

KETOGENIC THERAPIES

SPRING NEWSLETTER 2019 | TENTH EDITION



Ketogenic Dietary Therapies
Information • Training • Research • Support

Registered Charity No. 1108016

MATTHEWSFRIENDS.ORG

How often is antiseizure drug-free ketogenic diet therapy achieved?

Ketogenic Dietary Therapies are used when at least 2 appropriate medications have failed. This happens in approximately 30% of the epilepsy population and in many cases multiple medications are being used which can lead to challenging and difficult side effects.

After seizure control, drug reduction is one of the main reasons for trying the diet, patients want a quality of life in between the seizures as well as a possibility of seizure reduction or freedom. Inside (page 17) you will read about the paper that Professor Eric Kossoff and his team have recently published focussing on how often drug free ketogenic diets can be achieved.



SPECIAL FEATURES INSIDE:

• PROVIDING KETOGENIC DIETARY THERAPIES EDUCATION AND INFORMATION FAR AND WIDE - PAGE 05



• KETOCOLLEGE PROGRAMME
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30TH APRIL - PAGE 08



• FEAST YOUR EYES ON SOME
EXCITING EASTER RECIPES FROM
OUR KETOKITCHEN - PAGE 10



• MATTHEW'S FRIENDS KETO STAR
AWARDS! - PAGE 16



PLUS

PUBLICATION IN EPILEPSIA PAGE 03

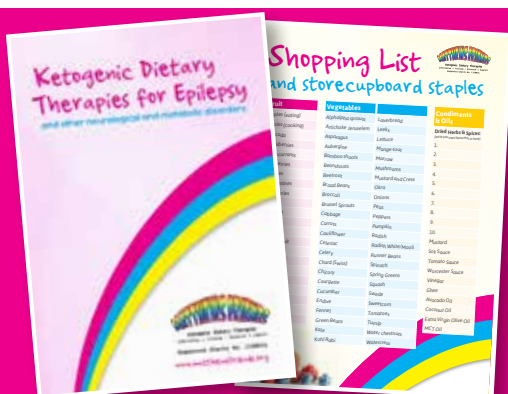
LEE'S STORY - UPDATE PAGE 04

ARTICLE BY ERIC H. W. KOSSOFF PAGE 17

UPDATE FROM MF CANADA PAGE 18

New Resources from Matthew's Friends...

Our new updated charity booklets are now available (more about those inside) and also our new Keto Shopping List and storecupboard staples lists - easy reminders for you when you are out and about. See all our available free resources listed on page 17.



Coming Soon – Summer newsletter..



**Read all about
our Purple Day
fundraisers
and activities**



**Professional
and family
online tutorials
being launched**

**If you would like to submit a story for our Keto Newsletter
then please send it in to Emma@matthewsfriends.org**



KetoGENIC Dietary Therapies
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TO HELP FUNDRAISING VISIT:

www.matthewsfriends.org/easy-fundraising/

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



No local ketogenic service available to you?

Long waiting lists?



Ask for a referral to the Matthew's Friends Clinics

MATTHEW'S FRIENDS CLINICS
KETOGENIC DIETARY THERAPIES

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

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

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

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

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



PUBLICATION IN EPILEPSIA

HOW DOES THE DIET WORK? ANOTHER PIECE OF THE PUZZLE?

Recently, a member of our Medical Board, Dr Anita Devlin, was an author of a publication describing how the medium chain fatty acid decanoic acid (C10), present in the ketogenic diet, could act in combination with an anticonvulsant drug at the AMPA receptor.



Much of the communication between nerve cells in the brain occurs through the release of chemical messengers called neurotransmitters, which then bind to specific receptors on other cells. The messages can be excitatory or inhibitory and the AMPA receptor is a receiver for excitatory messages mediated by the neurotransmitter glutamate. Epileptic seizures induce increases in glutamate and excessive excitatory stimulation through glutamate can result in damage to cells and long-term changes in brain signalling and networks.

Therefore, reducing the effects of increased glutamate at the AMPA receptor appears desirable and this can be achieved by blocking the receptor to glutamate. Perampanel (Fycompa) acts at this receptor and has been shown to reduce seizures in those with epilepsy.

Other recent studies have shown that decanoic acid (C10) a medium chain fatty acid also binds to the AMPA receptor but at a different site to Perampanel. The hypothesis tested in this paper is whether Perampanel and decanoic acid used together could amplify the effect of both - synergism.

The results show that synergism is seen including in human brain tissue, which emphasises the potential to translate this into our treatment approach to patients.

In the clinical setting, our observations suggest that in the presence of dietary decanoic acid, a reduced dose of Perampanel may be required to achieve effective seizure control but with fewer side-effects. Future studies would need to investigate therapeutic outcomes in patient groups on an MCT diet with additionally prescribed Perampanel.

