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WINTER NEWSLETTER 2018 • NINTH EDITION

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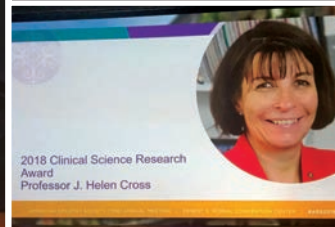
Newsletter

EXCITING NEWS FROM NEW ORLEANS!

Professor Helen Cross OBE has been awarded the prestigious 2018 Clinical Research Award at the American Epilepsy Society (AES) Annual Meeting for her fantastic work in the areas of Ketogenics, cannabinoid and surgery.

Congratulations to this amazing lady, who heads our Medical Board, for this well-deserved honour.

For the first time ever, Metabolism-based and Ketogenic Therapies for Epilepsy featured at the AES, with a symposium led by our keto-colleagues Professors Eric Kossoff and Jong Rho. This is a key development for the future of Ketogenic Diets! Huge congratulations to the faculty involved, that includes from the UK, Dr Anita Devlin from Newcastle-upon-Tyne Hospitals, a Matthew's Friends KetoCollege Mentor.





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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/>



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@mfcclinics.com and visit www.mfcclinics.com



PARKINSONS DISEASE AND KETOGENIC DIETARY THERAPY

New study results are released from New Zealand

A Brief summary of the paper is below but you can find the full paper via the following link: <https://onlinelibrary.wiley.com/doi/abs/10.1002/mds.27390>. Parkinsons has been on the 'list' of diseases that could possibly benefit from Ketogenic Dietary Therapy for a long time, more studies do have to be conducted but it is something that possibly could be hopeful for the future. Please don't hesitate to contact us if you would like further information.



Low-Fat Versus Ketogenic Diet in Parkinson's Disease: A Pilot Randomized Controlled Trial

Preliminary evidence suggests that diet manipulation may influence motor and nonmotor symptoms in Parkinsons Disease (PD), but conflict exists regarding the ideal fat to carbohydrate ratio.

The objective for the study was to do a piloted randomized, controlled trial to compare the plausibility, safety, and efficacy of a low-fat, high-carbohydrate diet versus a ketogenic diet in a hospital clinic of PD patients.

A protocol was developed to support PD patients in a diet study and then patients were randomly assigned to a low-fat or ketogenic diet.

47 patients were randomised, of which 44 commenced the diets and 38 completed the study (86% completion rate for patients commencing the diets). The ketogenic diet group maintained physiological ketosis.

The most common adverse effects were excessive hunger in the low-fat group and intermittent exacerbation of the PD tremor and/or rigidity in the ketogenic group.

Conclusions to the trial: It is plausible and safe for PD patients to maintain a low-fat or ketogenic diet for 8 weeks. Both diet groups significantly improved in motor and nonmotor symptoms; however, the ketogenic group showed greater improvements in nonmotor symptoms.



JOIN US & GO
#SUGARFREEFOREPILEPSY
IN NOVEMBER



At the time of writing we are 3 weeks in to our Sugar Free month, raising awareness of ketogenic dietary therapies for epilepsy.

Thank you to everyone who is supporting – it's not too late to join us! You can donate through our Matthew's Friends Facebook Fundraiser or via our JustGiving campaign here www.justgiving.com/campaign/sugar-free-for-epilepsy

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JEJU

KOREA 2018



What an amazing venue Jeju was for the 6th Global Symposium on Ketogenic Therapies for Neurological Disorders. It was a memorable start with the impending typhoon set to hit the island on the Friday night! The initial Friday afternoon of lectures went ahead with intermittent emergency alerts sent to our phones warning of the impending storm.

However, the odd nervous glances exchanged did not take away from the pre-congress workshops focusing on practical implications of Ketogenic Diet Therapy (KDT), setting the scene for the days ahead. Some delegates were stranded as flights were cancelled, including our own Professor Helen Cross who ended up skyping her early Saturday morning presentation from Seoul! Jennifer Fabe from Matthew's Friends Canada also spent a night stranded in Shanghai, but luckily her presentation was on the last day of the conference. They both arrived safely on Saturday night.

HERE ARE A FEW HIGHLIGHTS OF THE FIVE-DAY SYMPOSIUM

Guidelines: Professor Eric Kossoff gave us an overview of how far we have come in the world of KDT, with 7 RCT's published to date. He referred to the recently updated International consensus for the clinical management of children receiving dietary therapies for epilepsy (1). It gives a fantastic overview updating indications for use, recommended approaches, tackling side effects and compliance issues.

Infant consensus guidelines were also published earlier this year and 2019 will see Total Parenteral Nutrition (TPN) and adult therapy consensus guidelines published too.

Mechanisms: We know that the KDT works for many people with epilepsy and that the degree of ketosis is not necessarily key to its efficacy. The science of KDT mechanisms of action, grows and grows, increasing knowledge of its effect on downregulating glycolysis, enhancing mitochondrial function and influencing both inhibitory and excitatory neural pathways that change cellular function. Uniquely, KDT has the potential to deliver a disease modifying effect through its alterations in cell signalling pathways, inflammation, and cell death; explaining why the improvements made on KDT can be lasting, unlike the 'plaster' that is AED's. Dr. Susan Masino continues to look at KDT influence on Adenosine as a likely factor.

