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SUMMER/AUTUMN NEWSLETTER 2018 • EIGHTH EDITION

# Ketogenic Therapies

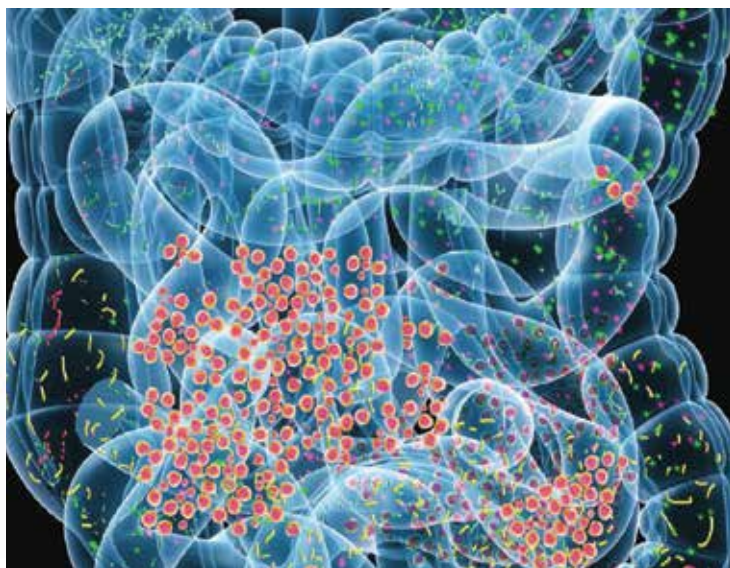
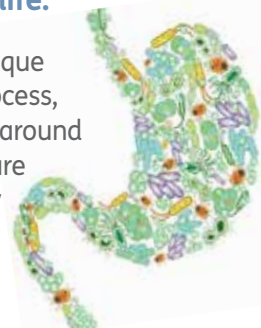
## Newsletter

# COULD GUT BACTERIA HOLD THE KEY TO SEIZURE CONTROL?

Living on and within us, is an unseen world of micro-organisms; bacteria, fungi, viruses and other classes of microscopic life.

Each one of us carries our own unique mix, influenced by our birthing process, the food we eat, the environment around us, exposure to antibiotics, exposure to disease, our genetics and many other influences.

See page 3 for full story.



KETOCOLLEGE AND THE 2ND EUROPEAN GLUT1 CONFERENCE WERE HELD IN JUNE, SEE INSIDE FOR NEWS AND PHOTOS.



GO

#SUGARFREEFOREPILEPSYIN NOVEMBER FOR MATTHEW'S FRIENDS  
VISIT [WWW.MATTHEWSFRIENDS.ORG](http://WWW.MATTHEWSFRIENDS.ORG) TO JOIN OUR CAMPAIGN!





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TO HELP FUNDRAISING VISIT:

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

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



## 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](mailto:info@mfcclinics.com)  
and visit [www.mfcclinics.com](http://www.mfcclinics.com)



# COULD GUT BACTERIA HOLD THE KEY TO SEIZURE CONTROL?

Living on and within us, is an unseen world of micro-organisms; bacteria, fungi, viruses and other classes of microscopic life. Each one of us carries our own unique mix, influenced by our birthing process, the food we eat, the environment around us, exposure to antibiotics, exposure to disease, our genetics and many other influences.

Our microbiota is essential to our health, a vital 'organ' on par with our liver and there is growing appreciation it plays an important part in brain health, with emerging evidence pointing to involvement with various psychiatric and psychological conditions such as depression, autism, stroke, Parkinson's disease and Alzheimer's disease. However, recently published research has now brought this fascinating microbial dimension to the attention of the epilepsy world.

One study found that the microbiota of infants with refractory epilepsy differed dramatically from that of healthy controls; noting a higher dominance of microorganisms known to be harmful alongside a decrease in those considered beneficial. However, when they re-examined the profiles after only one week on a ketogenic diet, they noted a significant improvement towards the microbial profile seen in healthy infants<sup>1</sup>.

Another recent study used a mouse model of epilepsy to investigate whether gut bacteria could play a role in the anti-seizure effects of the ketogenic diet. They found that mice fed the diet had substantial changes in their gut bacteria after about four days and experienced fewer seizures compared with mice fed a non-ketogenic diet. When they then examined the effect of the ketogenic diet on sterile mice (ie raised in a sterile environment or treated with antibiotics to kill their microbiota), they found that the diet no longer protected them from seizures. When they studied the bacterial colonies in the mice on ketogenic diet, they found that two species were particularly elevated.

If they transplanted these bacteria into the bowels of the sterile mice on ketogenic diet, the anti-seizure effect could be restored. Remarkably they also reported that they could convey seizure protection to mice on a standard diet simply by inoculating their bowels with a combination of these bacteria; with neither working if given alone<sup>2</sup>.

**"Each one of us carries our own unique mix, influenced by our birthing process, the food we eat, the environment around us, exposure to antibiotics, exposure to disease, our genetics and many other influences."**



Many more studies in animals, followed by trials in humans will be required before condition specific probiotics or faecal transplants are evidenced as an effective treatment strategy for a range of conditions. In the meantime, as the power of this unseen world becomes more evident, we realise how valuable and relevant our diet and lifestyle are to influence this. We jokingly talk about 'eating for two' during pregnancy but the reality is that we are all 'eating for billions' throughout our entire life.

For a background summary of probiotics and prebiotics please refer to <https://www.healthline.com/nutrition/probiotics-and-prebiotics>

#### REFERENCES:

Ketogenic diet poses a significant effect on imbalanced gut microbiota in infants with refractory epilepsy. Lead author Gan Xie. World Journal of Gastroenterology 2017; 23(33):6164-6171. <https://doi.org/10.3748/wjg.v23.i33.6164>

The gut microbiota mediates the anti-seizure effects of the ketogenic diet. Lead author Christine A Olsen. Cell 2018 <https://doi.org/10.1016/j.cell.2018.04.027>

Sue Wood RD



## WELL DONE GREG!

**MASSIVE well done to Greg Aldridge who raised £4826 completing the London Marathon for us in the brilliant time of 4hrs 38mins 39secs.**

It was a fantastic achievement – Greg was on the ketogenic diet himself when he was a child as part of the clinical trial that took place at Great Ormond Street Hospital published in 2008.

His life has turned around and now he is running a marathon, playing golf daily and playing football for Chelsea pan disability team. We are so very proud of him. Greg is the son of Val Aldridge who many families know from our Clinic team as she is our Dietetic Assistant and Greg's Dad, Richard is also a Trustee for the charity.





# KETOCOLLEGE CLASS OF 2018

19th – 21st June saw the 3rd annual UK KetoCollege programme held, where approaching 100 health care professionals, including 54 registered dietitians, from 17 different countries, came together for an exciting agenda of Ketogenic Dietary Therapy scientific and practical presentations and workshops.