If you would like to read the abstract then please put the following link into your web browser: www.ncbi.nlm.nih.gov/pubmed/30324610

#SUGARFREEFOREPILEPSY2018

November was #sugarfreeforepilepsy month and the following lovely people took part to raise awareness and funds for Matthew's Friends;

**PHIL & ALI AMEY
RAISED £205**

**RACHEL FOX WENT KETOGENIC
AND RAISED AN AMAZING £335**

**JAN BARBOUR'S SUGAR FREE MONTH
FOR EPILEPSY SAW HER GET A
FABULOUS £590 IN DONATIONS!**

**CATHERINE LAWSON
TOOK PART AGAIN THIS
YEAR AND RAISED £100**

In addition to this, £231 was given on our Facebook Donation page plus another £135 on our Justgiving campaign page, with gift aid of £284.50 (it really IS worth ticking that little box)

THAT'S A GRAND TOTAL OF £1875.50 RAISED!

JUST BRILLIANT – THANK YOU SO MUCH FOR YOUR SUPPORT! SAME TIME NEXT YEAR?

Public Health Collaboration Conference

A conference at the Royal College of General Practitioners in London that welcomes everyone from healthcare professionals to patients in order to collaborate for better public health.

Saturday 11th & Sunday 12th May 2019

For more information please visit: <https://phcuk.org/conference/>



Emma says "I am very pleased to be a Patron of this organisation that is doing great work promoting healthy eating and REAL food. We have sadly become a society relying on takeaways and highly processed foods that require very little cooking or preparation. We have seen so much of this over the years when families are wanting to try a ketogenic diet but then realise cooking is involved and we seem to be losing our ability to cook from scratch or even know what REAL food actually is. We feature the Public Health Collaboration on our Eating for Health and Wellbeing page of our website and I would encourage people to take a look at the campaigns they are currently working on and if you have an interest in healthy eating and real food campaigns – get involved with them."

LEE'S STORY... (UPDATE)

WE FIRST FEATURED LEE BACK IN SUMMER 2017 - BUT YOU REALLY NEED TO HAVE AN UPDATE...WHAT AN INSPIRATION HE IS.



I'm Lee, I'm 40 and I've had epilepsy since I was 16 and my seizure types are tonic clonic and myoclonic jerks. However, I haven't had a tonic clonic seizure for a long time now. I have been on many different types of medications, experiencing many of the side effects that come with them too. I have also been using the modified ketogenic diet since 2016. Now experiencing less side effects and my life is better with less limitations.

You may remember my previous story from the summer 2017 magazine, where I spoke about how I was before the diet and the benefits it has brought to me... If you haven't seen it or don't remember, it's still online and worth a read.

Well... I'm here again, and as if my life couldn't get better!

So, since the last magazine entry I've obviously learnt a lot about nutrition to make this amazing diet easier to manage as a lifestyle. Along the way, I've crossed paths with information about how versions of the ketogenic diet can help other conditions. I was fascinated and intrigued to learn more...

My interests and self education has explored things such as the microbiome, amongst other things. What was once just a diet for my epilepsy has now become a major interest... I had to take it further.

Summer 2017, I set myself a goal to go to university to study dietetics. However, it's not been easy, I'm not gonna lie!

At this time in my life, stepping out of my comfort zone, managing finances alone, and going back into education after a long time etc... were all major obstacles. But obstacles I overcame. I wanted this!!

So, I smashed my access to higher education course at college and got a place at Plymouth University, which I started in September 2018. I have entered a new world entirely... new challenges... new obstacles... new adventures... But I love it and I'm on the right path! I'm happier than ever.

I've joined a couple of societies here at university. One is the athletics society, where I mainly go running, circuit training and take part in random sporting events such as Dodgeball, and I believe next term we're getting involved in random hockey and volleyball tournaments. The other is the Adventure and Expo Society, where we do climbing, caving, slack lining, and loads of other outdoor fun stuff.

Who'd have thought that from where I was before this diet, struggling to concentrate and communicate due to previous medications, I'd get to where I am today with all these amazing opportunities, with many more to come! I feel amazing!



I keep thinking I'm going to wake up and find it was just a dream... But fortunately, I'm more than happy to say it's all real. This new journey is bringing me so much more knowledge and opportunities. I am thankful for everyone involved on this journey and look forward to meeting others as it continues. I look forward to the rest of my education and to be able to give back and help others too.

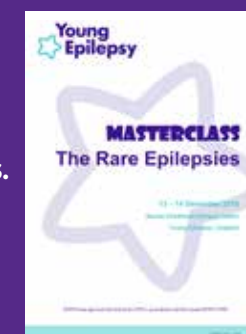
I'm sure this isn't the end of my story.

