends and the knowledge and access his mum (Emily) gained in her interactions with your organisation, we believe his time with us was optimised and made more comfortable ...and for that a big thank-you."

Emma says... "I remember Norman's mum being a very active member of our Matthew's Friends forum (before the days of Facebook) when we would come together to talk regularly and support one another in our online chat room. We wish all his family our most sincere condolences and feel very privileged that we were able to help in some small way and to have known this incredible young man and his very dedicated mum and family".

No local ketogenic service available to you?

Long waiting lists?



Ask for a referral to the Matthew's Friends Clinics

MATTHEW'S FRIENDSCLINICS
 KETOGENIC DIETARY THERAPIES

As part of the Matthew's Friends organisation, we provide our own clinics where we employ a team of experts to treat our clients using medical ketogenic dietary therapies.

Not only can we embark on new areas of expertise for ketogenic therapies such as our current Brain Tumour clients (in association with the Astro Brain Tumour Fund) but we can also provide services for complex epilepsy patients and Glut 1 patients where no local NHS ketogenic service is currently available or where there may be very long waiting lists.

Both adults AND children over the age of 1 year can be seen at our clinics on an outpatient basis. Full training and support is given to all our clients that attend our clinic. We do need a referral from your neurologist/managing physician and we always encourage people to be treated at their most local NHS centre whenever possible. Part of our mission is to make Ketogenic Dietary Therapies available to all those who may need them and providing an extra resource by way of our own clinics can alleviate some of waiting time for people who so desperately need to be seen.

We obviously continue to advocate for there to be ketogenic services for both children AND adults in all main tertiary centres throughout the UK, Ireland and beyond, but until that day, we will continue to support in whatever way we can.

For further information please contact info@mfclinics.com and visit www.mfclinics.com





MY STORY

LISA HERMANN

16th May 2017 was like any other day until about 4:30pm. I was sitting at my desk at work and needed to check something – so I called a colleague over and tried to say “The home form” – but the wrong words came out – “dog tree” ... no, “wood brush”.... I knew exactly what I was trying to say and could even write it down correctly. My colleague instantly recognised the symptoms of a stroke and within half an hour I was on my way to hospital by ambulance.

By the time I arrived my speech was back to normal and later that evening I was discharged having been told I had had a transient ischaemic attack (TIA). However, the next day my speech became distorted again. I was admitted to my local hospital and given an urgent CT scan – at which point I was told there was an area of damage on my brain, apparently from a stroke, and transferred to the regional stroke centre. I was put on drugs to lower my blood pressure and kept in hospital for tests.

I was aware that I had been under a lot of stress with a reorganisation at work and that I had been comfort eating since my son had left for University and had put on a lot of weight. However, I swam and walked regularly and considered myself fitter than most so the stroke came as a bolt out of the blue. I was angry with myself for not looking after my health and I made some major decisions – to reduce my working hours, spend more time with my family and to eat properly – and was expecting to have a couple of weeks off work. Then, following a MRI scan, the bombshell dropped. “I am sorry, you have not had a stroke. You have a brain tumour.” Less than a month later, following surgery, I was diagnosed with glioblastoma multiforme (the most aggressive form of primary brain tumour). The prognosis was very poor; the tumour would almost inevitably return but aggressive treatment would delay this. I had 6 weeks of daily radiotherapy with low dose chemotherapy and am currently having monthly high dose chemotherapy.

Having finished the radiotherapy, I felt totally powerless. I had nothing to do but to wait to see if the chemotherapy worked, knowing that the success rate for my type of tumour was low. I spent far too much time on the internet looking for hope and for someone to tell me the stats were wrong – until I found out that the ketogenic diet was subject to a clinical trial at a local hospital, following a good deal of anecdotal evidence of it working in individual cases.

I was interested for several reasons. I was already trying to improve my diet and in particular cut out carbohydrates and was losing weight and feeling better for it. I also wanted to use my diet to fight cancer, but with so much conflicting advice on what to eat and information about miracle cures involving buying expensive berries I didn't know how to help myself; how vital was it to eat raw tomatoes every day when I didn't like them? I'd also heard about the ketogenic diet for epilepsy and knew it had transformed lives where medication couldn't; the parallels with my own situation made me determined I would give it a try. I expected opposition from my GP and oncologist but my GP, a cancer survivor himself, said “In your situation I would go for it” and has agreed to prescribe testing strips and lancets and my oncologist has been supportive and positive. The clinical trial is only for patients from one hospital but Sue Wood, a dietician from Matthew's friends, agreed to work with me to follow the diet and to monitor my progress.

