

KETOGENIC THERAPIES

SUMMER NEWSLETTER 2019 | ELEVENTH EDITION



Ketogenic Dietary Therapies
Information • Training • Research • Support

Registered Charity No. 1108016

MATTHEWSFRIENDS.ORG

Matthew's Friends launch KetoCollege Online Tutorials

If you are a healthcare professional, family member or patient, we have a range of films and resources that will help you get started with your ketogenic dietary therapy.

We appreciate how difficult it is to travel to meetings for some people and our aim has always been to make sure we support not only all those patients and families who wish to go on medical Ketogenic Dietary Therapy, but all those medical professionals who want to administer these diets in a safe and responsible way in the best interests of their patients wherever they may be in the world.

Please go to www.matthewsfriends.org/ketotraining to gain access to these films and read more about this project on page 6



SPECIAL FEATURES INSIDE:

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SUMMER IS HERE
Going on Holiday with
the Ketogenic Diet!





Ketogenic Dietary Therapies
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Registered Charity No. 1108016

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🌐 www.matthewsfriends.org

🌐 www.mfclinics.com



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/>



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

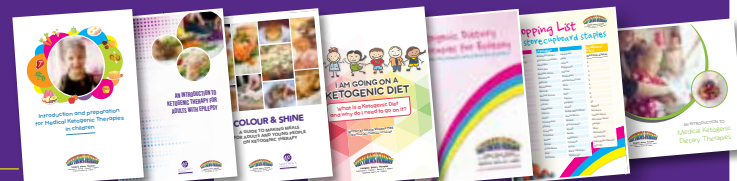
CONSIDER A MEDICAL KETOGENIC DIETARY THERAPY

Contact Matthew's Friends Clinics
info@mfclinics.com
for an information pack.
www.mfclinics.com

FREE COPIES OF OUR RESOURCES - 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.
- 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.



- Charity Booklet - updated version of our general charity booklet that gives an overview of the work we do as well as Ketogenic Dietary Therapies.
- Shopping List and Storecupboard Staples - never forget your essentials and favourites for your keto cupboards.
- Introduction to Medical Ketogenic Dietary Therapies.

NEW ADULT KETOGENIC SERVICE IN SHEFFIELD

We are an adult service based at the Royal Hallamshire Hospital in Sheffield. Dr Howell is the Consultant Neurologist for the service, supported by Dr Alice Brockington and Dietetic input is provided by Rowan Sutherill.

The service started approximately 9 months ago with a small number of refractory epilepsy patients from the South Yorkshire area. Patients were started on either ketogenic PEG feeds, Modified Ketogenic diets or classical ketogenic diet.

In addition, we have since received ethical approval to begin a trial of Low Glycaemic Index (LGI) diet in adults with epilepsy. The research is in the form of a randomised study of immediate versus deferred LGI diet in adults with seizures incompletely controlled by anti-epilepsy medication. Patients are randomised to a 12 week period on a LGI diet, followed by the opportunity for the control group to also undertake 12 weeks LGI dietary treatment.



The primary measure of the study is the tolerability of the LGI diet and efficacy of the diet will be one of several secondary outcomes.

Patients, who opt to discontinue the diet due to inadequate seizure control, intolerance or non-acceptability of the diet or other adverse effects after 12 weeks, may be offered Modified Ketogenic diet or Modified Atkins diet.

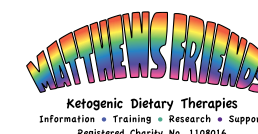
We are now welcoming adult patient referrals from beyond the South Yorkshire area.

Referrals need to be made to Dr Stephen Howell or Dr Alice Brockington at the Royal Hallamshire Hospital, Sheffield.

SAVE THE DATE
6-10 OCTOBER 2020
7TH GLOBAL SYMPOSIUM
ON MEDICAL KETOGENIC DIETARY THERAPIES
COLLABORATIVE SCIENCE AND CLINICAL CARE
HILTON BRIGHTON METROPOLE • KINGS ROAD • BRIGHTON, BN1 2FU, UK



#KETO2020
WWW.GLOBALKETO.COM



CALLUM GRAY

KETOGENIC DIET MAY 2019

“Callum is our 19 year old son who has Ring 20 Chromosome disorder. Callum went on the modified KD just before his 12th birthday. He did it for 2 years and 2 months. After 6 months he became drug free and seizure free. This was amazing!”

We noticed his seizures started coming back gradually after 2 years, Callum was now 16. There was the odd one or two a week, then by the time he was 17 he was having several partial absence seizures lasting 5 to 20 minutes daily.

We saw Dr Fuller the consultant at Gloucester Royal Hospital who suggested going back on KD diet.

I said to Callum it was his choice and I would help him do the diet if he was willing. He replied wanting to do the diet and said he liked being on it because it made his head feel clean! We are under Birmingham Childrens Hospital for the diet.

We did Low GI diet and high fats. This really helped reduce seizures. We had foods that were 50 or under GI.

Callum did this for a year and a half then gradually came off it. Straight away he had more seizures and after 8 weeks of daily seizures we went back onto KD.

Callum is still on the diet, now 19 years 5 months old. He has on average one seizure a day lasting from 5 to 20 mins. This still is much better than if he was off the diet. He is a lot more alert. At the moment he is on 3g Carbohydrate per meal and 60g fats. He takes Acetazolamide 250g twice a day.

The diet has a lot more supplements to offer now than 7 years ago.

VitaFlo, Nutricia and Ketocare supply Callum's diet supplements.

We test his blood twice sometimes 3 times a day for blood sugars and ketones. Callum's ketones are usually around the 2 level when we test him.

He is really good doing the diet. He even cooks food for us and he can't even eat it. I'm sure I wouldn't be as disciplined as he is!

It amazes me how food can do this and as we know with R20 does not respond to AED's.

By Dawn Gray (Callum's mum).



Ring chromosome 20 epilepsy syndrome, also known as r(20) syndrome, is a rare chromosomal anomaly resulting from a break on each arm of chromosome 20 resulting in ring formation. In r(20) syndrome, the breakpoint of most patients is in the p13q13.33 region of chromosome 20.

Two distinct forms are recognized, mosaic and non-mosaic ring chromosome 20 epilepsy syndrome. This syndrome is characterized by medically intractable epilepsy, nocturnal subtle seizures, behavioral problems and mild mental impairment. Unlike other chromosomal aberrations, dysmorphism (major or minor congenital malformation) is rarely reported.