Novel additions: Medium Chain fatty acids continue to be investigated with further advances in the understanding of C10 (Capric acid) suggesting that its effectiveness is enhanced when combined with small amounts of C8 (Caprylic acid) and its mechanism of action, interestingly, follows a similar pathway to that of Perampanel!

The novel fatty acid C7 (triheptanoin) continues to be explored in trials. In a small study of GLUT 1 patients, the addition of C7 to their normal regime delivered 50% seizure reduction in 5 of the 8 cases with 1 person becoming seizure free for 30 weeks. Gastro upsets appeared to be the biggest side effect noted. More patient studies are to come, possibly adding C7 to KDT.

The microbiome: The influence of our gut microbiota on brain health is creating increasing interest. Background population studies (epidemiological studies) have highlighted that shifts in the developmental pathways of the infant gut microbiota and the immature immune system likely come before neurodevelopmental and psychiatric disorders in infants and children. Could dietary interventions targeting the gut microbiota have the potential to treat or at least modify symptoms of these disorders? Early studies relating to epilepsy look promising. Interestingly a case study was presented of a patient having a fecal transplant which appeared to give some seizure protection. Perhaps pre and pro biotics and dietary additions will be even more streamlined to specific diseases in the future? Its early days but the science is very promising.

Neuroprotection: The science continues to research how and why KDT will be a useful treatment option where neuroprotection is key. We learnt of some novel areas where a small series of case studies has found KDT efficacious, such as in alternating hemiplegia of childhood (where it has been found to reduce hemiplegic attacks and improved cognition), Complex 1 mitochondrial disorders and Neiman Picks disease. The poster session showcased work looking at KDT use in schizophrenia (Ecuador & USA), tics associated with Tourettes (Denmark), multiple sclerosis (Germany & India) and many other areas.



Brain tumours and other cancers: Work with brain tumours continues and lab work is very promising but published clinical trial data is still sadly lacking. We exhibited our poster reporting the KDT experience of 25 of our supported adults with brain tumours, highlighting that quality of life may improve markedly with control over seizures and increased energy levels. However, there are currently no means of assessing the direct effect of KDT on tumours and it is thought that the responses may vary considerably, depending on tumour type and genetic alterations.



UK delegates at the Jeju meeting

Practice around the world: It was interesting to hear how teams delivered KDT across the world. The diversity of cultures and the lack of resources in some countries were both inspiring and humbling. Some have almost impossible financial restraints, and even USA have their constant battle with the medical insurance companies! So, although we moan when we have difficulties with KDT related prescriptions being filled (particularly for adults) our NHS seemed pretty damn good in comparison!

Initiation: Amazingly 80% of children worldwide start their Classical KDT in hospital! However, we did find teams who start KDT at home and they, like us, tend to favour the slower

initiation of treatment, to reduce episodes of drops in blood sugar and excess ketosis. Teams from Phoenix and Emory in USA let adults lead on their pace of initiation; starting by cutting carbohydrate intake by 50% then seeing how they manage with this for a few weeks before halving again, and so on until symptom management is achieved. Some find that they can achieve symptom benefits at a higher carbohydrate intake than in traditional KDT ie without actually needing to be in ketosis. Neurologist Pavel Klein in USA is attempting to improve compliance in adults on KDT by providing ready meals for the first month, he feels that if benefits are felt with less stress involved with food preparation adults will more likely continue KDT.

Training professionals: In India Dr Janak Nathan and his team have developed a four-week training programme for dietitians: a three-week distance learning course, studying the theory of KDT, after which they sit a test, followed by a week spent mastering the practical skills, diet prescription: calculation, weighing & cooking the food. The training has been rolled out to all the regions in India, foods can be very different from one region to another. At the end of the training they start their first patient. Janak advises that they choose the first patient wisely; a likely responder. In that way, all are inspired to get their next patient started and the patients and their families may become willing ambassadors to support future KDT patients.

We met a couple, both epileptologists from Uzbekistan, who have set up a residential KDT training centre around their personal experience of having a daughter with complex epilepsy who responded to KDT. It sounded amazing; purpose built with 19 'kitchen-stations' and families stay and learn how to manage the diet there. How we would all love this, but free to the families. We can dream!

So many countries were represented at the conference, some like South Africa who have spread their expertise to Ghana by sending a team to work with the local dietitians and families to get things started and of course, there is our own Ketocollege Training course each year and our forthcoming online tutorials for resource strapped areas of the world.

SAVE THE DATE

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SPOTLIGHT ON LAUNCH OF NEW 2.5:1 FEED from Nutricia

We are delighted to see the launch of a new product from Nutricia in their Ketocal range of a new 2.5:1 feed with 20% MCT included in the lipid profile.

This feed is ideal for older children and adults on Ketogenic Dietary Therapy and can be used as a stand alone feed or supplement any of the Ketogenic Diets that are currently in use. It has a nice Vanilla flavour to it and it makes a great frothy coffee, cappuccino or use some cocoa powder or 85% chocolate melted into it for a luxurious hot chocolate! Can be used in all the usual shakes and smoothies and can be an ingredient for a keto version of 'Baileys'! (at Christmas time that is always nice – but make sure you speak to your dietitian first about this!)

At Matthew's Friends we are keen advocates for the diet being available for adults with drug resistant epilepsy and this feed is a very welcome addition to those adults wanting to go on diet that are tube fed as well as those adults wanting something quick and easy to drink if they are on oral diets. Our own Matthew tested the product and found it very enjoyable (in fact Emma had to wrestle the cup off of him!)