"GOOD LUCK WITH YOUR OWN JOURNEYS, YOU CAN ACHIEVE ANYTHING YOU DREAM OF. WHERE THERE'S A WILL THERE IS A WAY! NEVER GIVE UP!"

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

EPILEPSY MASTERCLASS, FRIDAY 14TH DECEMBER AT YOUNG EPILEPSY, UK

Our CEO and Founder, Emma Williams was asked to present on the role of patient organisations in patient care at the recent Epilepsy Masterclass.



She focused on her experiences of running Matthew's Friends Ketogenic Dietary Therapies Charity for the past 15 years and her time at Dravet Syndrome UK, as well as her involvement with a lot of other condition related charities and EpiCARE (European Reference Network for Rare and Complex Epilepsies) where Ketogenic Dietary Therapies can be beneficial. Focusing on the positives, patient charities are obviously highly specialised and passionate about their cause as in a lot of instances the charities have been sent up for very personal reasons.

At best they can provide better informed patients, a sense of empowerment for the patient and families, reduced feelings of isolation for all involved, a better understanding of the condition and/or treatment they champion. These organisations can also help with access to services for families that would be otherwise denied to them and in some instances, can give financial support for equipment and services.

These organisations can also highlight the need for policy changes, fund research projects that otherwise would not be able to get done as well as provide vital information to the

professionals on what is important to the families and what services/research is needed in their particular area.

The whole synergy of professional, patient and/or patients' family, industry partners and patient organisations completes a circle and can complement one another really well. Some of the negatives were also highlighted, which can be summed up usually in one word and that is 'frustration'. Frustration that policies, research, services and support are not already in place, are costly and can take an awfully long time to get results as many systems/pathways/rules and regulations have to be navigated and this can be a very steep learning curve for the patient charities as well as the professionals trying to navigate all this. Emma used the fact that Matthew's Friends have always had a medical board attached to their organisation which has helped steer the charity in the most beneficial way for the long term benefit of those we serve.



INTERNATIONAL CHILD NEUROLOGY CONGRESS – MUMBAI, NOVEMBER 2018

Dr Janak Nathan, international advisor to Matthew's Friends for India, ran a very successful one day workshop together with his faculty (pictured) on Ketogenic Dietary Therapies at the recent International Child Neurology congress, with 85 delegates in attendance from all over Asia.

It was one of the most successful pre-conference sessions held and highlighted the fact that the ketogenic diet is growing in popularity and the thirst for knowledge and training is gaining momentum in all parts of the world. Dr Nathan runs training programmes throughout India and Asia and has trained hundreds of ketogenic teams over the years.

He is part of the Scientific committee that will be helping us plan the 2020 Global Conference that we are holding in Brighton and as always, he is a delight to work with.



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

BRITISH PAEDIATRIC NEUROLOGY ASSOCIATION MEETING – LIVERPOOL, JANUARY 2019

CEO and Founder Emma Williams, spent a few days in Liverpool connecting with the UK's leading neurology professionals whilst bumping into some friends from other charities too.

Our stand was very busy and lots of our information was taken away and ordered by various centres around the UK with meetings being had about increasing services for Ketogenic Dietary Therapies. Some of the photos include Chef Neil from Vitafo who came along to see us and took some of our information away with him ready for his cookery days, our Medical Board Chair Professor Helen Cross with Consultant Paediatric Neurologist Frances Gibbon from Wales and we also bumped into our friends from The Lily Foundation, Dravet Syndrome UK, CDKL5 UK and HOPE.



Lily Foundation at The Matthew's Friends stand



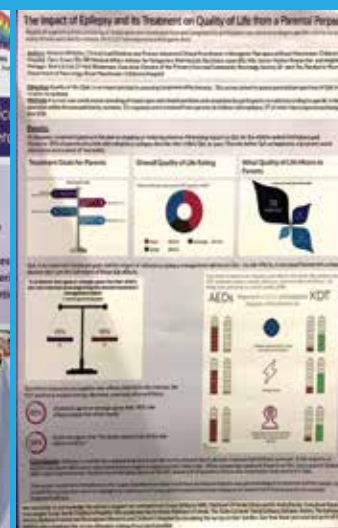
Chief Neil at Matthew's Friends stand



Helen and Francis Gibbon



Research Nurse with Emma



QOL Nutricia poster

PAEDIATRIC STATE OF THE ART SYMPOSIUM METABOLISM-BASED AND KETOGENIC THERAPIES FOR EPILEPSY: A TRANSLATIONAL APPROACH NEW ORLEANS 2018

Written by Dr Anita Devlin, Consultant Paediatric Neurologist, Newcastle Upon Tyne & Matthew's Friend's Medical Board.