For further information on Ring 20 please visit: www.ring20researchsupport.co.uk/

CONGRATULATIONS HELENA!



Congratulations to Helena Champion RD – MF Medical Board Member and Ketocollege Mentor winning a 'You Made A Difference Award'

Helena Champion joined Cambridge University Hospital in 2002 as a part time paediatric dietitian, finally settling into the specialist area of metabolic dietetics.



In 2008, Helena became involved in ketogenic diet management by taking on the care of a small number of children in order to prove the benefit of ketogenic therapy to children with epilepsy. Response to those interventions was positive and the permanent ketogenic service was fully commissioned in 2009, at which point Helena moved into a full-time role in order to lead and develop the dietetic element of the service. Since then, the service has gone from strength to strength and now every year supports 30 new patients and their families to undertake ketogenic therapy.

Helena has led the service throughout this time with a genuinely professional, dedicated attitude which has always been firmly rooted in a desire to do what is best for the child and family in her care.

This is reflected in the winning nominations;

“Helena is part of the paediatric neurology team and provides ketogenic diets for children with severe epilepsy. There is a growing body of evidence that ketogenic diets can reduce the number of seizures in certain patients and significantly improve quality of life where multiple drug treatments have previously failed. I spent a morning with Helena in a clinic and I was amazed at the difference this dietary manipulation can make to some of these families lives (even though I am a dietitian with over 20 years' experience!).”

“A mum of one of the patients sent a video showing her son riding a tricycle. Prior to the diet they could not have even imagined he could coordinate seizure free to do this. She was so happy and excited to share the news with Helena.

“It is a very difficult diet for the parents to follow and the amount of information, expertise, time and support they need from the dietitian is significant. In addition to the clinic appointments, the dietitians have frequent telephone and email contact with these families. I want to nominate Helena because the nutritional guidance, advice and support she provides to these families can really make a massive difference to the child, and to the whole family's quality of life.”

Matthew's Friends would also like to take this opportunity of thanking Helena for all the voluntary work she undertakes for us, in reviewing presentations, publications and information that we send to her as part of her role on our Medical Board as well as being a valuable member of the Mentor team for Ketocollage. Helena is definitely someone who makes a difference every day and we are delighted for her. It is well deserved.

ALERT

CHANGE IN FOOD VALUES FOR ALMONDS

Please note the details to the right which has been put on the EKM forum at www.ekmketocalc.com

You will need to update your Mealplanner and your recipes that contain almonds. If you are concerned about anything then please contact your dietitian.

EKM: Electronic Ketogenic Manager Multi-platform ketogenic calculator

Home Windows Mac OS iPhone/iPad Android Help & FAQ Useful Links Training Videos

Help & FAQ

Alert! *** Important product update: ***

McCance and Widdowson have issued an update to the data that we use within EKM. The main change that they have warned about relates to the figures for Almond based products. We are currently aware of the following changes that will need to be manually made, by yourselves, in any and all copies of EKM that you are using:

Almonds, toasted, new values: Fat=52.5, Prot=21.0, Cho=5.9

(Was: 56.7/21.2/7.0 - all changed)

Almonds, weighed with shells, new values: Fat=18.5, Prot=7.8, Cho=1.9

(Was: 20.6/7.8/2.5 - thus fat and cho change)

KetoCollege has expanded... Now **ONLINE** too!

At Matthew's Friends it has always been one of our missions to help make sure that all those who need access to medical ketogenic dietary therapy can gain access to a knowledgeable professional to help support them safely through the treatment.



Over the past 15 years since Matthew's Friends was founded, we have invested over £607,000 in the training, education and ketogenic knowledge of medical professionals not only from the UK and Ireland, but all over the world. We have supported and worked on global consensus statements, co-authored papers and influenced policy change as well as invested in clinical research which also supports the use of Ketogenic Dietary Therapies.

We are delighted to announce that the next phase of our education programme is now being launched – KetoCollege Online Tutorials

Our eleven educational presentation films, delivered by our expert Mentors, can be accessed via our charity website here.... www.matthewsfriends.org/ketotraining

Medical professionals from all over the world can access these films for a nominal fee (reduced for resource-limited countries), which will help towards future updates and subtitling of these films.

In addition to the films, there is an online professional support forum for further networking and where KetoCollege Mentors will be available to answer questions from their colleagues around the world should they need ongoing support when administering these dietary therapies.

Topics covered in our KetoCollege Online Tutorials are:

- Introduction and Overview of Ketogenic Dietary Therapies
- Therapeutic Options for Intractable Epilepsy (paediatrics)
- Preparing a family for Ketogenic Dietary Therapy
- Classical Ketogenic Dietary Therapy
- Medium Chain Triglyceride diet (MCT)
- Modified Ketogenic Diets and Low Glycaemic Index diets
- How to initiate Ketogenic Therapy
- Monitoring and Side Effects
- Discontinuation of the Diet
- Ketogenic Therapy for Adults
- What makes a good Ketogenic Centre?

Our sincere thanks go out to the Mentors that gave their time freely as always in order to take part in this project.



Professor Eric Kossoff



Professor Helen Cross OBE



Dr Anita Devlin



Dr Mackenzie Cervenka



Jennifer Fabe RD



Susan Wood RD



Dr Elizabeth Neal RD



Emma Williams MBE

A word from Professor Eric Kossoff....

How should ketogenic diet centers be trained? There is no single correct answer to this question, but it's an important issue as more people worldwide need this important treatment.

As a ketogenic diet community, we believe that nutritionists and doctors should be educated with the best available information and resources. Recognizing that not all ketogenic diet centers have either the funds to travel, or to pay people to come to them, these training videos are meant to be a source of information to be used by professionals learning about the ketogenic diet. They were filmed during the 2017 KetoCollege and are extensively reviewed and revised since then.

The vision for online training modules first occurred in 2014 through the International League Against Epilepsy's Task Force on Dietary Therapies, which I had the honor of chairing for 3 years. Unfortunately, it was not funded by this organization, so, as is often the case, Ms. Emma Williams and Matthew's Friends stepped up with the funding for this incredible project that is now available by way of fundraising, donations and grant applications.