International and UK expert Mentors delivered the in-depth presentations and workshops to hospital dietetic teams that are new to the rapidly-expanding, exciting area of medical Ketogenic Diets.

*“Such a fantastic course, practical and useful for my clinical practise”*

*“I am new to this and the whole day was very interesting, interesting facts and hands on advice by experienced speakers”*

## KetoCollege 2019:

Save the Date: **4th -7th June 2019**

Register Interest:  
[ketocollege@mfclinics.com](mailto:ketocollege@mfclinics.com)

Programme and Booking information:  
[www.mfclinics.com/keto-college/](http://www.mfclinics.com/keto-college/)

We thank the kind sponsors of KetoCollege 2018, that helped make the event unbiased and informative for all; Nutricia, Vitaflo, Ketocare, Cambrooke and Desitin Pharma.



Chef Derek from Nutricia absolutely knocked it out of the park for this year's 'show stopper' on the Nutricia stand - the cake was entirely sugar free (not necessarily carb free but certainly low carb). Just shows what can be done!



Our KetoCollege Keto Chefs - Mo, Derek and Neil who did an incredible job of demonstrations, not only in the teaching hall but also in the exhibitors space, providing delicious samples of different recipes for the whole 3 days. The food was amazing, you really are KETOSTARS!



Our Ketocook Mo sharing her knowledge on the MF stand.



China team - hard at work with our Medical Board Mentor, Helen Grossi RD.



## Kerry tells us about her daughter Hannah and her experience on the Ketogenic Diet. Hannah is 5 years old and has PDHD (pyruvate dehydrogenase deficiency).

“Hannah has been on the ketogenic diet now for over a year and it's the best decision we've made for her. She has developed in all areas both physically and mentally, she has lots more energy and even sleeps better!

She was underweight but is now thriving at a very healthy weight.

It took a few months to get to know the diet and for Hannah to get good ketones, but we were very patient and continued with it as it doesn't only work for her epilepsy but her PDH deficiency too! She has a lot more colour to her and barely ever naps through the day, she was so lethargic before.

She now has no high lactic acid or dehydration in her bloods, all her bloods have been spot on since starting.

She has good bowel movement and has started being very vocal and alert (she used to cry all the time).I

recommend this diet to anyone that has been offered it or considered it... once you get the swing of things it's easier to manage and we've always had full support especially from Sheffield Children's Hospital.

Dr Desurkar has been there all the way and the Dietician we have, Hannah Taylor, is absolutely fab, she is always on the other end of the phone or we email whenever we need her help, whether it's to ask how much of a piece of fruit she can have or whatever. It really has been a god send and it's prolonging Hannah's life giving her all the vitamins she needs. Hannah has also been seizure-free since April!”

We couldn't be happier for Hannah and her family - their positivity shines through in Kerry's words! We are looking forward to meeting up with the family and other PDHD families at the annual meeting of The (fantastic) Freya Foundation later this year.



Hannah pre diet.



Hannah pre diet.



Hannah on diet.



Hannah on diet.

## About PDHD

Pyruvate dehydrogenase deficiency is characterized by the build-up of a chemical called lactic acid in the body and a variety of neurological problems. Signs and symptoms of this condition usually first appear shortly after birth, and they can vary widely among affected individuals.

The most common feature is a potentially life-threatening build-up of lactic acid (lactic acidosis), which can cause nausea, vomiting, severe breathing problems, and an abnormal heartbeat. People with pyruvate dehydrogenase deficiency usually

have neurological problems as well. Most have delayed development of mental abilities and motor skills, such as sitting and walking.

Other neurological problems can include intellectual disability, seizures, weak muscle tone (hypotonia), poor coordination, and difficulty walking.

Some affected individuals have abnormal brain structures, such as underdevelopment of the tissue connecting the left and right halves of the brain (corpus callosum), wasting away (atrophy) of the exterior part of the brain known as the cerebral cortex, or patches of damaged tissue (lesions) on some parts of the

brain. Because of the severe health effects, many people with pyruvate dehydrogenase deficiency do not survive past childhood, although some may live into adolescence or adulthood.

Source: The Freya Foundation  
([www.thefreyafoundation.co.uk](http://www.thefreyafoundation.co.uk))





# 2ND EUROPEAN CONFERENCE ON GLUT1 DEFICIENCY

**A successful second European Conference on Glut 1 Deficiency organised by Matthews Friends was held on 22nd/ 23rd June at the Crown Plaza Felbridge, East Grinstead, Surrey.**

The Conference was an opportunity for families and professionals to learn together as well as providing access to professionals working in the field of Glut 1 Deficiency by the families.

The Keynote Lecture was given by Dr Darryl De Vivo, who is one of the world's foremost authors on Glut 1 Deficiency as well as being the man that actually discovered Glut 1D as a rare disease in the first place.

He spoke about Glut1 Deficiency (1991-2018) and his hopes for future screening for this disease so that patients are not 'missed', so that treatment can start as soon as possible which will obviously give them the best possible outcome. It is fair to say that to listen to this lovely man speak is truly inspiring and he was in great demand throughout the 2 days by both families and professionals alike.

There was a varied, informative Scientific Programme on Day 1 where a number of speakers discussed the up to date studies they are working on across Europe on aspects of Glut 1 treatment. This included an overview of the current research and the basic science by Professor Stephane Auvin, the Decanoic Acid Trial presented by Professor Helen Cross and Movement Disorders in Glut 1D presented by Dr Valentina De Georgis.



Dr. Darryl De Vivo, one of the world's foremost authors on Glut 1 Deficiency

Day 2 gave the families an opportunity to discuss their own specific issues with the professionals in a workshop setting. These workshops looked at the Ketogenic Diet Therapies in Infants and Paediatrics, with a different group looking at Ketogenic Diet in Puberty and adults. The other workshops discussed Movement disorders and Triheptanoin and Decanoic acid.

The families attending these workshops found them extremely useful and it is becoming quite clear that as our Glut 1D children grow up, the movement disorder is becoming a bigger problem. There was a great

amount of discussion as to where future focus needs to be with regards to research and treatment for this but sadly at the moment, it seems our professionals are learning along with our families.

The final session looked at the subject of transition and adults with Glut 1D where a range of experiences across Europe and the USA were discussed.

The exhibition hall was very busy too, with many stands demonstrating very tasty keto samples and it was great to see our Glut 1D kiddies able to sample a variety of goodies.

There were also some fun activities for the children attending and the MF team put on face painting, magician, disco dancing, puppet show, arts and crafts, games, videos and films.

The Conference was very well received with both families and professionals finding it very useful. Much networking was done among the professionals and research projects discussed which can only give further hope for the future treatment of Glut1 Deficiency.



First meeting of the Glut 1D consensus group led by Professor's Kossoff and Klepper



Professor Joerg Klepper.



Glut1 audience.



Panel discussion with professionals.



Emma with the lovely Dr. De Vivo and his wife.



Matthew and his friend Parys.