History was made at the Ernest N Morial Convention Centre, New Orleans on Saturday 1st December 2018 when the prestigious Paediatric State of the Art Symposium session at the American Epilepsy Society was dedicated to platform presentations about metabolism-based and Ketogenic Therapies for Epilepsy. The session was delivered by a truly international collection of invited speakers and the session was extremely well attended in the largest lecture theatre available to the conference.



The session was opened by Professor Eric Kossoff from Johns Hopkins hospital who outlined history of this treatment and the reasons for the recent interest in this therapy for epilepsy. Then Dr Susan Massino from Connecticut provided an up-to-date summary of how the natural ways that cells work lead us to develop therapies for epilepsy such as ketogenic therapies.

This was followed by Dr Kristina Simeone from Nebraska summarising the evidence that Ketogenic therapies are of benefit for the many co-existing problems for patients with epilepsy at all ages including problems with attention, sleep and behaviour. Dr Elizabeth Donner from the Toronto Sick Children's Hospital then provided a comprehensive summary of the evidence of clinical efficacy of Ketogenic therapies in childhood epilepsy along with the highlights of the up-to-date international consensus guideline published in Epilepsia 2018.

I then continued the theme of assessing the clinical efficacy of the diet but this time in infants with severe drug resistant

epilepsy whilst also highlighting the published guideline for the treatment of infants with epilepsy with ketogenic therapy published in the European Journal of Paediatric Neurology 2016

Professor Stephane Auvin from Paris then summarised the evidence for the anti-inflammatory effects of Ketogenic therapies which was followed by an excellent summary of the session given by Professor Jong Rho from Calgary. This was followed by a panel question and answer session involving all the speakers.

The speakers, Professor Kossoff and Professor Rho were delighted with the content of the session and how it had been received and the session only took place due to the combined hard work of Professors Kossoff and Rho who put the session forward to the AES competing against many alternative proposals for the prestigious State of the Art slot at the conference.

MATTHEW'S FRIENDS WILL BE HOSTING THEIR 4TH ANNUAL KETOCOLLEGE PROGRAMME

4TH – 6TH JUNE 2019

CROWNE PLAZA FELBRIDGE HOTEL, EAST GRINSTEAD, WEST SUSSEX, UK



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

DAY 1 MEDICAL MASTERCLASS

For health professionals working with or interested in ketogenic therapy. Included in the programme are Epilepsy, Neuro-oncology and Diabetes.

NEW FOR 2019!

Diabetes Session

- Treating Type 1 and Type 2 diabetes – current thinking and why it needs to change
- How to treat diabetic patients safely with KDT
- Case studies of patients with Epilepsy AND diabetes

Neuro-Oncology Session

- Clinical Research and current evidence available
- Current treatment available and where KDT could possible stand
- Dietary factors to consider for Neuro-oncology



Scientific Committee
Chair Professor
J. Helen Cross OBE

DAY 2 & 3 DIETETIC MASTERCLASS

Specifically designed for dietitians, specialist nurses and support teams. Includes workshops on the practical implementation of both traditional and modified ketogenic therapies, supported by cookery demonstrations and case studies.

For the full programme and registration details, please visit www.mfclinics.com/keto-college
or to register your interest please email: ketocollege@mfclinics.com

CONVENIENTLY LOCATED ONE HOUR TRAIN FROM LONDON AND 20 MINS TAXI FROM LONDON GATWICK

RCPCH APPROVAL PENDING

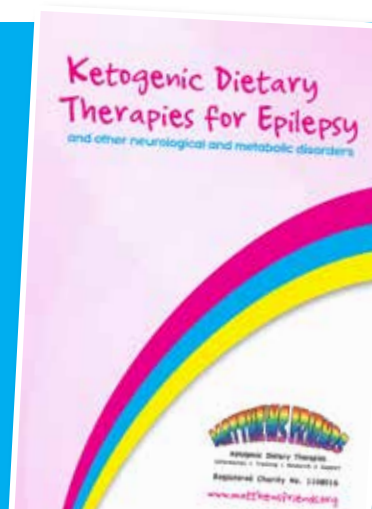
New for KetoCollege 2019

Emma Says.... “We receive wonderful feedback from our KetoCollege course every year and we are thrilled that it is helping so many new teams to get started and train new team members for existing centres. This year we are especially excited to have simultaneous English-German translation available for our German-speaking delegates. Again this goes towards our work with the European Reference Network for Rare and Complex Epilepsy (EpiCARE). Here is just one of the lovely messages we received from last year.”

“ I attended Ketocollege in June 2018. It was the best course I’ve been to – I’ve been qualified for 29 years! I couldn’t wait to get started with the diet. I’ve only started my post this month so I’m only getting to grips with everything but your website is invaluable and the You Tube channel is fab.”