It would not have been possible without their work and dedication to the field of Ketogenic Dietary Therapies, together with the filming expertise of Red Goat Productions. We also want to thank VitaFlo for their educational grant towards this project. These films will continue to be reviewed and revised as time goes on and hopefully subtitles added in various languages (subject to further funding).

Many thanks to all the fundraisers that made this project possible. I cannot stress how important this kind of work is and how beneficial it will be to a great many people around the world.

And not forgetting our ongoing Family Support...

As always, we never forget the most important people in all this..... The Families.

We have put together all our introductory films that we have made with our medical board in one easy to find place on our website and families can access all this freely. We have also launched our online Facebook support forum which families can access and receive support from other families as well as the Matthew's Friends Regional Co-ordinators and Ambassadors.

Our ketocook Mo will be a regular in the forum to answer any recipe/ingredient related questions and we will have guest professionals joining us from time to time to answer your questions on specific topics, these will be advertised in advance and will be held at different times so that as many people can access them that need to. This is all on top of our 24/7 Ketogenic Support Line. Again, it is our way of letting families know that you need never feel isolated or alone and help is either a click or a text away – which ever you prefer to use.

Professional Education Tutorials and the Family Introductory Films together with access to forums can be found at the following link:
www.matthewsfriends.org/ketotraining



KETOCOLLEGE 2019



Our Annual KetoCollege training meeting goes from strength to strength, this year we welcomed 150 participants from 26 countries for an intensive and full on 3 days and we also had the meeting translated into simultaneous English/German as we push forward to provide education and training for the European Reference network – EpiCARE for rare and complex epilepsies.

Once again we were full to capacity and already have a waiting list for the next KetoCollege which is going to be held on the 12-14th May 2020 at the Felbridge Hotel, East Grinstead, Surrey. If you would like to register your interest then please do so at ketocollege@mfclinics.com.

This year we were delighted to welcome Dr Colin Doherty from Ireland together with Dietitian Laura Healy who run the National Adult Ketogenic Service available in Southern Ireland which Matthew's Friends funded and helped to get started. We also welcomed dietitian Janette Buttle and Dr Andreas Brunklaus from Glasgow who added their expertise to our mentor list.

New topics were added this year including Dr Stewart Rust, a Consultant paediatric Clinical Psychologist from Manchester

who delivered a wonderfully enlightening presentation on 'How do psychological factors impact on adherence' and Dr Camilla Salvestrini, a consultant Paediatric gastroenterologist from Cambridge who delivered a fascinating talk on 'Practical Issues to overcome with feeding problems'. Both of these new topics were very well received and it looks like they will become part of our regular programme.

Our breakout sessions for Nurses and Dietetic Assistants continues to grow as Epilepsy and Ketogenic Nurse Martin Smith from Evelina took the helm this year and led this group. In the Brain Tumour and Ketogenic Diet session Dr. Michael Jenkinson, Consultant Neurosurgeon at The Walton Centre in Liverpool gave an overview of their work as well as Dr. Nel Syed from Imperial College London and our own dietitian Sue Wood delivering talks on the work that is currently being done in this field and how patients are responding.

Our metabolic session which covers Glut 1 and PDH was once again given by Professor Joerg Klepper from Germany and as always it is received exceptionally well. Elles van der Louw, a senior dietitian from The Netherlands also joined us this year presenting on the new TPN feeding guidelines as well as Tube feeds and blended diets. She had a massive amount of information to present and made us realise that her session is not nearly long enough! However, as always, Elles did a wonderful job.



Cooking demonstration being given by our MF Ketocook Mo



Chef Derek busy on the Nutricia KetoCal stand



Dr. Lyvia Dabydeen, Consultant Paediatric Neurologist for Matthew's Friends clinics.



Dr. Colin Doherty from St James's Hospital Dublin where he set up the National Adult Ketogenic Service for Ireland with funding from Matthew's Friends.



Janette Buttle, dietitian from Glasgow presenting at Ketocollege this year.

This year we also introduced a session on Diabetes as two GP's, Drs Helen Rutherford and Vipan Bhardwaj gave a very enthusiastic presentation about a pilot study they have carried out using a modified type of ketogenic diet and who have drastically cut their medication bill as well as helping many of their patients to a better quality of life. In some instances REVERSING their type 2 diabetes. They also presented on their plans for the future and we at Matthew's Friends are looking forward to working with them further in this field. Also our dietitians Helen Grossi and Helena Champion presented case studies on managing patients with type 1 diabetes and epilepsy using ketogenic dietary therapy, which is no mean feat, but can be done so long as good supervision is in place. With Diabetes being so prevalent this is an area that is certainly going to grow.

We would like to thank ALL the Mentors that give their time freely to KetoCollege as they pass on their expertise to new groups from around the globe.



Chef Neil at the busy VitaFlo stand



Save the date

MATTHEW'S FRIENDS WILL BE HOSTING THEIR ANNUAL KETOCOLLEGE PROGRAMME
12TH – 14TH MAY 2020 | CROWNE PLAZA FELBRIDGE HOTEL,
EAST GRINSTEAD, WEST SUSSEX, UK.

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

In its 5th year, KetoCollege 2020 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 epilepsy and other neurological disorders.

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



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



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

Our Founder and CEO, Emma Williams has been working with the group who are currently updating the SIGN guidelines in Scotland, which obviously includes the ketogenic diet.

She also presents at the meetings as a parent of a son with complex epilepsy and the challenges that this can present. This poster was recently exhibited at the Scottish Parliament in May giving details of why these guidelines are important.

Emma Says “Matthew’s Friends have always campaigned for policy change for ketogenic dietary therapies, it is important that these therapies are delivered as a matter of course so that all those who need them can gain access to them but without the necessary policy changes and inclusion of these diets in the guidelines, NHS Trusts can use the excuse that they are not listed and therefore they are not required to provide the service.

This MUST NOT be allowed. We will continue to work towards the necessary changes and thank all those medical professionals that are also working with us in order to change the guidelines and policies. Special acknowledgement must go to dietitians Janette Buttle from Glasgow and Helen Grossi from Matthew’s Friends Medical Board who have worked so hard on writing the new guidelines for SIGN in Scotland”.