A variety of keto goodies went down very well!

During the course of this meeting there was also a breakfast meeting among the patient advocacy groups to discuss further a European Federation for Glut 1D and the professionals met in order to discuss a Global Consensus statement for Glut 1 Deficiency, this is being led by Professor Eric Kossoff and Professor Jeorg Klepper, we also recorded several interviews with some of the main speakers and you can access these via the Matthew's Friends

website using the following link: [www.matthewsfriends.org/glut1uk/](http://www.matthewsfriends.org/glut1uk/) Many thanks to the speakers and the and the sponsors, Ultragenyx, Nutricia, Vitaflo, Dr Schar, Ketocare and Metafora, who made this meeting possible.

Visit [www.matthewsfriends.org](http://www.matthewsfriends.org) Glut1 section to view our #TalkingGlut1 films from the conference.

The 3rd European Conference will be held in Lille, France in 2020.



Matthew's sister Alice made a new friend at the Glut 1 conference and the handsome chap is Craig.

*"I just wanted to say thank you for an amazing conference. It was the first time we had met other families with Glut 1 and it was great to share stories and learn so much about the condition. A big thank you also to the great team who looked after the little ones and kept them so well entertained. It has been a tough year but this has been a real positive for us."*  
All the best, Sarah, Barry and Jess Tibble

## Statement of Interest - your involvement is requested!

The Conference brought together countries from around the world, educating and supporting, bringing Professionals and families together with the intention of spreading knowledge of G1D, it's treatment the Ketogenic Diet, and possible alternatives.

At the conference a new G1D European Federation planning meeting was held.

A representative from Italy, France, Spain, Belgium, Poland, Denmark, Estonia, Germany, Russia, Finland, and the UK, came together to discuss issues surrounding G1D, set goals, and begin the early steps to get the initiative off the ground.

Whilst at this conference Trudy Morgan, G1D parent and the

current European Glut1 Deficiency Foundation Outreach Director and Emma Williams MBE, CEO of Matthew's Friends Ketogenic Dietary Therapies Charity, discussed moving forward the G1D community within the UK. Although Matthew's Friends has been 'acting' as the UK Group for a while obviously as a Ketogenic Diet Treatment charity, the group also has many other commitments, so they are keen to see an official UK G1D group started.

Trudy Morgan is now leading this initiative with any new independent group formed continuing to work alongside Matthew's Friends and the Glut1 Deficiency Foundation. Trudy is looking forward to taking these exciting new steps both as a formal UK Parent organisation and an important part of the European Federation of G1D.

If you would like to help, or have further questions please contact: [tmorgan@G1DFoundation.org](mailto:tmorgan@G1DFoundation.org)



Trudy Morgan  
European Outreach Director  
Glut1 Deficiency Foundation  
[tmorgan@G1DFoundation.org](mailto:tmorgan@G1DFoundation.org)



Emma Williams MBE  
Founder/CEO - Matthew's Friends  
for Ketogenic Dietary Therapies  
[emma@matthewsfriends.org](mailto:emma@matthewsfriends.org)



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

The Matthew's Friends team have been out and about as usual presenting at various meetings and conferences, educating professionals and the public about Medical Ketogenic Dietary Therapies and the need for increased NHS services and further clinical research into other areas where these diets could be helpful.

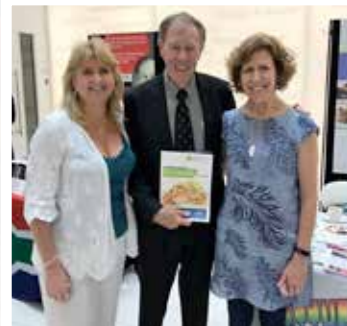
Here is a brief snapshot of what we have been doing. If you would like us to attend your event, or provide you with information then please do not hesitate to contact us.

## CANCER RESEARCH UK MEETING 1ST, 2ND AND 3RD MAY



Sue Wood RD attended this meeting on behalf of Matthew's Friends together with Katie Sheen from the Astro Brain Tumour fund who partner us in our work with Brain Tumour patients. Here we see them both with our poster on show on giving some further information on our work.

## PUBLIC HEALTH COLLABORATION CONFERENCE 19TH AND 20TH MAY



Emma Williams and Sue Wood with Professor Tim Noakes



Emma Williams and Sue Wood at our charity stand

Our Founder, Emma Williams MBE, is a Patron for this organisation which campaigns for better health, promoting using REAL FOOD and a change in the standard guidelines where fat is still vilified and a high carbohydrate diet is promoted. Emma and Matthew's Friends dietitian, Sue Wood, attended both days with our educational materials.

Guest Speaker was Professor Tim Noakes, he 'came out' stating that after years of promoting a high carbohydrate diets for sport, he was wrong, it was a high fat diet that was needed! He has written several books and a favourite one we recommend is The Real Meal Revolution. If you want to know more about this organisation and the work they do then please visit [www.phcuk.org](http://www.phcuk.org).

Trustee Julie and her volunteer husband Dave, attended the Angelman UK weekend family conference in August, held in Coventry. The agenda was a packed one, with many activities for the Angelman children and their families, as well as a busy programme of talks and presentations. We were delighted to meet so many lovely families and talk about Ketogenic Dietary Therapies (KDT) for drug-resistant seizures.

Julie attended the Epilepsy workshop provided by Professor Dan, who gave a great overview of epilepsy and seizures, covering treatment options, including KDT. We are happy to attend appropriate family meetings whenever and wherever we can. For more information about Angelman Syndrome, visit [www.angelmanuk.org](http://www.angelmanuk.org).

## EUROPEAN NEUROCONVENTION, EXCEL LONDON - 6TH AND 7TH JUNE



Emma Williams with Neil Binderman at the Neuro Convention

Dr Elizabeth Neal RD and Nutritional Therapist and Dietetic Assistant for Oncology, Catherine Zablowicz, both from Matthew's Friends clinics, were asked to speak at this 2 day convention.

Dr Elizabeth Neal spoke about Ketogenic dietary therapy with Epilepsy and Catherine spoke about our work with Ketogenic Diets and Brain Tumours, we had the added bonus that Neil Bindemann was also at the convention who is on the ketogenic diet to help manage symptoms with his brain tumour. His story is quite inspiring and he was able to reassure people that the diet wasn't so hard and he was feeling so much better for doing it. Both of our sessions were full and there was a great amount of interest on our charity stand too with lots of information being taken.

## EPILEPSY ACTION REGIONAL MEETING, GUILDFORD, SURREY - 6TH JUNE



Above: Neil and Catherine presenting at the Neuro Convention

Emma Williams was asked to attend the meeting and make a presentation about the Ketogenic Diet its use for adults.

It was a lively evening and some great new friends were made and plenty of information given out about how dietary therapy can be easily managed for adults, but we just need more service. Emma would like to take this opportunity to thank the group for inviting her as she really enjoyed meeting everyone and had a great evening.