New Charity booklet for 2019!

We are very pleased to launch our BRAND
NEW charity booklets, available NOW!



These are our first-line introduction to our charity and to Ketogenic Dietary Therapies. Where we go, so do these...

Conferences, training meetings, exhibitions and of course they are available in our information packs and Ketogenic Diet Starter Packs, which are available to all UK and Ireland families FREE OF CHARGE via our online Shop! Fundraisers in particular find these booklets so useful, as they explain everything that we do in one handy place. So, if you are planning an event or fundraiser, please get in touch with us at enq@matthewsfriends.org, we’d love to hear from you!

Grateful thanks go to Councillor Cameron McIntosh (pictured with our Founder/CEO Emma Williams MBE), our local Surrey County Councillor, who gave a generous donation from his Community Allocation Fund and to our fab friends at VitaFlo, makers of Ketogenic Diet products, for a grant towards the production of these booklets.



Innovation in Nutrition



EASTER RECIPES

FROM OUR KETOKITCHEN

We're looking forward to Easter and some tasty treats that the whole family can enjoy... thankfully Mo has worked her magic yet again and come up with some great keto recipes. We can't feature them all in our newsletter but if you go on to our website at the following link www.matthewsfriends.org/keto-kitchen you will find lots of Tried and Tested recipes that you can download freely. If you have a recipe you would like to share then please send it in to us at ketokitchen@matthewsfriends.org



HOT CROSS BUNS

INGREDIENTS

- 80g Almond flour flurry - Holland and Barrett
- 52g Eggs
- 12g Psyllium husk - Telephone Brand Sat-Isabgol
- 9g Sultanas
- 2g Orange zest
- 4g Butter
- You will also need a pinch of salt, 1 teaspoon BARKAT baking powder, 7g white wine vinegar, 85g boiling water, 1 teaspoon mixed spice or cinnamon and 10g STEVIA granules or sweetener of choice.

METHOD

- Pre heat oven to 180c / fan 160c / gas 4. Chop the sultanas and finely grate the orange zest then weigh it!
- In a heatproof bowl mix together the almond flour, husk, sweetener, baking powder, salt, mixed spice, sultanas and orange zest. In to this stir the beaten egg, vinegar and butter cut in to pieces, mix well.
- Pour in the boiling water then stir until a stiff dough forms.
- Divide in to three equal sized buns, mark each with a cross and place on a lined baking tray, cook in a pre-heated oven for approximately 25 - 30 minutes.

MO'S TIPS

They can be eaten as they are or split and spread with butter. You could divide in to 4 smaller buns which would make them an ideal snack, they would only need approximately 15 - 20 minutes cooking. When they had cooled, I glazed them with a little JOSEPH'S sugar free maple syrup, this is optional.

Each bun if divided in to 3 will have: 17.6g fat / 7.8g protein / 4g CHO



MKD
CHO: 12.07G
FAT: 52.80G
PROTEIN: 23.64G
KCAL: 618



EASTER FAT BOMBS

INGREDIENTS

- 11g Cacao Butter - Sevenhills Organic
- 17g Lindt 90% Cocoa Dark Supreme
- You will also need approx 2ml liquid sweetener (to taste) a few drops of flavouring orange extract is nice.

MO'S TIPS

The recipe made 11 fat bombs in the moulds I used giving 1.8g fat in each one Protein and Cho too low to count in each one. You may need to calculate according to the number you make.

METHOD

- Melt the cacao butter & chocolate together. Stir in the sweetener & extract. Pour into moulds set in fridge.
- They are best stored in the fridge but they do stay firm for quite a while at room temperature as long as it is not too warm! I used a little gold and silver food spray this is optional



CHO: 2.38G
FAT: 20.35G
PROTEIN: 1.70G
KCAL: 199



EASTER NESTS

INGREDIENTS

- 40g Egg White
- 60g Double Cream - Morrisons
- 10g Cacao Butter - Sevenhills Organic
- 14g Lindt 90% Cocoa Dark Supreme
- You will also need 30g of Sukrin or Natvia ICING a pinch of Cream of Tartar and a tiny pinch of salt

MO'S TIPS

The meringues will store well in an airtight container for at least 7 days. Put the whipped cream, 10g per nest, and the chocolate egg on the nests up to 3 hours before they are served. Use the spare chocolate to grate a little over the nests. One will be enough for 6 nests. You can of course increase the cream if you need more fat!