Ten weeks on, it's still early days but I am doing well with no sign of any new symptoms. I have recovered quickly after each bout of chemotherapy and have plenty of energy. My weight is still drifting downwards which I am delighted about although I am aware that I mustn't become underweight - no risk of that for a while though! I have enjoyed following the recipes and working out what I can eat. Especially when I am on chemo and don't feel like eating, having a prescription to follow helps me to eat regularly.

I don't miss sweet or starchy food and I certainly don't miss feeling bloated and sluggish! It's difficult if I am eating with friends; they want to find things I can eat but for me the most important thing is to enjoy their company and to eat what's right for me. It's early days for me; I don't know yet how the keto diet will help my condition but it's exciting to be part of research into a way forward for people with brain tumours.

To be continued.....

GREG'S STORY

After 10 years of uncontrolled seizures (age 4 - 14), emergency medications, hospital visits in status & challenging behaviour, Greg has experienced 7 years free of major seizures and the last 2 years completely seizure free.

The turning point for Greg and all his family was at the age of 8, joining the trial for ketogenic diet with Professor Helen Cross, Prince of Wales Chair of Childhood Epilepsy & Liz Neal PHD Ketogenic dietitian at GOSH.

Greg was on a ketogenic diet for 5 years. He is still very aware of what he eats and is careful to moderate his intake of refined carbohydrate. He loves to be fit. The PE coaches at Young Epilepsy Scott, Oli & Alex, when Greg was in school were great role models & encouraged him in every activity he did.

Golf coach Geoff of Kent & Surrey golf club puts Greg through rigorous

training & being part of the pan disability football team at Chelsea is his other passion, both have been & still do play so much a part in building his strength, confidence & social skills!

Despite, or maybe because of his autism (sport being his passion) Greg decided that he wanted to run the London marathon!

He is running for Matthews Friend's. This is why!

'Matthews's Friends has played such a big part in changing my life. I would like to use my strength to contribute in helping others to turn their lives around like I have'



If you would like to support Greg and Matthew's Friends please visit his fundraising page... <https://uk.virginmoneygiving.com/gregory-aldridge>

If you would like to read Greg's full story then please visit www.matthewsfriends.org/about-us/our-stories/children/gregs-story/

2ND EUROPEAN CONFERENCE ON GLUT1 DEFICIENCY

22ND - 23RD JUNE 2018

Following on from the First European Conference on GLUT1 Deficiency that was held in Milan in 2016, we continue with our biennial developmental programme of conferences to increase knowledge and awareness of this specific rare disease by bringing together experts in the field.

TOPICS THAT WILL BE INCLUDED ARE:

- Basic Science and Current Research
- Latest Trials
- Ketogenic Dietary Therapy Global
- Consensus Statement
- Cardiovascular Long Term
- Observational Study
- Movement Disorder in Glut 1D

WORKSHOPS:

- Infants and Paediatrics
- Puberty and Adults
- Movement Disorder
- Triheptanoin and Decanoic Acid (C10) trials
- Transition and Adult Glut1D Session
- Question & Answer Sessions with expert panels



Dr Darryl C. De Vivo

The discoverer of Glut1 Deficiency will give a Keynote lecture on 'Novel Treatment Options for Glut1D' to commence the 2-day conference.

Healthcare professionals and Glut 1D families are welcome to attend to learn more on the latest research and treatment options that are currently available as well as those being developed for the future.

This meeting will bring together Glut 1D families in an environment of support and understanding as well as giving healthcare professionals the chance to network and collaborate further with colleagues on future projects. We look forward to welcoming you to the UK for our Second European GLUT 1D Conference.

Book now: www.matthewsfriends.org/glut1uk/euroconf/euroconf-2018/

New to ketogenic therapy or needing a refresher course and an opportunity to network with other ketogenic teams?