# SAVE THE DATE !

## 3<sup>RD</sup> EUROPEAN GLUT 1D CONFERENCE

JUNE 5-6, 2020 - LILLE, FRANCE



For more information : [GLUT1-FRANCE2020@ant-congres.com](mailto:GLUT1-FRANCE2020@ant-congres.com)



## A Tribute to a very special young woman and her family

At Matthew's Friends we have the absolute honour of knowing some incredible families and their children. When we first set up the charity nearly 15 years ago, one of the first families we met via our online forum was Beatrice and her daughter Frances.

Frances was helped by the diet but she did eventually come off it as most children do after a couple of years. However, 'once a Matthew's Friend, always a Matthew's Friend' as our saying goes. Beatrice has kept in touch with us over the years and let us know how Frances was doing.

Sadly the email that popped into Emma's inbox this time was one that was not welcomed or wanted as Beatrice told us that she had

lost her beloved Frances to the 'Epilepsy Monster' after 6 long weeks in hospital. Frances fought very hard but in the end, it was her time to go. The Family are obviously heartbroken but wanted to let their 'keto family' know the news. Beatrice said...

"I wanted to thank you for all the support we have received from Matthews Friends over the years. If Frances hadn't been on the keto diet, she would have been



completely lost in her 'seizure fog'. The diet gave her back some clarity and alertness that made her last few years worth living."

Beatrice also wanted to pay tribute to her local community.. "We have been very fortunate to live in a community as supportive as Orkney, we really couldn't have asked for more"

### Emma Says;

*"As a parent of a special needs child, you get used to fighting for them all of the time and Frances certainly had the best on her side, fighting for her. Frances's family never stopped making sure that she got the best care possible and was as happy as possible throughout her life. It is always the small things that can matter the most at times and I remember working with Beatrice to see how we could get as much apple as we could into her ketogenic diet as Frances loved apples.*

*Beatrice would leave no stone unturned... if apple is what Frances wanted, then apple she was going to get.... somehow.... and she did! We had to get creative with the rest of the diet but we got apple in there. Frances was a very brave young lady that had endured so much in her short life but brought great joy to her family and those who knew her. My heart goes out to Beatrice and the family at this terribly sad time and all of us at Matthew's Friends send much love - it has been an honour to be a very tiny part of such a special young lady's life and to support such an incredible family".*

## 6th Global Symposium on Ketogenic Therapies for Neurological Disorders

We are very much looking forward to the bi-annual 6th Global Symposium on Ketogenic Therapies for Neurological Disorders, being held October 5-9th in Jeju, South Korea.

This is the first time that the symposium will be held outside of USA/Canada and the UK, a truly global meeting! As part of our charity mission to support education and research for Ketogenic dietary therapies, we are proud sponsors once again of this key event. Alongside our exhibit table, we also have two speakers from the Matthew's Friends organisation, presenting at

the meeting, as well as members of our medical advisory board. Susan Wood, MF Clinics specialist ketogenic dietitian and Jennifer Fabe, President of Matthew's Friends Canada and specialist ketogenic dietitian, will be speaking on 'How parent support groups may help' and 'Initiation of the Ketogenic Diet', respectively. We will report back on the symposium in our next newsletter!



Jennifer Fabe



Susan Wood

## The 2018 Global Consensus paper is now officially out

Professor Eric Kossoff from Johns Hopkins Hospital, Baltimore, USA, leads The Global Consensus group which brings together some of the worlds leading experts in Dietary Therapy.

Matthew's Friends are delighted to have members of our own medical board included in this group as well as our endorsement of the document as a whole.

We feel that this is one of the most useful papers you can have and refer to. You can read the entire document online using the link shown below, it is freely available to all. The summary of the paper is as follows:

Ketogenic dietary therapies (KDTs) are established, effective nonpharmacologic treatments for intractable childhood epilepsy. For many years KDTs were implemented differently throughout the world due to lack of consistent protocols. In 2009, an expert consensus guideline

for the management of children on KDT was published, focusing on topics of patient selection, pre-KDT counseling and evaluation, diet choice and attributes, implementation, supplementation, follow-up, side events, and KDT discontinuation. It has been helpful in outlining a state-of-the-art protocol, standardizing KDT for multicenter clinical trials, and identifying areas of controversy and uncertainty for future research. Now one decade later, the organizers and authors of this guideline present a revised version with additional authors, in order to include recent research, especially regarding other dietary treatments, clarifying indications for use, side effects during initiation and ongoing use,



value of supplements, and methods of KDT discontinuation. In addition, authors completed a survey of their institution's practices, which was compared to responses from the original consensus survey, to show trends in management over the last 10 years.

<https://onlinelibrary.wiley.com/doi/epdf/10.1002/epi4.12225>

A massive thank you to Eric and all the contributors for producing this Consensus Paper.

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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# Calling all our Scottish Professionals and Families....



Matthew's Friends are proud to be included in the consultation process for Ketogenic Dietary therapies (KDT) in the new Scottish Intercollegiate Guidelines Network (SIGN) for Epilepsy in Children.

Our Founder/CEO Emma Williams has been working with the team updating the information for KDT in Scotland and now the stage has been reached where there is a National Open Consultation meeting for the new guideline in its entirety – the details of this meeting are below together with all the relevant contact information should you wish to attend.



## SIGN guideline: Epilepsy in children

GET INVOLVED

### National Open Consultation Meeting 12.30 – 16.30 8 November 2018

Hotel Colessio  
33 Spittal Street  
Stirling FK8 1DU

To register for this meeting please go to [https://sign\\_epilepsy.eventbrite.co.uk](https://sign_epilepsy.eventbrite.co.uk)

For further information please contact  
**Euan Bremner:** [euau.bremner@nhs.net](mailto:euau.bremner@nhs.net)  
**0131 623 4729**

#### What is SIGN?

SIGN stands for Scottish Intercollegiate Guidelines Network. SIGN is part of Healthcare Improvement Scotland which is a public body that provides advice and guidance to the NHS in Scotland.

#### SIGN guideline: Epilepsy in children

- SIGN is developing a guideline for epilepsy in children working with doctors, nurses and other NHS staff, as well as with charities, patients, carers and members of the public.
- The first draft of this guideline will be shared with doctors, nurses and other NHS staff, as well as with patients, carers and members of the public at a meeting on 8 November 2018 in Stirling.
- The guideline will be published in summer 2019, with a version for parents, carers and families published after this.



## Save the date

**MATTHEW'S FRIENDS WILL BE HOSTING THEIR ANNUAL KETOCOLLEGE PROGRAMME**

**4<sup>TH</sup> – 7<sup>TH</sup> 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.

For further details please visit [www.mfclinics.com/keto-college](http://www.mfclinics.com/keto-college)  
or to register your interest please email: [ketocollege@mfclinics.com](mailto:ketocollege@mfclinics.com)

**RCPCH AND BDA CPD APPROVAL PENDING**



## It's all in the dough!

We've developed new recipes to add to our keto bread range.