If you would like further details on this product, speak to your dietitian. If you are an adult and would like further information on Ketogenic Dietary Therapies then please don't hesitate to contact us on enq@matthewsfriends.org



GUT BACTERIA... FOLLOW ON

In our last newsletter we highlighted the possibility of Gut Bacteria holding the key to seizure control, which sparked a lot of interest and discussion. In October two further interesting articles were published on the subject of how important our gut bacteria could actually be to us all for healthy aging and how we starve our gut bacteria. Both articles are quite thought provoking and links to the full articles are below which you will just need to type into your browser.

Are gut bacteria the key to healthy aging? Published 26th October 2018

https://www.medicalnewstoday.com/articles/323484.php?utm_source=newsletter&utm_medium=email&utm_country=GB&utm_hcp=no&utm_campaign=MNT%20Weekly%20non-HCP%20non-US%29%20-%20OLD%20STYLE%202018-10-31&utm_term=MNT%20Weekly%20News%20non-HCP%20non-US%29

How and why our bodies starve gut bacteria Published 30th October 2018

https://www.medicalnewstoday.com/articles/323509.php?utm_source=newsletter&utm_medium=email&utm_country=GB&utm_hcp=no&utm_campaign=MNT%20Weekly%20non-HCP%20non-US%29%20-%20OLD%20STYLE%202018-10-31&utm_term=MNT%20Weekly%20News%20non-HCP%20non-US%29

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GREAT ORMOND STREET HOSPITAL DIETITANS TRIAL THE MODIFIED KETOGENIC DIET!

Zoe, Chloe and Hannah who all work within the Ketogenic Diet Service at Great Ormond Street Hospital (GOSH) decided to trial the Modified Ketogenic Diet (MKD) for 2 weeks. This was to review the practicalities and any challenges of implementing and adhering to the diet.



CHLOE'S THOUGHTS PRIOR TO COMMENCING

"I initially was excited at the prospect of starting the diet. I had planned my meals and been food shopping to buy all the ingredients so I was prepared. I had some food-based social events during the trial so I was a little nervous about managing these."

WHAT WENT WELL?

It was such a good experience to see first-hand what our families go through and challenges they face. It was also a great way of finding new foods/recipes that I could then recommend to families as tried and tested. It was good to see how the prescription products would be used day-to-day. I tended to drink KetoCal LQ 4:1 for breakfast with fruit as an on-the-go meal.

ANY CHALLENGES?

The side effects of the diet were not pleasant. The high fat intake caused reflux and really impacted on my appetite, which made it even more difficult to eat the amount of fat! Some parents are under the impression the diet is a natural treatment for epilepsy but to some extent it's another drug, which also has side effects.

I regularly run 10K before work but found this impossible to maintain on the diet and had to reduce my running including distance and frequency



DIET PRESCRIPTION

- 3 meals a day with 1-2 optional snacks
- Total CHO 35g/day
- Fat choices per meal – 4
- Fat choices per snack – 2
- Overall energy - 1800kcal/day

ZOE'S THOUGHTS PRIOR TO COMMENCING

I can't really say that I had any expectations or thoughts. My main thought was "Right, let's get on with it!"

WHAT WENT WELL?

The food can actually be really tasty. I love cooking, but it took a lot of planning and hated all the washing up.

Never being hungry was good and once I'd planned my days I thought about food a lot less.

I didn't want the diet to impact my life, so I kept all my plans including going out for dinner lots, going away for the weekend and having a dinner party. I managed but it wasn't easy. A lesson in how to make good celeriac mash is needed! A low point was having a side order of clotted cream with prawn cocktail, whilst your friends have afternoon tea. I hate cream so having spent two weeks eating it I would happily never eat it again.

ANY CHALLENGES?

On the first day, I suffered with the most horrible reflux pain I've ever had, struggling to sit down. I do suffer with reflux normally. Regular Omeprazole helped ease the pain.

Following the MKD had a huge negative impact on my exercise tolerance. I really struggled to do what I normally do. I didn't run for two weeks and I have half marathon to train for!

HANNAH'S THOUGHTS PRIOR TO COMMENCING

"When preparing for starting the MKD, I felt very positive and was encouraging to those in the team. I enjoy cooking and trialling new products so I thought it would be enjoyable and the weeks on the diet would be a great experience. I was also keen to try lots of prescribed products and keto-friendly products available in shops."

WHAT WENT WELL?

On the first day, I enjoyed the meals eaten choosing lots of mayonnaise and cream as my fat choices. I also cooked meals that I have previously enjoyed when not on the MKD and looked forward to having these e.g. baked eggs with smoked salmon. I quickly realised that, although on the MKD, protein intake can significantly affect ketones levels. I found low carbohydrate dairy foods or oily fish a great way of meeting protein needs while also eating enough fat.

ANY CHALLENGES?

Unfortunately I had to come off the diet early due to negative side effects. Introducing the diet quickly may have led to greater side effects including increased fatigue, lack of hunger, reflux and vomiting. I didn't look forward to meals especially when trialling products that I did not enjoy. I trialled Lo-Dough and CarbZero but preferred to use "normal" options to increase overall enjoyment at meal times. I also struggled to think of variety and found that I relied on a small number of fat options including olives, cheese and mayonnaise.