KetoCollege offers both scientific background and practical training in all aspects of implementation of the different ketogenic therapies. Led by recognised ketogenic diet experts, it will include presentations, workshops and time for networking and group discussions.

MATTHEW'S FRIENDS WILL BE HOSTING THE ANNUAL KETOCOLLEGE PROGRAMME

19TH – 21ST JUNE 2018

CROWNE PLAZA FELBRIDGE, EAST GRINSTEAD, WEST SUSSEX, UK

LEAD MENTOR & COURSE CHAIR



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

SPECIAL GUEST MENTOR



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

SPECIAL GUEST MENTOR



Mackenzie Cervenka M.D.
Associate Professor
of Neurology Johns Hopkins
Hospital, Baltimore.



For further details please visit www.mfclinics.com
or to register your interest please email: ketocollege@mfclinics.com



KETO NEWS... FROM Dublin and Scotland!



In February, Julie and Emma had a very busy few days visiting our funded adult centre in Dublin, before travelling to Scotland for a family conference and visiting some of the ketogenic centres there.

We are delighted to see that the adult centre at St. James's in Dublin is continuing to grow and is really establishing itself as the national service for the Republic of Ireland. New referrals are being made and thankfully there is now somewhere for patients to transition to, so this also frees up availability in the paediatric ketogenic clinics. Dietitian Laura Healy and Consultant Neurologist, Colin Doherty lead the team and referrals should be made to them if you wish to consider using dietary therapy as an adult and you live in the Republic of Ireland.

They are also introducing the idea of looking at diet for general Health and Wellbeing in their epilepsy clinics for those who are controlled on their medication but just want to feel better in themselves. Laura sits in on these clinics so from the very outset, these patients have this type of possibility given to them and it makes the idea of diet, be it a general healthy diet or even looking towards ketogenic diet in the future, a very 'normal' concept for their epilepsy clinics. At Matthew's Friends we have always looked at trying to make the ketogenic diet a 'normal' choice in amongst all the other choices when dealing with epilepsy and we are working with our Irish team on a new project looking in to progressing this even further, so watch this space, there will be more news on this soon.

We then went to Scotland for the ASSERT family meeting (Angelman Syndrome) where ketogenic diet is a major indicator for this condition. We were joined by Dr. Andreas Brunklaus, Paediatric Consultant Neurologist from Glasgow and MF Funded dietitian Tracey Cameron (Ketogenic Diet Co-ordinator for the North of Scotland) where, together with our own Emma Williams, we gave a full overview of ketogenic therapy from a medical, dietetic and family viewpoint as well as giving advice on how Matthew's Friends can support families. We had a lovely message from Tracey at the ASSERT group once we came home:



"I wanted to thank you all for coming to our very well received conference on Saturday. The feedback from the whole day has been highly positive and we are hopeful that we can run other events in the future.

I thought your whole section was very well put together and very interesting. Also I thought that they were all pitched at a very good level, presenting on something as complex as seizures in an accessible way isn't easy. It seems like as in so many instances we are lucky to have a very supportive NHS team in Scotland who are willing to help those who require it.

Emma your whole story and what you have managed to achieve from a very desperate situation is quite remarkable."

As a medical Ketogenic Dietary Therapy charity, it means that we cover all the different Epilepsy conditions and syndromes where ketogenic therapy could be beneficial, so we have the absolute pleasure of meeting so many different families. A big thank you to all the Scottish Angelman Syndrome families that made us so very welcome.

We finished off our time in Scotland paying visits to various ketogenic colleagues around Scotland before traveling home.

Update from our Matthew's Friends funded service in Aberdeen

Since the part-time post at Royal Aberdeen Children's Hospital was funded by Matthews Friends in October 2017 the department has received seven referrals for the Ketogenic Diet and has successfully commenced four children on either the Classical or MCT Ketogenic diet.

Grampian has nine children and two adults, that have transitioned, on the Ketogenic Diet. In the North of Scotland there are 18 children and 3 adults on the Ketogenic Diet.