#### We now have keto recipes for:

- Chapati
- Tortilla wrap
- Mini Loaf
- Bread rolls
- Naan
- Pizza

These recipes add variety to the ketogenic diet. Great for lunch boxes, a side dish to main meals and used in recipes such as chicken or fish goujons.

Recipes available at

[myketogenicdiet.co.uk](http://myketogenicdiet.co.uk)





# HADRIAN'S WALL TREK

## WELL DONE TEAM MF!



### Many thanks to the MF team:

Emma and Alice Williams, Deidre Brown, Samantha Chute, Samantha Doe, Alan Burt, Allison Pettit, Michelle Maynard, Jade Cummings, Clare Szwec, Sarah Manley and Stephen Anderson.

On Friday 6th July, a team of 12 set off for Northumberland to help Matthew's Mum Emma (our Founder) and his sister Alice on Emma's 50th Birthday challenge for our charity, all of them ready to take on 26 miles of trekking and 2 nights of camping along Hadrian's Wall.

### Emma Says;

"We were extremely fortunate with the weather as it was a beautiful 2 days and the scenery was absolutely breath taking. The Trek was certainly challenging in some places and some of us liked the camping more than others – I strongly recommend a good blow up mattress! We met some lovely people along the way and our guides were all brilliant. To spend the weekend with friends, colleagues and supporters was really lovely and we even managed to listen to the football whilst on the trek as England were playing and we sang the National Anthem along the wall!"



A massive well done to all the MF team  
**who raised £3647.21**  
(some money still due in at time of writing).



MF supporters Sammy Chute and Samantha Doe settle into their accommodation.



Stephen, Sarah and Clare from Nutricia at the finish line with a well deserved drink



Emma and fellow past ketomum, Allison Pettit, completed the walk for their boys. Allison is mum to Timmy, who sadly passed away last year.



Some of whole group taking a little rest after a climb! All representing various charities which was great to see.



Obligatory 'selfie' of supporter, Sammy Chute, Admin Assistant Sam Doe and charity founder Emma Williams.

### ADVERTISEMENT



find all these super quick, simple and delicious recipes at

[www.ketogether.com](http://www.ketogether.com)

plus videos from our very own chef charlie!

keto  care  
practical solutions in medical nutrition



# New keto recipes and tutorials available now!

Lookout for our brand new films from the Matthew's Friends KetoKitchen! Mo, along with Matthew's Mum Emma and sister Alice, demonstrate various useful and tasty recipes and each film includes a link to the appropriate full written recipe on our website.



## NEW FILMS INCLUDES:

- Onion Bhajis
- Frankfurter Flan
- Keto shopping and cooking on a Budget
- Ready Steady Keto – with our Patron, celebrity chef Tony Tobin!
- Banana Bread
- Jam Doughnuts
- Chocolate Birthday cake
- Cooking with unusual veg with Tony
- + much more!



## #KetoKitchen YouTube channel

Subscribe for free and you will receive an alert each time a new film is added!

Please remember to always refer to your specialist ketogenic dietitian before adding new products to your prescribed ketogenic therapy.



# #CUT THE CARBAGE

SUPPORT KETOGENIC DIETARY THERAPY PATIENTS WHO ARE **#SUGARFREEFOREPILEPSY** EVERY DAY!

GO

## #SUGARFREEFOREPILEPSY IN NOVEMBER FOR MATTHEW'S FRIENDS

## AND RAISE FUNDS FOR CHILDREN AND ADULTS WITH COMPLEX EPILEPSY

Visit [www.justgiving.com/campaign/sugar-free-for-epilepsy](http://www.justgiving.com/campaign/sugar-free-for-epilepsy)  
and [www.matthewsfriends.org](http://www.matthewsfriends.org)



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



## Matthew's Friends awards a Research Grant of £8,715 for the treatment of Brain Cancer with Ketogenic Dietary Therapy.

The research laboratories of Dr. Adrienne Scheck (USA) and Dr. Nelofer Syed (UK) already has a proven track record of working together studying mechanisms of action of the ketogenic diet in brain tumors, with both of these doctors presenting at several of our educational meetings in the past and Dr. Adrienne Scheck serving on our Medical Board for Oncology.

In some of their work they have shown that when brain tumor cells are grown in the laboratory, a small percentage of them appear to be resistant to the growth inhibitory effects of ketones. These cells are likely to represent cells that would be resistant to the growth inhibitory effect of a ketogenic diet in an animal model. Cancers are genetically heterogeneous, that is, even the same cancer may have different molecular traits that govern not only its growth, but also its response to therapy. This is seen for all therapies currently available for the treatment of cancers. An understanding of the molecular traits that may lead to sensitivity or resistance to a ketogenic diet will lead to an ability to choose patients most likely to benefit from the therapy, thus allowing clinicians to "personalize" this therapy.



Dr. Syed says "We propose to compare the expression of genes in brain tumors derived from our standard mouse brain tumor cells and these same cells after selection for cells resistant to the growth inhibitory effects of ketones in vitro. This work will provide a large body of data that will not only provide

additional information on the anti-tumor mechanisms of the ketogenic diet, it will also provide us with a list of potential biomarkers of efficacy that could be used in patients to help determine who the best candidates are for this therapy. This work will also provide the basis for future studies that would add radiation and chemotherapy to determine if resistance to the growth inhibitory effects of a ketogenic diet also alters its ability to potentiate standard therapies."



Dr. Scheck recently made a trip to the UK to meet up with colleagues and discuss further research collaborations and some of the MF team were delighted to meet up with them for the evening to share in some of these discussions.

Many thanks to all our fundraisers and supporters who enable us make such research grants. How the ketogenic diet works, why it works and patients most likely to respond to the ketogenic diet have always been top priorities for us, so that patients can be targeted sooner and be given the help and support they need without having to wait for years.

## Position Statement

**We are being contacted more frequently by people who are wanting advice and support on ketogenic diets as a lifestyle choice.**

Obviously our information and recipes can be freely downloaded by all who need them or find them beneficial, but we felt it was time to make our position very clear as an organisation of where we stand as the waters are getting quite 'muddy' as to what are lifestyle 'low carbohydrate' diets and those who are needing MEDICAL ketogenic dietary therapies.

We are also quite concerned that those with chronic long term conditions are being encouraged to try these diets without any form of medical supervision. Although we can fully understand patients frustrations at the lack of service available, especially for adults, having appropriate supervision gives better outcomes for patients and considerations HAVE to be made for the existing conditions and the medications/treatments already in place.