SIGN159: Epilepsy in children and young people – diagnosis and management

1 Why the guideline is needed

1:220
1 in every 220 children has epilepsy in the UK.
Source: Joint Epilepsy Council UK & Ireland 2011

5000
Approximately 5000 children under 18 have epilepsy in Scotland.

Key Issues
Investigations
Clarity around diagnostic tests to:
• diagnose epilepsy
• reduce inappropriate testing
• improve quality of life by having the right treatment choices

Management
Increased awareness of non-pharmacological treatment in the management of epilepsy.
Greater knowledge about the use of new antiepileptic medicines.

Transition
Enabling young adults to feel confident by addressing the issues that are important to them for a seamless transition from paediatric to adult care.

What matters to young people with epilepsy?
Taking part in decisions about their health.

“It’s very important to be involved in conversations about epilepsy.”
Members of the Epilepsy Scotland Youth Group.

“Make sure people get support at the right time, managing epilepsy and coping with impact it has on daily living.”
Chris Fall, Young Person’s Representative on the SIGN Guideline Group

2 Developing the guideline

18 – 20
months to develop the guideline.

43
Issues identified as important to patients from a patient focused literature search.

29
Multidisciplinary guideline group members.

503
Research papers reviewed.

35
Expert peer reviewers.

5
Public engagement activities involving 128 people:
• young peoples’ discussion group
• SPEN family day
• SPEN members’ days
• SIGN National Open Meeting
• SUDEP Action Meeting

“We now know about SIGN and what they do and how they help.”
Parent at SPEN family day

3 Partners

12
Partners from across:
• health, community and social care
• academic groups
• charities
• the public

4 What we are doing

Publication
Summer/Autumn 2019
SIGN guideline for multidisciplinary audience making key recommendations about evidence-based practice.
Autumn/Winter 2019
A co-produced version of the guideline for young people.
Recommendations to be presented at the Scottish Parliament Cross Party Group on Epilepsy.

Key:
SPEN – Scottish Paediatric Epilepsy Network
SUDEP – Sudden Unexpected Death in Epilepsy

5 Predicted impact of the guideline

For young people with epilepsy

“It will help people with epilepsy and their families make informed choices about the options available to them.”
Anissa Tonberg, Charities Representative, Policy Officer, Epilepsy Scotland

“People will receive the best care at the right time which will result in a positive experience of services.”
Chris Fall, Young Person’s Representative on the SIGN Guideline Group

“Help services to treat people as equal partners in their own care.”
Anna Scott, Young Person’s Representative on the SIGN Guideline Group

For parents and carers

“The earlier the correct information, treatment and services are provided the better the outcome.”
Emma Williams, mother and carer of a child with epilepsy and SIGN Guideline Group Parent Representative

“This guideline will help clinicians, young people with epilepsy and their families to better understand ALL epilepsy risks, and the positive steps they can take to reduce them. Not only can this improve quality of life but could prove life saving for some.”
Christine Jeans, SIGN Guideline Group Bereaved Parent Representative

For healthcare professionals

“Psychological aspects of this guideline are so person centred.”
“This has given me direction as to where research needs to be done.”
Jay Shetty, Consultant Paediatric Neurologist and Chair of SIGN Guideline Group

“This will help inform service provision for the mental health and developmental needs of potentially vulnerable children, young people and their families.”
Aileen McCafferty, Clinical Psychologist, Paediatric Neuropsychology Centre for Child Health, Dundee and member of SIGN Guideline Group

“I would hope the guideline provides patients and carers with some clarity in the treatment pathway of epilepsy and contributes to continuity of care across the country. I think the guideline will clarify the referral criteria for epilepsy surgery and enable clinicians to identify potential surgical candidates sooner.”
Janice Fyall, Epilepsy Surgery Nurse Specialist and member of SIGN Guideline Group

“This will empower families.”
Celia Brand, Paediatric Epilepsy Nurse and member of SIGN Guideline Group

www.sign.ac.uk

Vitaflo hosted a KetoCooking day at St George’s Hospital in London and we were delighted to provide bags of goodies and starter packs to the families that attended.

As always, our starter packs are available to all families based in the UK and Ireland that are on a medically supervised ketogenic diet.



St George’s keto families with MF goodie bags



Matthew’s Friends Dietitian, Sue Wood, presenting at the Vitaflo European Ketogenic Meeting in Germany.

The Food Unwrapped programme on Channel 4 recently looked at the massive growth in popularity of low carbohydrate diets as a lifestyle choice and for losing weight.

However, thankfully they also featured a segment on MEDICAL ketogenic diets and this is where we stepped in to help. Our Dietitian Sue Wood was interviewed alongside one of our amazing keto families.

It was nice to be able to differentiate the two different reasons for the use of these diets and how important it is to be medically managed when you have a chronic condition such as epilepsy.



Dr. Helen Lawal (centre) with Harrison and his Mum and Dad, Rupert and Anushka.

THE NEW GLUT 1 EUROPEAN FEDERATION IS LAUNCHED...



Well done to Massimiliano Barone from the Italian Glut 1 Foundation who has put in an enormous amount of work in getting this Federation started. Mass said...

“First of all I would like to thank most sincerely Nuria from Spain (asGLUTdiece) and Agnieszca from Poland with her husband (Fundacja GLUT 1 Poland) that, together with the Italian Glut1 Association, gathered to sign the constituent act (see photo). Thanks also to all people who have worked to make this important goal possible. However, this is not an end goal but a new starting point to carry out together many projects with one single aim in mind, find the cure for our disease.”

Matthew’s Friends would like to congratulate all our friends from the Glut 1 foundations and groups from all over Europe and we look forward to supporting the newly formed Federation.



3RD EUROPEAN GLUT 1D CONFERENCE

SAVE
THE DATE

JUNE
5-6, 2020

LILLE
FRANCE



GLUT1-FRANCE2020@ANT-CONGRES.COM

HAPPY 18TH BIRTHDAY TO JACK



The 3rd July saw one of our Clinics patients, Jack Benson, celebrate his 18th Birthday and luckily for us Jack goes to school here at Young Epilepsy where we are based too.

So a party was organised by the house where Jack lives during term time and as a little present from Matthew's Friends, our Mo worked her magic and provided him with a Keto Birthday cake.

Jack loves buses so we arranged to get a cake topper and his mum made sure that she lifted that part of it off the actual piece of cake that Jack had. We think you will agree by the photos that Jack enjoyed his cake and he had a lovely party too.