Tracy Cameron has been mentoring Rachel Arthur, Paediatric Dietitian, to increase her knowledge on the diet and Rachel will work one day a week in Ketogenic Diets. Tracy and Rachel attended Robert Gordon University to educate third year dietetic students on their speciality and they have been invited back to teach next year. The department also has a cookery day organised for the 13th April 2018 in Aberdeen and all families from the North of Scotland will be invited.

Tracy Cameron also had the pleasure of joining Matthews Friends at the Angelman Syndrome Scottish Conference in February to discuss the use of the Ketogenic diet with children with Angelman Syndrome.



Keto Family Fun Afternoon

Saturday 7th April – our Julie and our Keto-cook Mo travelled to London, to the amazing venue, Ronald McDonald House Evelina, for a Keto Family Fun Afternoon.

We had the great pleasure of chatting with some of the families of the Evelina Paediatric Ketogenic Diet service, a service that our charity supports with the provision of starter packs and free helpful keto items and samples.

Mo brought along samples of her keto sausage rolls, cheese sandwiches (made with her wonderful keto bread roll recipe), biscuits and the hit of the afternoon – a chocolate party size cake – which created smiles all round! (Recipes are on our website).

This was a great opportunity for parents and carers to get to know each other and for the children that are on the diet too.

Huge thanks to Nutricia, the makers of KetoCal, for their organisation and funding of this event.



Keto Team: L-R Hayley from Nutricia, Anne-Marie, Ketogenic Dietitian, Julie & Mo from Matthew's Friends, Dr Ruth Williams, Mary-Anne, Ketogenic Dietitian, Elisabeth and Olly, fabulous Student Dietitians – who are in their final week, we wish them well and hope they are inspired to work in Ketogenics in the future!



Mo's Keto party food!

SEASONAL RECIPES

Following our recent article, Spotlight on Bread Products, featured in our Autumn 2017 Newsletter, we can now bring you a special discount code for Matthew's Friends families when purchasing Lo-Dough.

When ordering a medium box (3 pouches of 2 pieces per pouch), enter **MATTHEWSFRIENDS** in the code input field to receive the box for £9, discounted from £14. Mo has also started you off with a couple of very simple recipes too. The pizza is especially delicious.

Visit their website <https://lodough.co/> and thank you Lo-Dough!

Visit Matthew's Friends **#KetoKitchen** YouTube Channel for ketogenic recipe demonstrations and tutorials and also don't forget visit our website for downloadable recipes to add to your collection.

New recipes are developed and added every month and most can be adjusted to fit your individual prescription.



www.youtube.com/watch?v=1c1qAnrwaUg
KETOGENIC CHOCOLATE WORKSHOP WITH CHEF DEREK AND EMMA PART 1



www.youtube.com/watch?v=3P5fTCygtcc
KETOGENIC CHOCOLATE WORKSHOP WITH CHEF DEREK AND EMMA PART 2

KETO CHOCOLATE DELIGHT!

Ava is a very happy girl! Mum Catherine followed our Keto Chocolate Workshop tutorial, featuring Nutricia's Chef Derek, who creates the most wonderful chocolate creations using KetoCal powder (a nutritionally complete ketogenic formula, available on prescription).

Using KetoCal means that the chocolate does not need to be refrigerated - very useful coming in to Spring/Summer! View Part 1 and Part 2 of the Chocolate Workshops on the Matthew's Friends YouTube Ketokitchen Channel.



Please don't forget to consult your ketogenic specialist dietitian before adding new products to your prescription.

LO-DOUGH PIZZA

INGREDIENTS

- 28g LO-DOUGH bread alternative
- 7g Tomato puree
- 30g Mushrooms
- 16g Cheese - mature cheddar
- 13g Salami
- 11g Olive oil
- 10g Green olives in brine - drained
- 22g White cabbage
- 10g Carrots
- 12g Mayonnaise - HELLMANN'S



You will also need some dried herbs and a little GIA garlic paste.

METHOD

- Pre heat oven to 180c / fan 160c / gas 5
- Slice the white cabbage, grate the carrot and mix with the mayo and a little seasoning to make a coleslaw
- keep in the fridge until needed
- Grate the cheese, slice the mushrooms and salami
- Mix the tomato puree with half the olive oil and spread over the Lo-Dough base, then add the mushrooms, salami and olives, top with the grated cheese
- Drizzle over the remaining olive oil and cook for approximately 8 minutes until bubbling and golden
- Serve with the coleslaw for a complete meal.