If you are wanting more information on MEDICAL ketogenic dietary therapies for the management of a chronic/long term condition then please email us on [enq@matthewsfriends.org](mailto:enq@matthewsfriends.org)



**The Matthew's Friends Ketogenic Dietary Therapy organisation strongly believes that ketogenic diets used as MEDICAL therapies for people with chronic, long term conditions should ALL be managed by a specialist doctor familiar with treatment, as well as a registered dietitian with training in ketogenic dietary therapies.**

**These specialist dietary therapies have real side effects that require fine-tuning and close laboratory supervision and in the case of children, growth supervision too.**

**Matthew's Friends support the use of ketogenic dietary therapies for epilepsy and other neurological and metabolic conditions, but does NOT advocate their use without appropriate medical guidance and help.**



## CONGRATULATIONS TO OUR LATEST KETOSTARS.....

**CASTLE INN, BRADWAY: NOMINATED BY AMY CHAMBERS WHO IS ON THE KETOGENIC DIET AND HER FAMILY.**

Amy's mum Julie Chambers says...

"I would like to nominate The Castle Inn, Bradway for the Keto-Star award. They have been amazing since our daughter started the diet for her epilepsy."

"We love eating out as a family but feared it would be too difficult when Amy started her ketogenic diet. However, we have great meals out thanks to The Castle Inn. We pre-order Amy's meals in advance, they'll buy ingredients specially for her and cook something specifically for her. They make Amy's meal look special so she feels like she's having a treat too! If I bring something along for her dessert, they'll plate it up in the kitchen with cream and strawberries. Nothing is ever too much trouble for them and we still love our family meals out."

You can see here the Keto meals cooked for Amy by the Castle Inn.



**GRACIE EYRE'S FAMILY HAS NOMINATED HEATHROW CLASS, BOUNDS GREEN SCHOOL, LONDON.**

Mum Sarah says, "Before starting the diet, we were fully prepared to provide all snacks and meals for Gracie throughout her day. What we totally underestimated was the care and support that the staff in Heathrow class were going to give Gracie from day one. After meetings and discussions as Gracie started her time with them it became really clear that they were willing to listen and understand her dietary needs and weren't afraid of embracing them.

They have supported Gracie to make 'good' choices from the snack table and then ask an adult if she wants one of her special snacks which they make up for her. They monitor her lunch and take so much of their own time to make sure she eats the important bits in her lunch box. They always check what snack supplies she has and are brilliant at letting us know what she needs. If the class is going to be baking or making food they are always quick to ask what alternatives they can make with her so she doesn't miss out. I don't think Gracie would even notice she does anything differently.

From the first day Gracie started Katy and all the staff in Heathrow class have been nothing but amazing in supporting Gracie. Thank you"



**Emma Says.....**

"We have many phone calls from schools who are either worried about how to manage a child on a ketogenic diet or even worse, refusing to accommodate such a treatment and we have done many education sessions in schools around the UK. To read how well Heathrow Class and Bounds Green School have embraced the diet and supported Gracie and her family is wonderful and is a leading example to other schools of what true support looks like, they truly are KetoStars!"

At Matthew's Friends, we know and understand how vital 'support' is when on a prescribed Ketogenic Dietary Therapy. We want to recognise not only the patients, be they children or adults, but also those around them that contribute so much and can make the difference between success and failure.

This is your opportunity to say 'Thank You' to a special person or family member, group, school, hospice. Perhaps a certain restaurant or hotel has gone that 'extra mile' that has helped your family eat/holiday together happily?

**Visit [matthewsfriends.org](http://matthewsfriends.org) AND NOMINATE YOUR KETOSTAR!**





# KETOGENIC DIET THERAPY FOR ADULTS: LET THEM EAT FAT!



**By Susan Wood**  
Specialist Dietitian; Ketogenic Therapies,  
Matthew's Friends Clinics & Charity

**Susan works full time for Matthew's Friends Clinics and Charity as a specialist ketogenic dietitian, treating children and adults with drug resistant epilepsy and adults with brain tumours.**

The following article was written for and published in the NHD magazine digital edition for May 2018 giving an insight into three very different adult cases; two with epilepsy, one with a brain tumour, and how ketogenic diet therapy has influenced the quality of their lives.

A ketogenic diet (KD) is low in carbohydrate, high in fat and adequate in protein. It triggers a shift in metabolism that mimics the fasted state; leading to increased fat oxidation and ketogenesis. Ketogenic diet therapy (KDT) is widely implemented for children with drug-resistant epilepsy and metabolic conditions such as Glut 1 deficiency disorders.<sup>1,2</sup>



Despite published evidence indicating feasibility, tolerability, and efficacy of KDT in adults similar to that in children, few epilepsy centres worldwide offer these therapies to adults.<sup>3</sup> This also means that families with children requiring KDT around the teenage to adult service transition stage, or those requiring continuation of their existing KDT beyond 18 years, have immense problems accessing services.<sup>4,5</sup>

The publication of randomised controlled trial evidence, equivalent to that endorsing KDT use in children, would make all the difference to adult service provision, but no such trial is on the horizon at present. In the meantime, around 30% of adults continue to live with drug-resistant epilepsy, enduring poor seizure control and an impaired quality of life.<sup>6</sup>

The following cases illustrate the effect that KDT has had on the lives of two very different adults with drug resistant epilepsy.

## MATTHEW

**Matthew is 22 years old. He lives with his parents who provide all his day-to-day care.**

**Diagnosis:** He has a complex syndrome with microcephaly, severe learning disability, drug resistant epilepsy, dysphagia (a gastrostomy was placed at one year of age), visual difficulties and intolerance to many additives.

**Epilepsy history:** Matthew started having seizures at the age of seven. In 2016, prior to referral for KDT, he was having frequent absence seizures every few days and up to five times a day. He was also having clusters of tonic clonic seizures regularly every three to four weeks. For many days during the build up to these, he would become extremely irritable and hyperactive (shuffling around on his bottom), shouting, crying, hitting-out and self-harming by biting, poking or punching himself. He would not sleep for days and, in desperation, to help other family members to sleep, his mum would drive him round in the night, so his continual noise would not disturb the others. He also had migraine activity in association with his seizures, would stop eating orally and would only manage relatively small volumes of his enteral feed before experiencing reflux.

Despite having tried numerous anticonvulsive drugs with limited impact throughout his 14 years of living with epilepsy, and being unsuitable for epilepsy surgery, he was not referred for exploration of KDT until 21 years of age.

Over seven different anticonvulsant medications had been tried off and on over the years with inadequate control of seizures and associated symptoms.

"We asked about ketogenic therapy when Matthew was a young teenager, but the neurologist at the time was dismissive and suggested that there were a couple of new drugs coming onto the market that they might try. Still, nothing worked and by 2016 Matthew's quality of life was zero. The local neurology team were unable to give us any assistance to manage his seizures, pain and distressed behaviour and the whole family was at breaking point, even considering taking him to Switzerland to end his immense suffering.

In desperation I called an Epilepsy Charity helpline and they suggested we ask for a referral to a specialist epilepsy centre for assessment. Eventually, after much chasing and waiting, we got there and the alteration of his medications led to a slight improvement in his distressing seizure, symptom cycle. We also got a chance to ask about ketogenic therapy again and a referral to a specialist ketogenic team was finally agreed. After many months delay, awaiting CCG funding, we started KDT."