Each nest gives:

Fat: 8g Pro: 1g Cho: 0.5g

METHOD

- Melt the chocolate & cacao together add a few drops of liquid sweetener and some flavouring (I used Orange Extract). Then divide into 7 little egg moulds leave to set in fridge.
- Reserve the cream, whisk the egg whites with the icing, cream of tartar and salt. Whisk until stiff.
- Place in 6 equal sized nest shapes on nonstick parchment lined baking tray. Place in a preheated oven 130c/ fan 110c/gas 2 and cook for 40mins. Turn off the oven and leave to go completely cold in the oven. If you can leave them overnight all the better!!
- The meringues will be very dry and crunchy. When ready to Serve decorate with whipped cream and the chocolate eggs & chicks.



CHO: 2.92G
FAT: 48G
PROTEIN: 6.62G
KCAL: 470



FAMILY EASTER CAKE

INGREDIENTS

- 200g Almond Flour Flurry - Holland & Barratt
- 180g Butter
- 300g Raw eggs
- 2g Orange zest
- 10g Psyllium Husk Telephone Brand Sat-Isabgol
- 25g Raisins
- 25g Sultanas
- 50g Tinned Pineapple
- 19g Coconut Flour TIANA
- You will also need 100g of SUKRIN GOLD, 1 teasp cinnamon(optional) and 50g of Sukrin or Natvia ICING a few drops of almond Extract and 1 teaspoons of Barkat Baking Powder

METHOD

- Start by making the marzipan. Mix together 50g of the ground almonds with 50g ICING sweetener with a few drops of almond extract and 1 teasp water.
- Stir to a stiff paste then divide into 12 balls/eggs. Set aside to dry best done the day before!

- You can leave them plain or have some fun painting them with food colouring.
- Chop the sultanas, pineapple & raisins finely. I use scissors to make this easier.
- Heat oven to 170c/Fan 150c/ gas 4
- Mix together the 150g Almond Flour & TIANA coconut flour with the Barkat and cinnamon if used Soften the butter and beat in the SUKRIN GOLD sweetener then the flour mixture.
- Whisk the egg til light & frothy Stir into the mixture and combine well Stir in the fruit & orange zest
- Place in a greased and lined 7 or 8 inch cake tin.
- Cook for approx 45mins til cooked through. Decorate with the marzipan balls and any other Easter themed items you may have



CHO: 60.0G
FAT: 290.0G
PROTEIN: 85.5G
KCAL: 3,193



MO'S TIPS

I have added a some whipped cream to decorate the top of the cake this is optional or, you could make some butter cream which would keep better. Either will of course add more fat to the recipe depending on how much you use. You can use any ground almonds I find Whitworths to be a very good substitute.

12 even sized portions + 1 marzipan egg each it will give
Fat: 24g Pro: 7g Cho: 5g

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



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www.myketogenicdiet.co.uk

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Patients Views Needed...

Would you be happy to be recorded during your dietetic consultations?



Robert Gordon University Aberdeen is doing research on patients views on the use of audio and visual recording in dietetic consultations.



If you or someone you care for has seen a dietitian, they are looking for your views on this subject. Please help by filling out this quick survey.

Here is a link to the questionnaire: <https://robertgordonuniversity.onlinesurveys.ac.uk/patients-questionnaire-copy>

As always Matthew's Friends would like to thank all our keto families both past and present who take part in these types of survey's and research projects. We do appreciate the time you give up by doing this and only by ongoing research projects and studies can we make sure that Ketogenic Dietary Therapies become general 'policy' within treatment pathways and it will secure ongoing funding for the future of ketogenic services within our hospitals for both adults and children. Many thanks for your help with this.

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visit www.ketogether.com

keto care

muesli

porridge

bread

snack bar

bolognese meal

chicken meal



MASSIVE CONGRATULATIONS TO GREG ALDRIDGE (AGAIN!)

For regular readers of our newsletter and stories on our website, you will be familiar with Greg Aldridge, who was on the diet at the same time as Matthew was, as they were both part of the Great Ormond Street Clinical Trial that was published in 2008.

Some of you will also know Greg as the son of our Dietetic Assistant, Val Aldridge, who works in our clinics with all our lovely patients. Well not only did he run the London Marathon in April 2018 for us, he has now added to his amazing achievements by picking up the Player of the Year and best 27 holes trophies from the Kent & Surrey Golf Club!

We're all massively proud of him and it is great to see him doing so well. Greg is happily seizure free and his epilepsy and ketogenic journey can be read on our website here.

www.matthewsfriends.org/our/children/gregs-story/

HAPPY 18TH BIRTHDAY DAN!

Dan is a charity funded patient at Matthew's Friends Clinics and has recently celebrated his 18th birthday!

His Mum Sally made this incredible chocolate Keto birthday cake, which he enjoyed immensely. Each slice is 4g carbs and calculated in to Dan's Ketogenic Diet meal plan for the day.

The recipe is available on our website, another amazing creation by our Keto-cook Mo in the #ketokitchen!