MKD 5.15g CHO

CHO: 5.15g

FAT: 32.63g

PROTEIN: 10.75g

KCAL: 357



LO-DOUGH AVOCADO WRAP

INGREDIENTS

- 28g LO-DOUGH bread alternative
- 35g Avocado
- 10g Lettuce
- 15g Mayonnaise - HELLMANN'S



METHOD

- Slice or chop the avocado (make sure it is ripe), and mix it with the mayo
- You can add seasoning or dried herbs for flavour
- Wrap the filing with the lettuce in the Lo-Dough wrap
- The wraps can be used straight from the packet.

MO'S TIPS

Easily adapted to other fillings.

MKD 3.24g CHO

CHO: 3.24g

FAT: 18.82g

PROTEIN: 3.51g

KCAL: 196



MINI DANISH PASTRIES

INGREDIENTS

- 17g Double cream - MORRISONS
- 43g Ground almonds - MORRISONS
- 27g Eggs
- 125g Italian mozzarella - MORRISONS
- 10g Blueberries
- 6g Pecan nuts - MORRISONS (shelled)
- 6g Mature cheddar cheese
- 10g Psyllium husk



You will also need ½ teaspoon of MARMITE, 1 teaspoon of JOSPEH'S sugar free maple syrup, ½ teaspoon of TRUVIA or NATVIA granules.

METHOD

- Pre heat oven to 180c / fan 160c / gas 5.
- Mix together the almond and husks.
- Mix together the egg and cream.
- Melt the sliced mozzarella in a microwave for 60 seconds, stir then melt for a further 30 seconds.
- Beat in the almond mix, then the egg mix, beat until a dough is formed and leave to cool for 3 minutes.
- Using parchment paper roll the pastry out to an 8 inch square. By folding the paper and rolling towards the fold you can get a nice square edge - see photo.
- Cut in to 4 equal squares:
- **SQUARE 1:** spread with the Marmite then roll up like a swiss roll. Cut in to 4 slices. Turn on it's edge and place on a non-stick baking tray or in shallow patty tins, press them down to flatten a little - see photo.
- **SQUARE 2:** Grate the cheddar cheese finely, sprinkle evenly over the pastry, roll up and proceed as you did with square 1.
- **SQUARE 3:** Chop the blueberries and mix with the sweetener, sprinkle evenly over the pastry and proceed as before.
- **SQUARE 4:** Chop the pecans, sprinkle evenly over the pastry and drizzle with the maple syrup, proceed as before. Cook for approximately 15 minutes until golden. Cool for a few minutes before removing from the baking tray.



CHO: 5.28g

FAT: 68.58g

PROTEIN: 40.41g

KCAL: 800

4 x MARMITE pastries:

15.5g fat / 9.5g protein / 1g CHO

4 x CHEESE pastries:

16.5g fat / 11g protein / 1g CHO

4 x PECAN pastries:

20g fat / 10g protein / 1.3g CHO

4 x BLUEBERRY pastries:

15.5g fat / 9.5 protein / 2g CHO

MO'S TIPS

These make great treats / snacks with the values shown below. By using just ONE pastry as a treat, you are getting a good portion of FAT, some protein, but a tiny amount of carb. I sprinkled a little SUKRIN GOLD over the sweet ones for extra flavour, but this is optional. These will batch up and freeze well.

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

PURPLE DAY!

Quizzing for Purple Day!



Curry & Quizzing fun was had by all at the Time Well Spent pubs, The Red Lion Betchworth and The Sportsman Mogador in Surrey! A magnificent £713 was raised! Huge thanks to Marc and his team for supporting our Purple Day campaign.



Staff from Dorking based financial advisors HJP Ltd joining in the fun!

The winning team at The Red Lion – Stitches!

The team was named in honour of Jemma, far right, who is discreetly holding her flag over her injuries from being kicked in the face by a horse 3 days earlier – ouch! Left to right, the winners are Catherine, MF Clinics Ketogenic Dietetic Assistant for Oncology, our Emma Williams MBE, Teresa our MF office Manager and Jemma her daughter!