**Matthew's parents**

### Outcome

Matthew responded extremely rapidly to his ketogenic feed and food change and his cycle of seizures and associated behaviours was halted immediately. It turns out that Matthew's seizures are very responsive to KDT and he is now seizure free; a result we see in around 10% of cases of drug resistant epilepsy.

"The epilepsy took Matthew's quality of life away. As a result of the ketogenic diet, we've got Matthew back - he's no longer hyperactive, now laid back about everything. He now sleeps much better at night; he no longer needs to wear a bib all the time (he soaked over 20 thick towelling bibs per day due to dribbling) and the circulation in his hands and feet has improved immensely; they are not cold and white anymore. He is the heaviest he has ever been, seems stronger and no longer catches every bug that is going. His medications are being gradually tapered to see how much, if any needs to remain."

**Matthew's parents.**

## ELAINE

**Elaine is 51 years old and lives with her husband and their two children.**

**Diagnosis:** Elaine has a generalised epilepsy syndrome with tonic clonic seizures, absences and myoclonic jerks and a history of cervical dystonia, requiring regular botulinum injections across face, neck and shoulders. She also experiences generalised motor dysfunction and extreme muscle stiffness.

**Epilepsy history:** Elaine developed absence seizures before school age, with tonic clonic and other seizure types emerging during her school years and continuing into adult hood. Seizure control worsened over the last 10-15 years, with daily life disrupted by 20-30 absence seizures per day with the peaks occurring first thing in the morning and then again in the afternoon.

She slept very poorly at night. By 2016, the escalation in symptoms resulted in four hospital admissions in three months and she was unable to function normally.

At least 10 anticonvulsant medications had been tried over the years.

"I was on a combination of three anticonvulsants and the side effects were atrocious. I had no support at all. It was my family who brought me through multiple hospital admissions through A & E. In May 2016, I was having one seizure after another. I was referred to neurology services twice as an emergency. No neurologists available. There was a massive emotional impact on my children and my husband and there were many tears as I was becoming more dysfunctional.

I was having absences all the time; I was unable to follow a phone conversation; I would have to ask what an object was, in the same way that a two-year-old would ask. I walked like I'd had a few vodkas with breakfast. I could have fallen asleep while sitting on a pin. I could no longer feel life.

August 2016 was my pivotal moment. I was very unwell. My muscles were moving involuntarily. I had been awake constantly for days. I couldn't close my eyes. Every drawer in my brain was open and I was being bombarded with images. And then, everything stopped working. I crumpled and couldn't talk. An ambulance was called. I was locked into a body that wasn't responding. I told myself to stay calm and breath. When I came out of hospital after a number of days I had two sticks and had to learn how to do things again. I felt locked into my body."

**Elaine**

A supervised KDT started in October 2017.

### Outcome

"I withdrew all sugar. Easy? Definitely not. The healthy plate that had been the mainstay in our house had to be psychologically binned. That's difficult. If I wanted ketones to keep my brain happy, then I had to fuel with intelligence and knowledge. I felt no changes for 14 days. And then (I just cannot explain what happened), my world changed. Two weeks that's all it took. TWO WEEKS."

**Elaine**

Elaine initiated a ketogenic diet in November 2016 after reading research papers and ketogenic diet books extensively and managed extremely well under the difficult circumstances. Our specialist role was to help her to fine tune the regime to stabilise her fuelling through her day to gain more consistent control over her symptoms. The absence seizures have all but disappeared, her sleeping has improved significantly and her muscle tone has relaxed. However, recent episodes of pneumonia and hospitalisation have challenged her metabolic control significantly. Elaine is a very unusual case, with seizures and motor dysfunction that may connected in some way. She has a family history of epilepsy and Friedreich's Ataxia and is currently awaiting the results of genetic screening for Glucose Transporter 1 Deficiency.



## WHY ARE SOME ADULTS WITH BRAIN TUMOURS CHOOSING TO PURSUE KDT?

**Contrary to improvements in the quality of life and survival for many cancers, the outcome for those with malignant brain tumours has not improved in decades.**

Research conducted by Otto Warburg in the 1920s onwards, led to his proposal that tumour cells typically display a shift in metabolism characterised by an increased reliance on glycolysis even in the presence of oxygen; a fundamental difference from the metabolic characteristics of healthy cells of the same origin.

While knowledge of oncogenetics and the development of targeted therapies has expanded and progressed significantly, exploitation of the basic metabolic variance between healthy cells and cancer cells has been slow to progress. Preclinical studies in mouse models of high grade brain tumours and metastatic cancer suggest that a KD alters the regulation of multiple pathways associated with tumour growth and progression; reducing blood glucose and insulin levels, modulating oxidative stress, down regulating inflammatory pathways, upregulating the host immune response and modifying tumour gene expression.<sup>8</sup> Therefore, it is no surprise that those facing a brain tumour diagnosis may consider their options and decide to try a KD alongside their standard care (surgery, chemotherapy and radiotherapy) and ask for professional clinical help with this.

With KDT services not even readily accessible to adults with epilepsy, it is no surprise that support for adults with brain tumours is practically non-existent. It is for this reason that we provide charitable dietetic support to adult brain tumour cases who approach us for help; enabling them to explore KDT appropriate to their needs as a means of, a) improving their quality of life (particularly in relation to fatigue and seizure management) and b) achieving nutritional ketosis.



It will be some time before mechanisms and any certainty about the impact of KDT on brain tumours emerges. In the meantime, those who do not have the luxury of time to wait, can read the existing evidence and make their own decisions.

### What is a brain tumour?<sup>9</sup>

The commonest type of primary brain tumours are the gliomas. They develop from the glial cells that support the nerve cells of the brain. Grade 1 tumours are benign, whereas Grade 2-4 gliomas are malignant. Symptoms, treatment and prognosis can vary widely, even for patients with the same histological subtype of tumour, being also dependent on molecular profile and tumour location within the central nervous system. The median survival for Grade 2 gliomas is seven to 10 years while Grade 4 gliomas have a median survival of 12-15 months. Brain tumours are the leading cause of cancer-related death in patients under the age of 40.

## HEATHER

**Heather is 46 years old and lives with her husband and their two children.**

**Diagnosis:** Heather had a glioblastoma multiforme (a Grade 4 glioma) diagnosed in July 2017.

**Treatment:** She had surgery to remove the tumour followed by six weeks of radiotherapy and chemotherapy. Heather is currently undergoing monthly cycles of high dose temozolomide chemotherapy.

"I had a Grade 4 Glioblastoma removed in July 2017 following a collapse or fit- type of episode. My surgeon mentioned looking into a low carb diet. The neurosurgical nurse told me to make it my business to research the diet, but no one gave us further information.

I then met with my neurologist who is also a friend and she asked me if I knew about the ketogenic diet and to look into it. Stefan my husband looked at the research with mice and if there were any negatives about the diet and we decided it was a very important thing to do.