SAVE THE DATE
6-10 OCTOBER 2020
7TH GLOBAL SYMPOSIUM
ON MEDICAL KETOGENIC DIETARY THERAPIES
 COLLABORATIVE SCIENCE AND CLINICAL CARE

BRIGHTON

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MATTHEWS FRIENDS
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UCL
 INSTITUTE OF CHILD HEALTH

QUIZ NIGHT!

FRIDAY 10TH MAY 2019

AT THE OXTED ROYAL BRITISH LEGION
 42 CHURCH LANE, OXTED, SURREY RH8 9LB

FROM 7.30PM

TEAMS OF UP TO 6 PLAYERS
£7.50 PER PERSON ENTRY, INCLUDES NIBBLES
 RAFFLE, FREE PARKING, CHEAP BAR!

EMAIL ENQ@MATTHEWSFRIENDS.ORG
 OR CALL 01342 836571 TO ENTER YOUR TEAM

RAISING FUNDS FOR LOCAL CHARITY

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FREE COPIES OF OUR RESOURCES ARE AVAILABLE TO FAMILIES AND PROFESSIONALS

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

- Introduction and preparation for medical ketogenic Therapies in Children.
- Introduction to ketogenic Therapy for adults with Epilepsy.
- 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.

MATTHEW'S FRIENDS KETO STAR AWARDS!

We love it when someone is nominated to get a Keto Star and, in this issue, we are delighted to say that no less than 4 awards have been given – something of a record and all well-deserved!

The Lawsons nominated the team at their daughter Ava's School – The Hill Primary School in Reading – more about this in the next issue.



Another school related nomination, Yvonne Pearce from the Catering team at Solihull School was nominated by Aneesa Ahmed for (in her own words) 'giving our daughter, Enaya a wonderful 3 week rolling menu at Solihull School. Enaya very much feels included now as lunch time is quite a sociable time for children and she doesn't feel like the odd child who stands out.

I myself know how hard it is to create a meal with only 7g of carbs and with so many children to cater for we are extremely grateful. Enaya is now (at the time of the nomination) 115 days seizure free with no medication, just the Keto diet. School meals have been a huge part of making this happen' Thank you!



Unbeknownst to Aneesa, Enaya had nominated her to receive a Keto Star award too! She thought her mommy should earn an award because of all the yummy dinners and low carb snacks she makes her and the hours she spends planning and buying for her Ketogenic Diet.

Her medication had made Enaya's hair start to fall out, so her mommy and daddy put her on the Ketogenic Diet instead. At the time of the nomination Enaya had been 115 days seizure free AND her hair had nearly grown back. Just look at that smile, wonderful!



Beth was nominated to receive a Keto Star award by her partner Geraint for the following reasons – in his own words 'Beth is my nomination as she's managed to adapt the keto diet for our son David without any prior knowledge and minimum information. She quickly found ideas and adaptations to put into food for David to eat.

The stress pressure and unknown of the diet along with working full time nights did not dishearten Beth as she continued to make up recipes basically on her own, following nothing more than a few guidance sheets - birthday cakes, surprise teas and treats were all adapted for David - a nomination is well overdue for her continued patience skill and sheer determination.'

We whole-heartedly agree and are delighted that Beth was pleased with her award.

Beth's response was lovely to read;

'Woah! I can't believe what happened: I won a Keto star award from Matthews Friends charity...

a lovely certificate: 'In recognition of the patience, skill and sheer determination you show in adapting the ketogenic diet and caring for David.'

I'm so overwhelmed, thank you Geraint and David for nominating me. A big thank you to Matthews Friends also,

these guys are fab.. they have always been so helpful and supportive to us and many families in our position... they have many many amazing staff and of course the amazing Matthew himself...

Our first ketogenic starter kit came from Matthews Friends they work tirelessly for families far and wide...

Thank you so much to Matthews Friends for my lovely flowers certificate and amazon gift card and all the support and resources they provide for families like mine..'

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](http://www.matthewsfriends.org) or by following this link http://www.matthewsfriends.org/pdf/nomination_form_d.pdf

How often is antiseizure drug-free ketogenic diet therapy achieved?

Article by Eric H. W. Kossoff, M.D. Professor, Neurology and Paediatrics, Johns Hopkins Hospital, Baltimore, USA.



The most common reason for starting the ketogenic diet in children and adults with epilepsy is to see if it's possible to reduce seizures (or make them shorter). However, a very important reason for many parents is to reduce (and maybe even stop) antiseizure medications.

We as neurologists do counsel families that it's usually a "partnership" between drugs and the diet - they are not mutually exclusive treatments. Despite this, many of the families I see do ask if it's ever possible to stop all antiseizure drugs if their child does really well on dietary therapy.