A gathering of Parys' family, who is on a ketogenic diet.



Dressed for the occasion!

Sara and Aiden dressed in their Matthew's Friends purple polos for Purple Day. Sara said "We are going purple for today. Your page has been soo helpful with ideas and recipes for my boy and his diet. Which is amazing and works for him so well."



Chef Neil and his Vitaflo colleagues supporting our Purple Day campaign!



We're so happy that the Ketogenic Diet is helping Aiden's epilepsy!



Innovation in Nutrition

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Give their diet some Ketobility™ with Vitaflo



keyo®

Make a fun ice pop



betaquik®

Spice it up with a curry



Give soups a creamy texture



Delightful dessert ingredient

Use as a creamer for coffee or tea



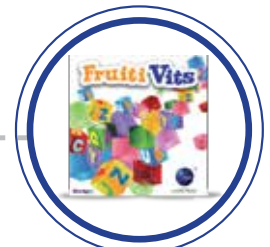
carbzero™



MCTprocal™



Get saucy with cheese or herbs



FruitiVits™



My Ketogenic Diet
www.myketogenicdiet.co.uk

What is 'Ketobility'? Maybe it's more flexibility, or more choice, or more flavours. Maybe it's all of these things. Whatever they need, the Vitaflo® range of innovative ketogenic products provides a little something extra to those on a restricted ketogenic diet.

Keyo, carbzero, betaquik, MCTprocal and FruitiVits are foods for special medical purposes. Use under medical supervision.

For more recipe ideas please visit www.myketogenicdiet.co.uk



Flying the Flag for Purple Day!

The Manchester Ketogenic Diet Team held a bake sale, raffle and manned an information stand for Purple Day awareness, raising an amazing £120 for our charity!

Huge thanks to Vicki, Lindsay, Lucy and Amy for their hard work and brilliant awareness raising!



The whole of the Paediatric Dietetic Department at Bristol Children's really clubbed together to bake lots of yummy cakes for their Purple Day cake sale in aid of Matthew's Friends! They also made some ketogenic jellies and coconut and Nutella fat bombs to give out as free ketogenic tasters during the cake sale! Thank you all!

www.keto2018jeju.org

6th Global Symposium on KETOGENIC THERAPIES FOR NEUROLOGICAL DISORDERS:

Embracing Diversity, Global Implementation and Individualized Care

October 5-9, 2018

International Convention Center Jeju, Jeju, Korea

Important Dates

Opening of Online Abstract Submission	March, 2018
Abstract Submission Deadline	June 15 (Fri.), 2018
Pre-registration Deadline	August 31 (Fri.), 2018



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Matthew's Friends and Astro Brain Tumour Fund

working in partnership using Ketogenic Dietary Therapy in the management of Brain Tumours and their side effects.

In this issue of our newsletter, you have read the inspiring story of Lisa who is supported by the Matthew's Friends Clinic team. Lisa is one of over 108 patients whose treatment has been or is currently charity funded by Matthew's Friends and Astro Brain Tumour Fund whom we work in partnership with.

We have requests every week from patients wanting support and if you can help us fund more patients then we would be really grateful as this is helping us build towards a full multi-centre clinical trial and also ensures that those patients who have been diagnosed with a low grade or high grade brain tumour and who wish to use ketogenic dietary therapy, can have the expert support they need through a very difficult time for them. There are no guarantees that the Ketogenic Diet will help in all cases, but unless we try, we just don't know. If you can help us do more for these patients, then please contact emma@matthewsfriends.org



NUTRICIA
Metabolics
 Inspiring Futures

KETOCAL: MAKING THE KETOGENIC DIET EASIER THAN EVER BEFORE*



KETOCAL PROVIDES:

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

SERVICES INCLUDE:

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

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

0800 093 3675

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

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

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

Matthew's Friends Canada – Update!

Matthew's Friends Canada has been moving at its careful pace working on recipe development, cooking demonstrations, supporting family retreats and academic meetings.

Check out this fantastic cauliflower risotto recipe! Nicole Turner, ketogenic registered dietitian, modified the Matthew's Friends recipe for Canada and demonstrate its preparation at the 2017 Epilepsy South Central Ontario Family Retreat in Hamilton, Ontario!