OVERALL THOUGHTS

We all had different experiences on the MKD but overall found it a valuable experience. Planning and preparing was key to meeting dietary targets. As a team, we really pulled together. We bought different snacks for each other and made ketogenic friendly foods e.g. a delicious smoked mackerel pate and a not so delicious bacon and egg muffin. Many of us had to answer friends and colleagues questions regarding the ketogenic diet highlighting the limited knowledge.

TAKE HOME MESSAGES

- A slow introduction may have minimised negative side effects
- Careful planning was necessary to adhere to diet prescription
- Eating out posed challenges but was enjoyed by all when on the diet
- Tolerance potentially more important than pushing variety for patients
- Prescribed products improve variety/texture/ease

Matthew's Friends says....

A huge WELL DONE to the Gosh team for trialling the MKD for 2 weeks. It is a short time to do the diet, so it would be common that the normal exercise regime would be affected, however evidence shows that once the body has adjusted to fat burning mode then exercise can be continued as usual and Ketogenic Diets are currently being used by elite sportsman and women. Also, as has already been stated, slower initiation can definitely reduce side effects of the diet and give the body a chance to adjust to burning fat for fuel.

END TO ULTRAGENYX TRIAL FOR GLUT 1D

It was sad to receive the news back in October that the Triheptanoin (C7) trials that were being carried out by Ultragenyx were being stopped, a press release was sent to all support groups and the summary was as follows:

"Novato, Calif. — October 26, 2018 — Ultragenyx Pharmaceutical Inc. (NASDAQ: RARE), a biopharmaceutical company focused on the development of novel products for serious rare and ultra-rare genetic diseases, today announced its Phase 3 study of UX007 in patients with glucose transporter type-1 deficiency syndrome (Glut1 DS) experiencing disabling paroxysmal movement disorders did not achieve its primary endpoint of demonstrating a statistically significant reduction in the frequency of paroxysmal movement events with UX007 treatment compared to placebo, and did not demonstrate a meaningful difference between treatment groups.

The study also did not meet its key secondary endpoints. The safety profile observed in this study was consistent with what has been previously reported with UX007. Ultragenyx plans to discontinue the Glut1 DS development program, and will work with investigators and patients on a reasonable transition plan for patients with Glut1 DS who are still on UX007."

If you wish to read the full press release then please visit www.matthewsfriends.org/Glut1uk/

Providing Ketogenic Dietary Therapies education and information far and wide...

Special Tribute to a special Dietitian....

The 15th and 16th November found our CEO and Founder, Emma Williams MBE in The Netherlands to pay tribute to a special dietitian who was about to retire.



Caroline Troost has provided Ketogenic Dietary Therapies at the complex Epilepsy Centre in Kempenhaeghe for over 20 years, even before we had the 'class 1' evidence to prove the efficacy of the diet. Caroline started as a lone dietitian, quietly keeping the diet flame alive when others wanted to extinguish it altogether. However, today there is a whole team at the centre providing ketogenic diets to both adults AND children, it is wonderful to see the diet come such a long way and they have many patients going on the diet every year. Caroline asked Emma to do a presentation at her farewell conference about Matthew's Story and the Matthew's Friends organisation.

Emma said of her visit to the centre: "It was an absolute honour to be asked to make a presentation and pay tribute to such a special lady. I have known Caroline for quite a few years now and her dedication to the diet is just so inspiring and I have a very strong feeling that her knowledge will be put to very good use in The Netherlands in the near future - so watch this space!"

My visit to the Kempenhaeghe centre actually blew me away, it is an amazing place with such a great feeling about it. We have similar types of places in the UK but nothing on this scale dedicated to complex epilepsy. One of my highlights was meeting the gorgeous Mike and his grandparents.

I always miss my Matthew when I am away, so the chance to have a cuddle, play with some toys and have a beautiful smile from such a special young man always does my heart good and it reminds us all of why we do what we do. Mike has been on the diet for 10 years now and is doing so well on it with no thoughts of him coming off of it. His grandparents visit him every week and bring all his food in for him, all marked up in his little pots. Such an inspiring and wonderful family. It was a real pleasure to meet them all. "



Emma with Mike and his grandparents Holland trip



Emma with Nutricia Benelux Team



Emma with Elles van der Louw and Simone at the Erasmus Hospital Rotterdam

Whilst in Holland, Emma had several other meetings and interviews, all on ketogenic therapies and the importance of making sure that there were more resources available for those who want to try them to control their seizures. She also presented at a meeting in the other main Ketogenic Diet centre which is the Erasmus Hospital in Rotterdam with dietitian Elles van der Louw whom Emma has worked with several times over the years. Elles will be speaking at next year's Ketocollege on the new TPN guidelines that are about to be launched and they are also working on some new projects together - but more news on that will come in the New Year.

Emma also met up with the Nutricia Benelux team to explain more about Matthew's Friend's work and future plans, it was an extremely busy couple of days but extremely productive ones too. A huge thank you to all those in Holland that made this trip possible, especially Simone, Karina and Emma from the Nutricia Holland and Global team.

13TH EUROPEAN CONGRESS FOR EPILEPSY, VIENNA - AUGUST 2018

Pictured here: Our Medical Board Chair, Professor Helen Cross with our CEO Emma Williams at the Matthew's Friends information table. Whilst at this congress they were also both involved in several of the ERN-EpiCARE Meetings (European Reference Network for Rare and Complex Epilepsies).