"I was recovering from brain surgery and started eating low carb within a couple of weeks of coming out of hospital albeit a bit of guessing! I recovered from surgery very quickly and after a couple of weeks of feeling tired and dizzy (may have been the diet, but mixed with recovery), I felt as though I had a lot more energy and didn't feel as tired as normal and was able to get out for long dog walks very quickly. I have continued to feel very well.

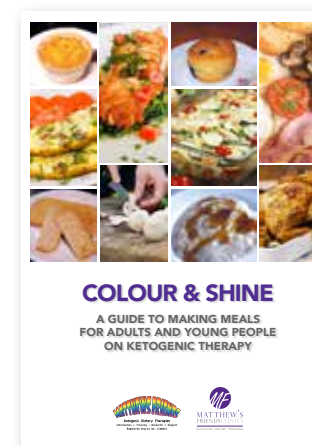
"I have to admit that I found the process of changing diet quite difficult to begin with. I was very anxious and threw myself into it without knowing what I was doing. I had very little appetite due to anxiety at the time. I craved carbohydrate a lot! Especially cereal which I had been snacking on pretty much all day most days on top of my meals.

"I had been what I considered to be very healthy with a very healthy diet. I ate a lot of carbohydrate and exercised until I was exhausted a lot of the time. I could not relax unless I had trained so that I could eat. Mentally, it was quite a lot to try to 'retrain' my brain into thinking that fat is not bad and that I actually don't need to eat my own weight in fruit and veg to be healthy. This has become a lot easier seeing the results and feeling so much better.

"Not only have the changes been maintained, but my whole family has changed how they eat and feel better for it. My husband and son have both noticed that their asthma has improved and my husband is no longer pre-diabetic! We are getting used to building meals from scratch and working out the content of meals. I am also becoming more confident in eating out and choosing the foods I can eat. I have maintained these changes for seven months now and I would not go back to eating a high carb diet." **Heather**

Heather uses our Colour & Shine adult recipe booklet (available from your dietitian) as a basis for some of her meals and has adapted and added to these to suit her tastes and requirements.

"A typical breakfast would be a breakfast pancake (I add a little stevia to the mix and I have a bit more cream on the pancake). I might make a porridge from milled flaxseed with double cream and a bit of MCT oil added to the mix and serve with more cream and berries. I also use the nut granola and make a batch to draw on as it's quick.



Lunch and dinner vary from a made recipe to more frequently a piece of fish/chicken with either salad or cooked veg and a coconut roll with butter. I add more fat by either cooking the vegetables in coconut oil or adding olive oil / MCT oil to salad. I have found that a lot of my meals can look traditionally healthy with salads and fish. That surprised me when I had visions of having to eat butter out of the packet. My taste buds have changed a huge amount. I can taste things so much better and really enjoy all the food I eat." **Heather**

#### References:

1. Neal EG, Chaffe HM, Schwartz RH, Lawson M, Edwards N et al. The ketogenic diet in the treatment of epilepsy in children: a randomised, controlled trial. *Lancet Neurology* 2008; 7:500-506
2. Kass HR, Winesett SP, Bessone SK, Turner Z, Kossoff EH. Use of dietary therapies amongst patients with GLUT1 deficiency syndrome. *Seizure* 2016; 35:83-7
3. Fang Y, Xiao-Jai L, Wan-Lin J, Hong-Bin S, Jie L. Efficacy of and patient compliance with a ketogenic diet in adults with intractable epilepsy: A meta-analysis. *J Clin Neurol* 2015; 11(1): 26-31
4. Nabbout R, Camfield CS, Andrade DM, Arzimanoglou A, Chiron C et al. Treatment issues for children with epilepsy transitioning to adult care. *Epilepsy Behav.* 2017; 69:153-160
5. [www.matthewsfriends.org/medical-section/keto-centres](http://www.matthewsfriends.org/medical-section/keto-centres)
6. [www.epilepsy.org.uk/press/facts](http://www.epilepsy.org.uk/press/facts) (accessed 23.3.18)
7. [www.epilepsy.org.uk/info/seizures-explained](http://www.epilepsy.org.uk/info/seizures-explained) (accessed 23.3.18)
8. Poff A, Koutnik AP, Egan KM, Sahebjam S, D'Agostino D, et al. Targeting the Warburg effect for cancer treatment: Ketogenic diets for management of glioma. *Seminars in Cancer Biology* 2018, <https://doi.org/10.1016/j.semcancer.2017.12.011>
9. [www.braintumourresearch.org/info-support/what-is-a-brain-tumour](http://www.braintumourresearch.org/info-support/what-is-a-brain-tumour) (accessed 23.3.18)



# 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](mailto:enq@matthewsfriends.org)



## THREE PEAKS CONQUERED!

**Team Warrington said... 'Why have we chosen this charity?**

Close friends of one of us 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.



Beth's Mum, Jenny, said "At a time when we were really struggling with Beth's health I reached out to Matthews Friends for help. Emma Williams, the charity's founder, was able to offer practical advice on how to adapt recipes to allow us to continue to implement the ketogenic diet, as well fantastic emotional support.

At first, placing your child on a specialised diet can seem a little overwhelming but we have been able to see the benefits of it over the last 12 months in Beth's improved levels of happiness and alertness, as well as a reduction in the lengths of her seizures, and hope that other families can too. Matthews Friends have a crucial role to play in ketogenic diet research and education and any monies raised towards helping them achieve their significant goals would be hugely appreciated. Epilepsy affects 600,000 people in the UK.

The work Emma and her team are doing is incredibly important.'

*We just want to say a HUGE well done and thank you to Team Warrington for raising over £2,300 for us – you are all brilliant and we will put the money to very good use.*

## WELL DONE TO KATHRYN ON HER FIRST 10K RUN FOR MATTHEW'S FRIENDS

Kathryn said: "Matthews Friends is a charity close to my heart since I live with Epilepsy myself. Matthews Friends is an amazing charity who tirelessly do Ketogenic research and provide successful therapies for those living day to day with Epilepsy, Glut1, and other neurological conditions. They really do give food for thought!"



*We just want to say a MASSIVE well done and thank you for raising £435 for us – we will put the money to very good use.*



## Rock 'n' Roll Liverpool Marathon

Stephen Robertshaw raised £460 taking part in the Rock 'n' Roll Liverpool Marathon on the 20th May! Stephen said: "I have witnessed the positive effects that a Ketogenic diet had on a young boy named Lewis, reducing the number of seizures he suffered which in turn led to a happier boy and more relaxed parents."

Thank you Stephen and congratulations!

GO

**#SUGARFREEFOREPILEPSY**  
**IN NOVEMBER FOR MATTHEW'S FRIENDS**

VISIT [WWW.MATTHEWSFRIENDS.ORG](http://WWW.MATTHEWSFRIENDS.ORG) TO JOIN OUR CAMPAIGN!

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](mailto: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.