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



15th Anniversary Ball

SATURDAY 28TH SEPTEMBER 2019

CROWNE PLAZA FELBRIDGE • FELBRIDGE • EAST GRINSTEAD

JOIN US FOR A FABULOUS EVENING OF CELEBRATION

£65 PER TICKET ON SALE NOW AT WWW.MATTHEWSFRIENDS.ORG

BLACK TIE • WELCOME DRINKS 7PM

CARRIAGES MIDNIGHT • 3 COURSE DINNER • RAFFLE • SILENT AND LIVE AUCTIONS

NICOLE'S KETO HOLIDAY

Summer is now upon us – would you take your child away with the Ketogenic Diet? Many families are put off of this idea but it can be done – preparation and organisation is what is needed and this is the story of a family holiday abroad with the Ketogenic Diet.....

Gail shared with us her family's recent holiday to Turkey, with daughter Nicole on a Ketogenic Diet. Devastatingly, both of Gail and Matthew's daughters have been diagnosed with Batten Disease. Read more about Nicole and Jessica's Batten Journey at their Foundation website www.thenicoleandjessicarich.foundation and Facebook page www.facebook.com/nicolesbattenjourney



"Our holiday was a challenge in a new way because it is the first holiday with Nicole being on the ketogenic diet. When we first attended the Ketogenic diet clinic all those months ago & found out what the diet entailed, there is no way we could have pictured being able to transfer a restrictive, prescriptive food regime to a week abroad. But we did!

It is all down to (Dad) Matthew & his amazing organisation skills, planning and prepping the ingredients into bags and Tupperware before we left.

Lisa (our travel counsellor) had contacted the hotel to explain what we would need & ensure the staff were aware of Nicole's needs & our specific requirements like getting an extra fridge in the room to store the food. This is another reason we book through Lisa at Travel Counsellor's because we have so many specific requirements & needs so we need to be fully confident that everything will be done as it needs to be & we always know it will be with Lisa, who is always on the other end of the phone to make sure everything goes smoothly & is our personal link to the hotel.



When we got there, Matthew spoke to Guest Relations & arranged to go down to the hotel kitchen & meet the Executive Chef Ozgur, who could not have been more helpful. He told us that they had gone out & bought specific milk & mascarpone just for Nicole!

Along with another very helpful chef, they showed Matthew around the kitchen & then helped him to cook some of Nicole's food, blueberry muffins & chocolate muffins, which are an ideal meal as they keep well & are portable to take out with us as they don't need heating up.

Matthew went down a couple of times during the week at 5pm when they were waiting for him, to cook for the next few days ahead.

There are so many different factors to take into account with the diet, then, times that by a hundred for taking it all on holiday! We had to do more regular ketone & glucose level checks to make sure things were remaining at a good constant level - if not, we could make adjustments & monitor the meals more closely.

But, we never want to say 'we can't do it' without trying. The worse case scenario was Nicole would have lived on double cream, mascarpone & raspberries for a week!!!! With lots of planning & organising, we tried & we did it!

So our first Keto experience abroad & it was a success & makes us feel we can easily do it again. It certainly made us feel accomplished & happy that Nicole was healthy happy & had a nice full tummy on her holidays!

The care & attention we received at The Royal Holiday Palace was unrivalled, they could not have done more to look after us & accommodate us.



Big brother Louis, Jessica, Dad Matthew, Nicole and Chef Ozgur

It was lovely to see Ozgur on our last morning in the dining room, it was nice for him to meet Nicole & it was lovely to thank him & his team for his help. It's reassuring to know that they will be familiar with the diet next time!"

For more information about Batten Disease, visit the Batten Disease Family Association website www.bdfa-uk.org.uk

HELPFUL HOLIDAY TIPS

Some general guidelines on travelling with the ketogenic diet:

Easy Option Number 1: Self-catering in your home country

You will have access to your familiar products and basically it can be 'home from home' and a lot of meals can easily be batched up beforehand and transported in cool bags ready for the fridge/freezer once you get to your destination.

The more you can prepare beforehand, the less you will need to do whilst on holiday so it can be a break for everyone and you can also take your mealplanner/food choice lists with you and be confident in all the ingredients and foodstuffs that you normally use. Keep meals as simple as possible, this is not the time for complicated recipes.



Also do a little research into the surrounding area and eateries – there may be a favourite chain there where you know the products and the choices are familiar. If going out in the evening is not an option for your family or the thoughts of organising that is just too overwhelming for you – how about a family brunch? – one of the most keto friendly meals there is and most people love a bit of bacon and egg or a nice fluffy omelette with ham and cheese – find yourself a good local café and you can usually choose your breakfast items. This is a great choice for families to enjoy.

If you are going on a long car/coach journey to get to your destination then another option to consider is packing meals in dry ice – this has been done by families before to keep things really cold/frozen and they have arranged it all with the coach company beforehand. Also you can try to arrange to have your prescription food products delivered to your holiday address for your time there.



Easy Option Number 2: Camping (or Glamping) in your home country

Apart from needing a lorry size car in order to transport everything, pretty much the same rules apply as above but you won't be able to pre-prepare as many meals due to lack of freezer/fridge space – although looking at some people's camping equipment that may not be a problem after all!

Option Number 3: Self Catering / Camping – Abroad

Self-catering is always easier because you choose what you are eating, however when you go abroad, the familiar brands will change and even the ones that don't can have different food values – so now you do have to start being extremely careful and read food labels (where you can) – google translate is really good for that! We have lost count of how many times food labels have been sent through to us from a family at a holiday destination asking what the carbohydrate contents are! Hellmans Mayonnaise is a good example of this, on the continent, what looks like our full fat version is not, it is a lot lighter on fat and heavier on carbohydrates – so be careful – double check all the brands you buy.

We would also recommend you definitely take your mealplanner with you. If you don't have one – ask your dietitian about gaining access to the Electronic Ketogenic Mealplanner (EKM) which you download freely to your computer or your smart phone. It will make life a lot easier for you when calculating meals. Again do your



research about the local area and possible places to eat out and again, keep things as simple as you can.

If you can, take some branded products with you such as mayonnaise. You MAY require a letter from your doctor explaining why you are carrying such items – especially if flying to your holiday destination and it would be a good idea to phone the airline beforehand as well.