It was a great chance to meet up with colleagues from across Europe and it was also a chance for Emma's daughter Alice to volunteer on the information table and be part of the meeting whilst on her summer holiday from Medical School.



Professor Helen Cross with our CEO Emma Williams at the Matthew's Friends information table.



Emma and daughter Alice, pictured here with Maaike Ballieux from an Epilepsy Patient organisation in The Netherlands.



Emma is pictured here with Shirley Maxwell from Epilepsy Connections in Scotland.

MATTHEW'S FRIENDS INVOLVED IN THE NEW SIGN GUIDELINES FOR PAEDIATRIC EPILEPSY IN SCOTLAND

On the 8th November, Our Founder and CEO Emma Williams made her way to Stirling in Scotland to present at the National Open Consultation Meeting which she spoke about how important these guidelines are to both families and professionals. Emma was also involved in the team who drew up the new guidelines for Ketogenic Dietary Therapies and pictured here is Glasgow Dietitian Janette Buttle who presented the new dietary guideline.



Janette Buttle at SIGN

NATURAL LOW CARB KITCHEN VISIT...

Whilst Emma was in Scotland she paid a visit to the team at Natural Low Carb Kitchen to see what latest developments they were working on and try some of their new products. Here she is photographed with some of the team and she said about the visit "it is great to see what is in development and how helpful these products can be to families, personally I am a big fan of the Caramel and Sea Salt Fatt bar. I had a lovely time tasting new products and it is just another thing that I do love about my job! Huge thanks to Hannah Sutter and her staff for making me so welcome."



Emma with the Hannah Sutter and some of the Staff from Ketocare Foods.

ITALIAN MEETING IN PAVIA - SEPTEMBER 2018

Back in September Emma was invited to speak at an Italian Meeting in Pavia dedicated to Ketogenic Dietary Therapy and the development of the European Reference Network for Rare and Complex Epilepsies (ERN-EpiCARE) and the work that was going on in developing dietary therapy and information across Europe. Emma is pictured here with some of the delegates and speakers from that meeting.



FREYA FOUNDATION FAMILY WEEKEND

Mo and Julie were kindly invited, once again, to attend the Freya Foundation Family Weekend, held at the fantastic Bluestone national park resort in Wales. Freya had a lovely warm welcome for Mo!

The weekend is a great opportunity for families of children with PDHD to come together in a magical place. Mo and Julie spent the morning with the children who are on a Ketogenic Diet and their parents, with Mo making some tasty keto treats and sharing recipes, information and resources. The Freya Foundation are an amazing charity and we are glad to support them whenever we can.



HAPPY 8th BIRTHDAY LILLY

Lilly is a patient of Matthew's Friends Clinics, on a prescribed ketogenic diet therapy for epilepsy.

Lilly's Mum organised an amazing surprise for Lilly's 8th birthday – a professional cake maker made this gorgeous cake, using our Tried and Tested cake recipe from our #ketokitchen! Some of the decoration on the cake was definitely not keto, but easily removed when it was time to eat.



ETHAN'S DAY AT TWICKENHAM!

17th November saw Ethan Middleton and his sister Erika, join Emma and some of her family for a day at Twickenham watching England play Japan at Rugby.

Independence Homes for Adults with Epilepsy won the tickets at the live auction at the recent Matthew's Friends Ball and Ethan was voted the person to receive them. The day started in the Bollinger tent where a glass of champagne (or two!) was in order, followed by a trip around all the stands and something to eat.

The match started quite shakily but thankfully England picked up in the second half and won the match. Much singing of 'Swing Low' was done as well as jumping up and down in their seats and cheering the team on. Many thanks to Nick Atkinson for donating the prize and he is pictured alongside Erika, Ethan and Emma.



ANITA KAUFMANN FOUNDATION

Emma With Debra Josephs who founded the Anita Kaufmann Foundation from America. Debbie set up the foundation in honour of her best friend Anita who sadly died from her seizures.

The Anita Kaufmann Foundation now runs special workshops and gives out information on first aid for seizures and educates the general public on what to do if you see someone having a seizure. Their other job has been to be the major force behind the 'Purple Day for Epilepsy' Campaign and Matthew's Friends were the first group to sign up to this cause in the UK. Purple Day is such a wonderfully simple way of increasing the knowledge and awareness for Epilepsy. 26th March is Purple Day – so get involved and visit our website for further details.



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Ketogenic Dietitians Research Network

The **Ketogenic Dietitians Research Network** is a group of paediatric and adult ketogenic dietitians and researchers. The aims of the group are to:

- Provide a support network for dietitians undertaking, or interested in undertaking ketogenic diet-related research
- Share practice and research ideas between UK ketogenic centres
- Apply for funded research time for dietetic-lead projects and promote evidence-based practice by publishing results from our projects.

Our dedicated and enthusiastic team have presented at national and international conferences, including the British Paediatric Neurology Association annual conference, Ketoconference, and the 6th Global Symposium on Ketogenic Therapies for Neurological Disorders. We are currently working on four research projects, including:

- **NICE to know:** impact of NICE guidelines on ketogenic diet services nationwide
- **Nutritional biochemistry** for patients on ketogenic diets
- **Modified ketogenic diets:** practice in the UK and beyond
- **Use of non-prescription ketogenic products** in the UK

If you are interested in joining the group, or collaborating with us, we would love to hear from you! Please contact Dr. Natasha Schoeler on n.schoeler@ucl.ac.uk.