Members of Matthew's Friends Canada also showcased their work at the 2017 Canadian League Against Epilepsy Conference in September 2017 in Vancouver, BC. Medical advisory board member Dr.Linda Huh and colleague Dr.Qi Xu presented a poster entitled: Efficacy and tolerability of ketogenic diet in treatment of epileptic spasms after failure of steroids and vigabatrin.

CAULIFLOWER RISOTTO

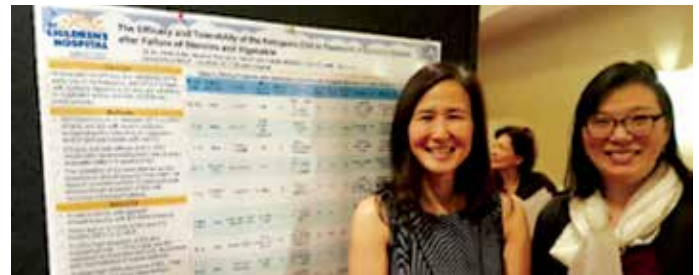
INGREDIENTS	AMOUNTS
Cauliflower – grated, raw	85 grams
Red Pepper – diced, raw	7 grams
Green Pepper – diced, raw	7 grams
Onion- chopped, raw	5 grams
Ham (Schneiders Deli, Shaved, Smoked)	35 grams
Parmesan Cheese (Tre Stelle), grated	20 grams
Whipping Cream 35% MF	35 grams
Olive Oil	20 grams
Desired Seasoning (optional)	5 grams (or less if desired)

METHOD

1. Grate the cauliflower to form 'rice' and set aside
2. Dice the onion and fry gently in half the oil
3. Dice the red and green peppers and add to the onions, cook for one minute
4. Chop the ham and add to the pan along with the cauliflower, herbs and remaining oil
5. Stir for a few minutes until the cauliflower starts to cook: you don't want it too soft.
6. Add the cream and parmesan cheese until heated.
7. Serve dish while warm

Nutrition per 1 serving

Calories	Total Fat	Total Protein	Total Carbs	Keto Ratio
432 kcal	39.28 g	14.1 g	5.45 g	2.01 to 1



Preliminary results from a national survey of ketogenic diet centres supported by Matthew's Friends Canada in partnership with University of Toronto and McMaster Children's Hospital. Thank you to all the centres that contributed.



(Left to Right: Dr.Salah Alzubarek, Dr.Eduard Bercovici, Jennifer Fabe and Carol Pereira).

Medical advisory board members, Dr.Eduard Bercovici (adult epileptologist) and Carol Pereira (social worker) continues to provide lectures throughout Ontario to raise awareness for ketogenic diet therapy and Matthew's Friends Canada.



MAKE SURE TO VISIT US:

 /MF_Canada  /Matthews Friends Canada

Adult Journey with Ketogenic Diet

| Erin's Testimony

At the age of 6 I had my first seizure due to having spinal meningitis at 10 months old. The spinal meningitis caused scar tissue on both sides of my brain. At this time I was put on medication and remained on meds until around the age of 10 when they removed me from medication as I had not had any seizures.

I remained seizure free until around the age of 12 when I began having complex partial seizures. I was put back on medication but unfortunately the seizures continued. We tried many medications but there was still no luck in finding a solution. At the age of 25 I was sent out to the London Hospital to figure out if I was a candidate for surgery. I was admitted into the monitoring unit where we found out my seizures were happening too far back in the brain for the EEG to pick up so they decided to do subdurals. Finally, we got some answers. They were able to determine that my seizures were starting on the right side of my brain and transferring to the left. This made me a candidate for surgery but was informed that there was a 20% chance I would continue to have seizures due to the scar tissue on the left side of my brain.

I made the decision to have the surgery to remove part of my right temporal lobe. A few months after surgery I began having simple partial seizures and 6 months after surgery I had a tonic clonic. Doctors did not know why, at this point, I had the tonic clonic and was sent back into the monitoring unit. Unfortunately, I didn't have a seizure during the time spent in the monitoring unit. All I was told was they were seeing abnormal activity but they needed for me to have a seizure to confirm where they were starting from. We changed my medications again and began retrying medications I had been on in the past. The seizures would continue no matter what medications we tried.