If you need a draft copy of a holiday letter then please let us know and we can email you a copy which your doctor can use as a template.

When travelling outside the UK – A few things to remember:

- You will need a letter from your GP/Keto Team for Customs for any food items you are taking with you, especially for your prescription products.
- Check the country information before you travel to see if you CAN take any food items through customs – Australia and the USA are particularly strict on this.

Advise airline well before you fly

- If you are taking any liquid supplements with you as

you may be required to open all of them and in some cases try them in front of customs officials.

- If you request space for a cool box on the flight remember that ice bricks contain fluids – so you may be asked to get rid of them.
- Make sure you have copies of all your prescription/letters from doctors etc in case anyone asks to see them.
- Ask for extra cabin luggage space if needed.

Option 4: Hotel – home or abroad

Again pre-planning is the key – phone ahead and discuss your needs with the hotel. Give them details of the diet, ask for a fridge in your room or even fridge space in the main kitchens. Take some of your favourite brands with you if you can, if not ask the hotel what brands they use of different food stuffs and do your research before you go. As you have already read in Nicole's story – the hotels can be absolutely brilliant and if you get a good service from a hotel – let us know – we would love to highlight them!

In case of Dire Emergencies (stuck in strange place, mealplanner not working, no scales, car broken down and everything going wrong that can go wrong)....

Go for a protein and fat meal such as plain meat, fish, Quorn, eggs or cheese with no coating or batter if possible – however, if not possible, scrap as much batter or coating off as you can. Again an Omelette is a good option if you can as that is just eggs and cheese, add extra butter and oil to any meal and if you have access to salad stuff



– go for the low carb veggies first such as salad leaves, cucumber, mushrooms.

If you like KetoCal then always make sure you have a couple of cartons of this available as it is great in an emergency. (Matthew's mum Emma swore by this when Matthew was on the diet and never went anywhere without a ketoshake with her!)

Always make sure you discuss an emergency travel plan with your dietitian before you go away.

SUMMER RECIPES

FROM OUR KETOKITCHEN

Everyone loves the Summer, long days and warm weather puts us all in a good mood and Mo has once again created some lovely recipes that are proving very popular. The Salted Caramel Ice Cream is gorgeous, as is her summer pudding and for those of you who are wanting to cut down on your meat intake or are vegetarians, we can highly recommend the Stroganoff!

If you are looking for inspiration then please visit our website at the following link www.matthewsfriends.org/keto-kitchen where you will find lots of Tried and Tested recipes for all the different types of ketogenic dietary therapy. They can all be downloaded freely and if you need any of them adjusting for your own prescription then please speak to your dietitian or email Mo here at ketokitchen@matthewsfriends.org Don't forget to send in your favourite recipes so we can put them up on our website and share them with everyone else.

VEGETARIAN STROGANOFF

INGREDIENTS

- 56g White cabbage
- 11g Onions
- 47g Full fat crème fraîche
- 40g Mushrooms
- 16g Quorn pieces
- 4g Olive oil
- 8g Butter
- 3g Dijon mustard - SAINSBURYS
- You will also need a good pinch of paprika, ½ teaspoon of lemon juice and seasoning.

METHOD

- Finely slice the cabbage, mushrooms, onions and quorn (defrost first if frozen).
- Melt the butter and oil in a pan over a medium heat. Add the onions and fry until just tender but not browned.
- Add the cabbage and mushrooms, stir fry for a few minutes then add the quorn with the paprika and Dijon mustard.
- Cook for a few minutes then stir in the crème fraîche and lemon juice. Stir until heated through.
- Season with a little salt and pepper, then serve.



CLASSICAL 2.94:1 RATIO
CHO: 5.24G
FAT: 30.23G
PROTEIN: 5.06G
KCAL: 313



PLEASE ENSURE YOU CHECK PRODUCT LABELS FOR VALUES.

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

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

SALTED CARAMEL ICE CREAM

INGREDIENTS

- 69g Double cream
- 50g Almond milk - ALPRO
- 28g SUKRIN gold
- You will also need a tiny pinch of salt and DaVinci sugar free caramel syrup or flavour of your choice (optional).

METHOD

- Start by heating the Alpro and Sukrin gold in a small pan, simmer for a few minutes until it reduces and becomes syrupy.
- Add a pinch of salt and leave to go cold.
- Whisk the double cream until it starts to thicken then add the Sukrin syrup and continue whisking until thick and fluffy.
- Place in plastic container's suitable for freezing.
- Before serving leave in the fridge for approximately 15 minutes to soften a little.

MO'S TIPS

This recipe makes two good helpings. If you can, divide in to two portions before freezing, this will make life a lot easier when you need it. Freeze for at least 6 hours. It will keep in the freezer for up to 3 months. If you want the ice-cream to be a little softer, whisk in 10g of sunflower oil or MCT oil to the Sukrin syrup when it is cooling - this will of course increase the fat content. Serve drizzled with DaVinci sugar free caramel syrup or flavour of choice (optional).



MKD
CHO: 1.57G
FAT: 35.39G
PROTEIN: 1.23G
KCAL: 330



SUMMER PUDDING

INGREDIENTS

- 30g Keto bread with psyllium
- 30g Raspberries
- 28g Blueberries
- 30g Double cream
- You will also need a small basin / pot that holds 125mls of liquid. You will need to make the keto bread recipe if you have not got a little left over and will need sweetener to taste, I used 5g TRUVIA.

METHOD

- Cut the blueberries in half and chop the raspberries. Place in a small saucepan with 50mls of water and the sweetener.
- Bring to a simmer to dissolve the granules, cook for 3 minutes.
- Set aside. Line the basin with slices of bread, I found 30g fitted perfectly, keeping one piece to make a lid.
- Place the fruit in the lined basin, top with the bread lid then pour over any residue juice.
- Place in the fridge and leave overnight. Un-mould and serve with the cream poured over.

MO'S TIPS

I lined the basin with cling film to ensure it did not get stuck! You can then fold the cling film over the top and press down to make the filling firm. I put a pot of yoghurt on the top as a weight, this encourages the juices to get in to the bread. It works well with frozen fruit too, but defrost before weighing.