Matthew's Friends supporting the KDRN (Ketogenic Dietitians Research Network)

"Matthew's Friends sponsored a multidisciplinary meeting for one of our research projects. This was invaluable, enabling us to collaborate with other healthcare professionals within a convenient, comfortable location. Thanks to this meeting, we were able to refine our project, move forward and are now looking to publish our findings."

Natasha Schoeler, on behalf of the Ketogenic Dietitians Research Network

MO HAS A SPECIAL GUEST IN THE MF KETOKITCHEN!

Great Ormond Street Hospital Dietetic Assistant Assunta Aversano joined our Ketocook Mo in the Matthew's Friends KetoKitchen recently to go through some recipes and pick up some new ideas for the team at GOSH and their patients.

Assunta said "It was a privilege to join Maureen for a cookery day. Maureen greeted me with great warmth on the day which I'm grateful for. Her passion for the ketogenic diet was contagious. She eagerly shared with me a wealth of knowledge that I was only too happy to absorb.

I had a thoroughly enjoyable day. I picked up valuable and practical tips which will help bring our paper calculations of ketogenic meals to life. Already being a confident cook myself this training helped me to extend my knowledge. I look forward to sharing these nuggets of recommendations amongst my colleagues at Great Ormond street Hospital for Children NHS Foundation Trust. I am feeling inspired and I can't wait to start adapting our standard ketogenic meals into tasty achievable creations."

Mo thoroughly enjoyed her day with you Assunta and was glad to be of assistance.



Winter Recipes from our KetoKitchen

Winter is upon us and we want something warm and tasty...thankfully Mo has worked her magic yet again and come up with some great recipes. We can't feature them all in our newsletter but if you go on to our website at the following link www.matthewsfriends.org/keto-kitchen/keto-recipes/

you will find lots of new recipes that you can download freely. We have even included a keto Christmas pudding for the festive season should you need one (very tasty it is too!) If you have a recipe you would like to share then please send it in to us.



PASTA DISH USING NICK'S PASTA ADAPTED FROM AARON'S MUM'S RECIPE MKD

INGREDIENTS

90g Frankfurter MORRISONS
VACUUM PACKED
63g Pasta sauce
SACLA INTENSO
20g Green soybean Fettuccine
- NICK'S

METHOD

Cook the pasta for a few minutes - follow the instructions on the packet. Slice the frankfurters and heat through in the pasta sauce. Stir in the cooked pasta just before it is ready to serve.

MO'S TIPS

Can be served with fresh parmesan cheese 2g is plenty! This recipe will easily take some extra oil if needed! The pasta sauce was purchased from Tesco.



CHO: 5.25G
FAT: 35.09G
PROTEIN: 20.62G
KCAL: 419

CHAPATTI

INGREDIENTS

35g Coconut flour - TRS or EAST END
10g Psyllium husk
You will also need some seasoning or spice to flavour and approximately 100mls HOT water.

METHOD

Mix the coconut with the psyllium husk with enough HOT water to form a dough. Form in to two equal pieces, then pat or roll into rounds.

Place in a dry HOT frying pan and cook for 2 minutes on each side.

MO'S TIPS

When you turn it over press down on the surface, this will make it puff up a little and makes the chapatti lighter.

EACH CHAPATTI GIVES: 10.8G FAT /1G PROTEIN /1G CHO



CLASSICAL 5.17:1 RATIO

CHO: 2.24G
FAT: 21.70G
PROTEIN: 1.96G
KCAL: 212

ONION BHAJIS

INGREDIENTS

50g Eggs
40g Almond flour flurry - HOLLAND & BARRETT
90g Onions
20g Vegetable oil

You will also need 1 teaspoon of ground cumin, 1 teaspoon of ground coriander, ¼ teaspoon of salt and extra oil for frying.

METHOD

Slice the onion as finely as you can. Put the frying oil into a deep sided frying pan and heat. Mix together the almond flour, spices and salt, beat in the egg and 20mls of oil to make a batter. Add the onion and coat well in the batter. When the oil is really hot drop spoonful's of the onion mixture in and cook for a minute or two, then turn to cook evenly on the other side, you should get 6 bhajis. Do not cook too many at the same time. When they are crisp and brown, remove from the oil and place on kitchen roll. Serve as soon as possible

MO'S TIPS

Each bhaji will have a little extra fat as it will be taken up from the cooking oil. If you need to know the amount, weight the oil before heating then weigh it again after cooking, you can then calculate how much was used. If you have any left over for another meal, they will reheat in a hot oven quite well.



MKD
9.96G CHO TOTAL
1.6G CHO PER PORTION
CHO: 9.96G
FAT: 46.97G
PROTEIN: 15.60G
KCAL: 525

CHRISTMAS PUDDING

INGREDIENTS

20g Coconut powder - EAST END or TRS
11g Double cream - MORRISONS
16g Eggs
8g Shelled pecan nuts - MORRISONS
2g Raisins
8g shredded suet - ATORA

CLASSICAL 4:1 RATIO

CHO: 3.87g
FAT: 32.33g
PROTEIN: 4.21g
KCAL: 323

METHOD

Reserve the cream for serving. Grind the pecan nuts until fine, chop the raisins in to small pieces (snip with scissors). Combine ALL ingredients with the beaten egg and 15mls Alpro light or water. Place in a lightly oiled pudding basin and steam for at least 20 minutes. Serve with the cream.