I was admitted back into the monitoring unit a few more times, all to get no answers. I was getting extremely frustrated as my seizures were starting to increase. I was averaging 4-7 complex a month and anywhere from 5-20 simple partials a week. At this point I knew I had to try something new. Medications weren't working, and I wasn't getting answers with the EEG so it was either suggest doing subdurals again to get answers or try the ketogenic diet.



For me, trying the ketogenic diet was a better option than having surgery. At my next follow-up with London I asked to be referred to Toronto to see Dr. Bercovici to try the keto diet. It took some convincing but I am extremely glad I made the decision to try the diet. Since starting the diet, my seizures have dropped by about 90%. I am currently having around 5 simple partials a month (sometimes less), and about 2 complex partials every 3-4 months. When I do have a seizure, my recovery time has also been reduced. When I first started the diet, it was very overwhelming but with all the support I received from my medical team, as well as family and friends, I was able to stay strong through the transition.

In the beginning of starting the diet I still had some seizures but I noticed they were decreasing as my body was adjusting to the diet and trying to figure out the proper amounts of foods to eat. The fact that I noticed my seizures decreasing made me want to remain on the diet that much more and continue to work at it. One very important thing I do daily is track my food which allows me to stay within the required levels to control my seizures. I will admit the diet can be time consuming at first with trying to figure out meal plans and making sure to not go over your limits but if you stick with it and continue working at it, it will pay off.

There are days I have my frustrations because I want to be able to eat like everyone else but then I just think how much my seizures have decreased and I don't want to ruin any of that. Not only has the keto diet helped my seizures it's also helped with my migraines. I also have much more energy and am not as tired a lot of time.

Fundraising for Matthew's Friends

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

Back in September 2017 our friends at Wildside Cycles in Tunbridge Wells organised the annual Tunbridge Wells Bike Ride, which for the second year in succession raised funds for our charity.

351 riders took part, 15 volunteers helped throughout the day and big names sponsored the event, such as BMW, AXA PPP, Savills, Natural Low Carb Store and Nutricia. A fantastic event, which raised £948.78 for the Matthew's Friends Glut1 fund!

Pictured, Nutricia Manager, Stephen Anderson, who kindly volunteered his services for the day!



Three cheers for our National Three Peaks Challenge team!

Emma Warrington, Charlotte Daws, Louise Gahan, Thomas Bullet and Peter Bullet are planning a 3 peaks challenge, climbing Scafell Pike - Ben Nevis - Snowdon, over the 2nd and 3rd June!

The team write: "Close friends to Emma have a two-year-old daughter, Beth, who suffers from difficult-to-control epilepsy. Beth has been on the ketogenic diet for the past year and Matthews Friends have provided amazing support and information to the family on a subject for which there is still much to understand."



The team completed a recent training climb of Pen y Fan in the Brecon Beacons National Park.

Please visit their JustGiving page to read more about Beth and the amazing team challenge. At the time of publication, the team are just over half-way to their target of raising £1,000!

www.justgiving.com/fundraising/team3peaksformatthewsfriends

Join our epic charity CHALLENGE



Matthew's Friends Rainbow Walk along Hadrian's Wall 6-8th July 2018

This most ancient of charity treks takes us from Lanercost Priory to Brocolitia, encompassing some of the most visited and fascinating ruins.

Hadrian's Wall was built in AD122 on the orders of the Roman Emperor Hadrian, and stretched from the East to West coasts of Britain, from Bowness on Solway in the West to Wallsend in the East. It is the most remarkable Roman monument in the country and quite unique throughout the former Empire. Now a UNESCO World Heritage Site which cuts through Northumberland National Park, Hadrian's Wall attracts trekkers from all over as it offers great challenging walks, filled with a stunning backdrop and history. It's a perfect location for a UK charity challenge!

Visit our website here for all the details and to book your place: www.matthewsfriends.org/keto-fundraising/fundraising-events/hadrians-wall-trip/



SAVE THE DATE

MATTHEWS BIRTHDAY BALL 8 SEPTEMBER 2018

visit: www.matthewsfriends.org

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 2018 and beyond, thank you.