CLASSICAL 2.26:1 RATIO
CHO: 5.23G
FAT: 22.02G
PROTEIN: 4.51G
KCAL: 237



MATTHEW'S FRIENDS KETO STAR AWARDS!

We love it when someone is nominated to get a Keto Star and, in this issue, we are following up on a nomination made in the Spring.

The Lawsons nominated the team at their daughter Ava's School, The Hill Primary School in Reading, for being such an amazing and supportive team and for the understanding and care they have shown to the family during Ava's, sometimes challenging, ketogenic journey.

Here is Ava presenting the certificate to the Head, Mr Beavan, during a special assembly in which Ava got the chance to talk to the school about her 'magic food'. Thanks to all at The Hill Primary School – you certainly are Keto Stars!



We received a lovely message in via our Facebook page and after reading it, there was no question that Kaitlyn is a KetoStar and we are sure you will agree. HUGE well done to Kaitlyn and her family.

"Hi - just re read an old message I sent you back in 2014 when things were clearly very different. Today, after 4 years and 4 months on the diet, we have been told by the dietician at the John Radcliffe (who Kaitlyn is now under) that she can come off the diet. We have been gradually weaning ratio's for a while now - but today was the day! We still have to take it easy and not go mad on the sugar front, but Kaitlyn's beam said it all today.

She just kept saying 'We did it Mum!' and is very much looking forward to macaroni and cheese for tea tonight! Thank you so much to everyone at Matthews Friends for all your support. You were amazing and were there for us throughout it all. Such a lovely team and I will never forget what you did for us. The ketogenic diet has given me my girl back with no seizures for a prolonged period

of time. The fear of them returning will never go completely but my word - we survived! No more mayonnaise or double cream to weigh out! Not sure what I am going to do with all my spare time! In the meantime just know that our family will not forget you Matthew's Friends, and will continue to bang the ketogenic diet drum to anyone who will listen. Thank you!!" Catherine Doyle (Kaitlyn's Mum).

Jessica Sullivan was nominated by our own Emma Williams for doing so well on her Ketogenic diet and being an inspiration to others.

Emma Says *"I was recently attending a Ring 20 group meeting where I met Jessica and her family. Jessica is 12 and has been on the diet a while now. I listened to her parents tell her story and how well she doing and how at times, the diet can have challenges to overcome as most girls her age want to be the same as their friends and this includes eating the same as their friends. Jessica is very good when it comes to her diet and knows it helps so has overcome these types of challenges and just 'got on with it' so to speak. I really admired Jessica and her family and I felt she deserved a little reward and acknowledgement for how far she has come".*

To read Jessica's story and more like hers then please visit.... www.matthewsfriends.org/about-us/our-stories/children/



We get some delightful feedback from people that have received a Keto Star award. They are usually overwhelmed and thrilled that their efforts have been recognised and appreciated.

If you know someone, a parent, friend, someone at school or even in a local restaurant that goes above and beyond then please do nominate them for their own Keto Star award!

The form can be downloaded from our website matthewsfriends.org or by following this link www.matthewsfriends.org/pdf/nomination_form_d.pdf

SPOTLIGHT ON KETO BROWNIES...



We are very fortunate in the Matthew's Friends office that we get sent some lovely low carbohydrate products from various companies to try (it is a tough job at times trust us!) and this month was no exception.

The company is London Keto Brownies and they sent us the snack size box and they were lovely. Great flavour, a really deep and rich chocolate flavour with a good 'brownie' consistency. Ideal for a snack or used as a pudding with whipped cream or even clotted cream and needless to say they didn't last very long around here! We were all in agreement that they were delicious and we would recommend them. You can find out more about them at: londonketobrownies.co.uk

However, a couple of things to be aware of:

- They do contain Polyols and some people might be sensitive to these.
- They are a little pricey but they are homemade and sent out freshly – so the price does reflect this. You might want to consider them as a special treat.
- They are designed for lifestyle low carbohydrate way of eating not a Medical Ketogenic Dietary Therapy but they could certainly be useful for some people.

As always – please check with your dietitian before adding anything new to your diet.



Other options to buy Brownies are Natural and Low Carb Kitchen at the following link: www.nlckitchen.com/product/chocolate-brownie/

Or if you are feeling brave – have a go at making your own and try the recipe below that was sent in by one of our parents.

BROWNIES | INSPIRED BY Dervla – HARRY'S MUM | 3.02:1 RATIO

INGREDIENTS

- 40g Cacao – LINDT 90% DARK SUPREME
- 48g Butter
- 50g Ground almonds – MORRISONS
- 4g Cocoa – BOURNVILLE
- 50g Egg
- You will also need ½ teaspoon baking powder and a good squirt of liquid sweetener.

COOKING INSTRUCTIONS

- Pre heat oven to 180c / fan 160c / gas 4.
- Melt the chocolate and butter in a bowl over hot water, gradually beat in the egg.
- Add liquid sweetener.
- Mix in the dry ingredients.
- Pour in to a greased and lined cake tin.
- Cook in pre heated oven for approximately 12 – 15 minutes.
- When cold cut in to portions.



If you cut in to 9 portions, this will give you 1g CHO per portion

Total recipe values: 94.66g fat | 22.06g protein | 9.90g CHO | Kcals : 980

GARY AND MATT'S LONDON TO DUBLIN BIKE RIDE – MAY 2019



We have some madcap fundraisers and we love you all and we are very appreciative for all you do... Gary and Matt are no exception!

They undertook a 5 day mad bike ride from London to Dublin for us via B roads, Coastal paths, bridle paths, bridges, tunnels, tow paths and very sore backsides (as well as legs and numb hands apparently)! Total mileage 327. Their fundraising efforts were for both ourselves and the Isabel Hospice dividing the proceeds between both charities. Matt and Gary raised a wonderful £769.71 for Matthew's Friends, which is fabulous.

You can read their full story together with their day by day account and route with some lovely photos on our website at the following link: www.matthewsfriends.org/keto-fundraising/some-of-our-fabulous-fundraisers/

GO TRACY – 2 OUT OF 3 COMPLETED!