MO'S TIPS

You can make this as two smaller puddings and serve as a snack or dessert. I used SUKRIN GOLD because it gives a lovely flavour and texture, but you can use any granular sweetener of your choice. If you have a suitable bowl, you can cook in the microwave on high for 1 - 2 minutes. Check after 1 minute.



Save the date

MATTHEW'S FRIENDS WILL BE HOSTING THEIR ANNUAL KETOCOLLEGE PROGRAMME
4TH - 6TH JUNE 2019 - CROWNE PLAZA FELBRIDGE HOTEL, EAST GRINSTEAD, WEST SUSSEX, UK

AN ADVANCED CPD COURSE FOR NEW AND REFRESHER KETOGENIC THERAPY LEARNING AND NETWORKING.

In its 4th year, KetoCollege 2019 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. Registrations are welcome from allied medical health care professionals currently working with or looking to expand their knowledge of Ketogenic Dietary Therapies.



Scientific Committee
Chair Professor
J. Helen Cross OBE

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

RCPCH APPROVAL PENDING | CONVENIENTLY LOCATED ONE HOUR TRAIN FROM LONDON AND 20 MINS TAXI FROM LONDON GATWICK



PLEASE ENSURE YOU CHECK PRODUCT LABELS FOR VALUES.

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

More than a ketogenic food!

Did you know, you can use keyo® to have a ketogenic shake or a tasty ketogenic hot chocolate, simply add soya milk and mix, then gently heat to create a hot chocolate. To find out more, visit VitaFlo's recipe website www.myketogenicdiet.co.uk
Always check with your dietitian for what is suitable for you.



Innovation in Nutrition

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WARNING: SLIM PASTA CHECK YOUR VERSION!

Attention has been drawn to the different types of so-called low-carb/carb free versions of slim pasta that are currently available in the supermarkets.



This version of slim pasta says it is Carbohydrate free.



However, this version of slim pasta is quoted as having 8.4g of Carbohydrate contained per 100g of product.

As with all your ingredients – make sure you regularly check the labels to see if food values have changed, especially if the product has 'new and improved' on the front or is labelled as 'improved recipe'. It is always useful to make sure you go through your cupboards and keep an eye on things.



The Natural & Low Carb Kitchen team have been keeping very busy this year!



Putting our focus on improving our already popular range of delicious ketogenic ready meals, many of the recipes have now been carefully reformulated to offer a cleaner ingredient list, reduced carbohydrate level and an increase in those tasty fats. Our dishes now range from only 0.8g to 6g carbohydrates per portion and are conveniently ready to eat in just a few minutes.

We're also excited to share with you FattBar, our delicious ketogenic snack bar range that launched in the UK in May. FattBars are 100% natural and truly sweetener free - no stevia, no erythritol, no polyols, no sorbitol, no xylitol! Sweetened only with chicory fibre and inulin they are high in pre-biotic fibre, and packed with nuts and seeds for a hit of fat fuelled energy. Available now in 3 delicious flavours; Caramel & Sea Salt (2g carbs), Coconut & Macadamia (3g carbs), and Raspberry & Seed (4g carbs).

www.nlckitchen.com

Ketogenic way of eating (woe): can it make a difference in lipedema and other lymphatic and fat disorders?

BY LESLYN KEITH, OTD AND CATHERINE SEO, PHD

Catherine Seo, PhD and Leslyn Keith, OTD met at the first National Institutes of Health (NIH) symposium on lymphatics held in Bethesda, Maryland in 2015. Catherine was impressed with Leslyn's research presented at the symposium on the Ketogenic Way of Eating (WOE) applied to the management of lymphedema and obesity (Keith, et al., 2017).

The participants in Leslyn's study who implemented a Ketogenic WOE achieved greater weight loss, percent body fat decrease, and limb volume reduction than those who chose not to adopt this eating plan. The NIH meeting was fortuitous for Catherine and Leslyn. They have been working together ever since on a path of discovery for people with lymphatic disorders in general, and lipedema specifically.

Heather's Story

Heather tried everything to lose weight for over 40 years - unsuccessfully. No matter how many times she earnestly tried to explain her efforts and failures, as a fat woman (unknowingly Stage 3 lipedema), her pleas for help were dismissed by clinicians. That all changed when she saw the documentary, *The Disease They Call FAT - Lipedema*.



Heather wrote to us:

"I was just so tired of being fobbed off, shamed and insulted. I was sick of leaving doctor's offices feeling worse than when I walked in. This part of my life needed to change."

I needed to be heard. Being diagnosed was wonderful...to finally put a name to it, to have a doctor who didn't insinuate that I did this to myself and that the fat was my fault, was euphoric... It's not my fault, I'm not alone, and it's not the end of my story."

What is Lipedema?

According to *Lipedema - The Disease They Call FAT: An Overview for Clinicians* lipedema (lipoedema in Europe) is an inherited genetic disease, affecting at least 11% of women of all sizes, from the extremely thin to the morbidly obese, resulting in localized fat that is bilateral, symmetrical and usually from the waist to just above the ankles. It can also affect the upper arms. Unlike the "normal" fat of obesity, lipedemic fat cannot be lost through diet and exercise. It is not uncommon for the comorbidity of overweight or obesity to accompany lipedema. Allen and Hines, physicians at the Mayo Clinic, first named lipedema in 1940 (Wold et al., 1951).

can become increasingly heavy in their affected limbs. The multiplying and expanding fat cells interfere with pathways of lymphatic vessels, resulting in gradually worsening swelling. Lipedemic fat can be very painful, the condition can worsen as it advances, and women can become progressively less mobile.

The Path to Successful Outcomes

Heather was one of the first to sign up for a pilot group offered by The Lipedema Project in Fall 2016. At the time a small group of 16 brave women were willing to be pioneers to explore the possibility of making a difference in their condition through a ketogenic WOE. Something new started to emerge as women reported a steady weight loss, reduction of symptoms such as pain, swelling and inflammation, and an overall sense of increasing well-being.

At 10 weeks Heather wrote us:

"2 1/2 month measure: I have lost 24 inches in total (61cm) Which includes 3 1/2 inches (9cm) off my hips and 3 inches (8cm) off my waist and 3 inches (8cm) off each upper thigh, 1.5 inches (4cm) off each upper arm."

On the down side I have lost nearly an inch off my bust. Official 10 week weigh in: weight lost: 24kg (53 pounds) Doc kept checking the numbers... couldn't believe it."



Believed to be hormonal in nature, lipedema usually begins at puberty, but can be triggered or exacerbated during or after pregnancy, at peri-menopause, and following major surgery. As lipedema progresses, women with the disorder



To date Heather has lost 90 pounds, no longer needs walking sticks, plays with her young son Ace, and overall reports feeling "freer than I could ever have believed."

Why Does Keto Work for Lipedema?

Keto WOE, low carbohydrate, moderate protein, high fat, is radically different from the more common high carbohydrate diet recommended and consumed by most industrial nations. Anecdotally, it appears that women with lipedema must severely restrict carbohydrate consumption to less than 20 grams per day as well as eliminate all artificial sweeteners, fruit and seed oils.

Today almost 7,000 women worldwide with lipedema have joined together in a support group. They are contributing to a growing bank of anecdotal success stories. These narratives include accounts of weight lost, pain diminished or completely resolved, upper and lower body measurements

decreased, blood panel results improved, and quality of life increased. We are still learning about why this way of eating seems to work so well. We developed and are offering a MasterClass that is a comprehensive approach including physical, mental/psychological, emotional, spiritual, and social aspects of managing and treating lipedema. We plan further research in a clinical trial, but in the meantime thousands of women with lipedema are having their lives transformed merely by changing how they eat.

References

- Keith, L, Rowsemit, C & Richards, L. (2017). Lifestyle modification group for management of obesity and lymphedema results in significant outcomes. *American Journal of Lifestyle Medicine*, doi.org/10.1177/1559827617742108.
- Dayan, E, Kim, JN, Smith, ML, Seo, CA, et al. (2017). *Lipedema - The Disease They Call FAT: An Overview for Clinicians*. Boston, MA: Lipedema Simplified Publications, The Friedman Center for Lymphedema Research and Treatment at The Center for Advanced Medicine at Northwell Health in collaboration with Lymphatic Education & Research Network (LE&RN).
- Wold, LE, Hines, EA & Allen, EV. (1951). Lipedema of the legs: A syndrome characterized by fat legs and edema. *Annals of Internal Medicine*, 34(5), 1243-1250.

Resources

- <https://keto.lipedema-simplified.org/>
- <https://lipedemaproject.org/>
- <https://www.facebook.com/groups/LipedemaKetoWOE/>



FREE COPIES OF OUR RESOURCES ARE AVAILABLE TO FAMILIES AND PROFESSIONALS

If you would like to order a copy of any of these then please email our office on enq@matthewsfriends.org

- Introduction and preparation for medical ketogenic Therapies in Children.
- Introduction to ketogenic Therapy for adults with Epilepsy.
- Introduction to Medical Ketogenic Dietary Therapies.
- Colour and Shine - a Guide to making meals for adults and young people on Ketogenic therapy (patients can obtain this booklet via their dietitian).
- I am going on a ketogenic diet - a social story for children and their families going onto a ketogenic diet.

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 [Facebook](#) Matthew's Friends and Twitter [@matthewsfriends](#) for up to date news on all our events. Please support us and request an MF fundraising pack today from enq@matthewsfriends.org



BLACK COUNTRY HALF MARATHON FINISHED FOR MATTHEW'S FRIENDS

Jessica ran the Black Country Half Marathon for Matthew's Friends and raised £212 plus gift aid

Here's what she said...

'I am running the half marathon for Matthews Friends because they helped my foster niece when she was put on the ketogenic diet. They helped us so much while she was on the diet we could contact them 24/7 and they would help us no matter what. I just want to thank them by raising money for them to help other people get the help they need. Thank You for reading. Thank You ever so much for the donations.'

THANK YOU SO MUCH FOR YOUR SUPPORT JESSICA!

ROYAL PARKS HALF MARATHON

These 3 lovely people, Justyna Rundle, Rosie Streater & Martin Jukes all took part in the Royal Parks Half Marathon in October to raise funds for Matthew's Friends.

Between them they have raised almost £1300!!

Fabulous effort – thank you so much for your fantastic support!



Rosie and Martyn bumped into each other at the end, both looking very fresh after running 13.1 miles!



Justyna proudly showing off her finisher's medal. This was her first ever half Marathon!

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 2019 and beyond, thank you.