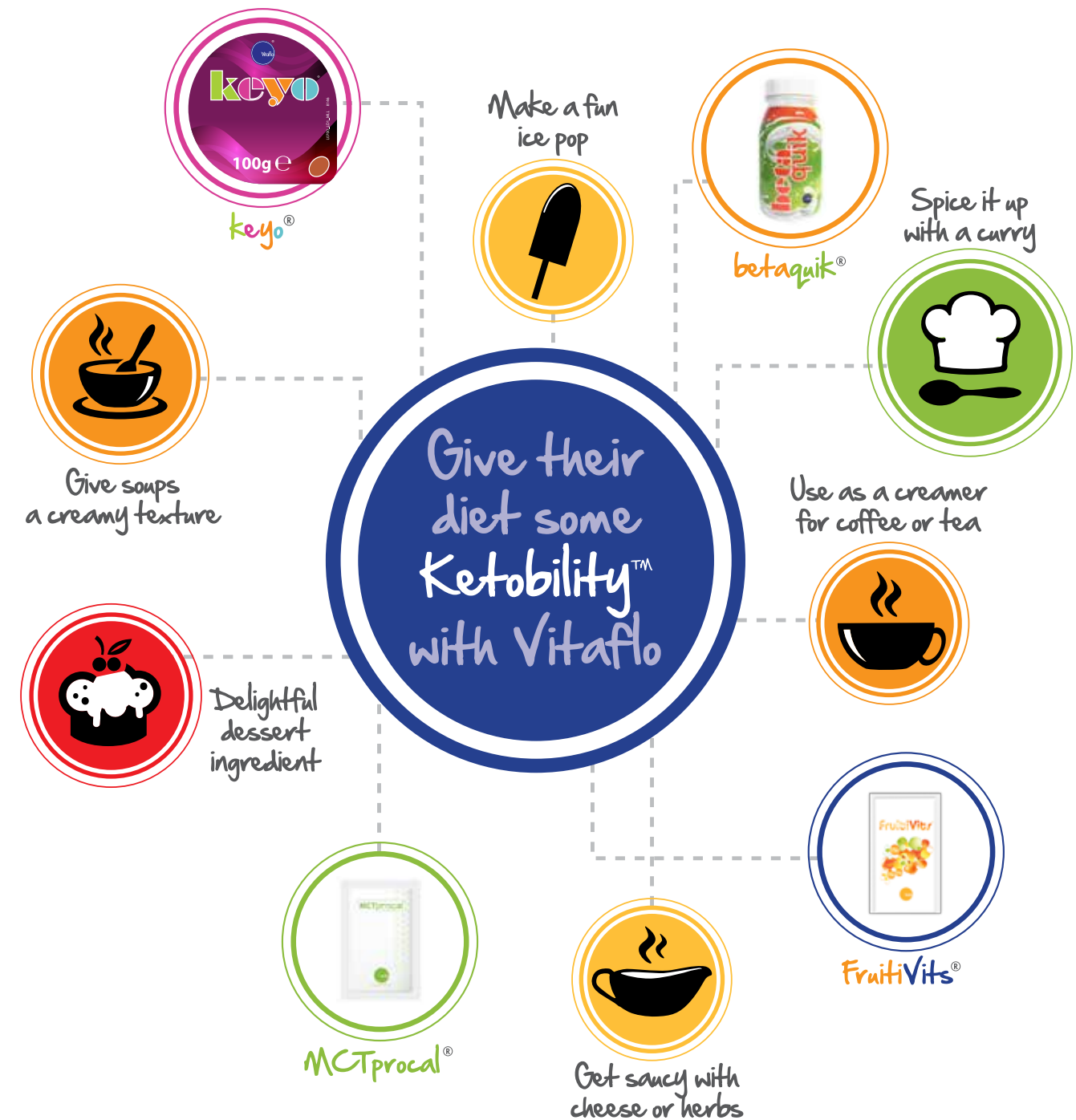
Our MF Funded Dietitian in Aberdeen, Tracy Cameron has just completed the 2nd of her 3 marathon challenges by completing the Dundee Half Marathon.

On the 14th September 2019 Tracy undertakes the Crathes half marathon. She decided to do 3 half marathons this year in each of the of the big health boards that she covers: Grampian, Tayside and Highland. We are delighted that she did and are extremely grateful for her fundraising activities for us.

Please follow the link to give Tracy and Matthew's Friends your support so we in turn, can fund more centres, provide more education and support more families. Every penny is put to good use. To donate please visit: www.justgiving.com/fundraising/tracy-cameron6



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

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



DERVLA'S LOVELY MESSAGE AFTER RUNNING THE VIRGIN LONDON MARATHON 2019!

"Lining up with over 40,000 people to run the London Marathon was a dream come true. 4 years ago I promised Julie Fountain that if my ballot place ever came up I would run for Matthew's Friends. It seemed a fitting way to show how much the support and help we received from her and the whole Matthew's Friends team meant to me and my Family.

When I made the promise my son had been on the Ketogenic Diet for over a year, it had given him seizure freedom from desperately debilitating Myoclonic Astatic Epilepsy.

For every step of the marathon there were crowds cheering and it was really emotional to see so many people running for others. I really enjoyed the experience and am overwhelmed with the support given by friends and family to raise this amazing sum for Mathew's Friends.

I highly recommend applying for the ballot and running for Matthew's Friends!"

Thank you so much Dervla, for raising a magnificent £1350.00 including Gift Aid! We are truly grateful to you and your amazing supporters!



PURPLE DAY

EPILEPSY AWARENESS DAY - 26TH MARCH



Enaya and her school friends pictured here, raised £175 by making and selling scrumptious cakes at school for Purple Day for epilepsy awareness! They did a fantastic job and those cakes looked marvellous. Well done Enaya and thank you for all your hard work.

Nicki Bain and her boys dyed their hair purple for epilepsy awareness for Matthew's Friends!

Nicki said 'It was a very last minute decision to do a Purple Day fundraiser and we ended up being 2 days late!! We decided to try and raise £200 which we thought was a do-able amount to fundraise, so are totally delighted to have raised £580! I am wondering if we can stretch it to £600!!



Angus (is 12) and is currently being weaned on to the Keto Diet for his Epilepsy, and to say that I am enjoying it would be a huge exaggeration!! Anyway hopefully we will get there.'

Nicki, Angus and Fergus raised a belting £715 including Gift Aid and smashed their target!

Amazing, thank you!

A total of £1288 was raised for our JustGiving Purple Day campaign this year – thank you so much to everyone who took part!



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.