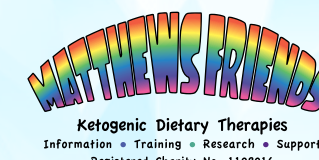
In this study, published in *Epilepsy and Behavior*, we investigated the chances of being on "diet monotherapy" (otherwise meaning that all drugs were stopped after being on the diet). We looked at all children started on the classic ketogenic diet at our 2 main hospitals (Johns Hopkins Hospital in Baltimore MD and Johns Hopkins All Children's Hospital in St. Petersburg FL). Altogether, there were 232 children.

We found at our 2 hospital's keto programs, that the chances of being off all antiseizure drugs at 1 month was 18.5%. However, a percentage had to eventually restart medications (usually due to worsening of seizures over time). If those children are excluded, then 14% of all keto children were able to come off antiseizure medications and stay off them

the rest of their time on the ketogenic diet. Those who were younger, were on fewer drugs when the diet was started, had Glut1 Deficiency or Doose syndrome were more likely to become drug-free. Those with gastrostomy tubes (perhaps since medications are easy to give?) and with Lennox Gastaut syndrome were less likely to become drug-free.

What does this mean? It is certainly feasible for children to be successful on the classic ketogenic diet and even be so successful that all of their antiseizure medications can be stopped. Although a minority, this happened in about 1 in 7 children. As we stated in the discussion of the paper, it's certainly worth a try if the diet is really helping. If seizures do become worse when medications are withdrawn, they can always be restarted. This is important to discuss with your local keto team.

To read the abstract then please use the following link in your browser: <https://www.ncbi.nlm.nih.gov/pubmed/30831398>



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

Matthew's Friends Canada – Update!

Jennifer Fabe, President, Matthew's Friends Canada



Matthew's Friends Canada members continues to carefully move forward in their activities to raise awareness and provide education for ketogenic diet therapy.

Matthew's Friends Canada continues to partner with other epilepsy agencies to share ketogenic diet therapy information to staff and their clients in different parts of the country. We were fortunate to provide education at the last Youth Retreat hosted by Epilepsy South Central Ontario, Epilepsy Toronto staff as well as with Epilepsy Saskatoon.

Continuing to further our mission to share information of medically supervised ketogenic diet therapy in our academic community – we have fostered a few collaborations listed below:

- We are proud of our medical advisory board member Dr. Eduard Bercovici who presented at the CLAE annual conference on the first adult ketogenic diet therapy clinic in Canada. We are very proud of Dr. Bercovici and Debra MacGarvie RD who have been the pioneers in this work. Well done.



- **McMaster Children's Hospital:** Pediatric Nutrition Days Conference will also be showcasing a ketogenic diet lecture in their upcoming May 2019 conference! <http://nutritiondays.ca/>

- **Invited article:** Pediatric Network with Dietitians of Canada entitled 'Cautions for the Ketogenic Diet for Lifestyle' has been published.

- **Webinars:** Recent unrestricted education webinars for ketogenic diet therapy for epilepsy with Nutricia, Cambrooke Therapeutics and VitaFlo provided by our ketogenic RDs. We would like to thank Nicole Turner RD for providing her time to support lectures at these conferences and a recent webinar as well.

- As well – we look forward to the upcoming Dietitians of Canada national conference in Ottawa, Ontario in June 2019 where our president Jennifer Fabe has been invited to speak on 'Ketogenic Diet as a medical therapy and lifestyle'. <http://dcconference.ca/>



- University of Saskatchewan to provide an invited two-part lecture by Jennifer Fabe to the College of Pharmacy and Nutrition students. We thank Dr. Phyllis Paterson for this invitation.
- **Children's Hospital in Saskatoon:** ongoing partnerships of support and education with the growing ketogenic diet program in their new hospital. Well done: Katelynn, Carolyn and Dana as well as Dr. S. Almubarak.
- Canadian Nutrition Society for an upcoming webinar 'Ketogenic Diet Therapy for Epilepsy' with Jennifer Fabe RD and Dr. Eduard Bercovici MD. Stay tuned for this webinar to be released in the late spring.



FROM A FUNDRAISING PERSPECTIVE

- Chef Patrick Wiese – the chef with a big heart! Continues to support us with his 'Intimate Evenings'. Chef Patrick also fundraised & raised awareness for MFC through a local Hamilton Chef Cook Off! We congratulate Chef Patrick for winning this event! Your food is just amazing!
- Annual Matthew's Friends Canada / Epilepsy South Central Ontario Golf Tournament



March is both Nutrition and Epilepsy Awareness Month in Canada!

With the nutrition month theme 'Unlock the Potential of Food', we at Matthew's Friends Canada thank our ketogenic RDs and health care professionals who stand ready to serve!

MFC will be raising awareness through our social media platforms to educate the public on the impact of

ketogenic diet therapy as a treatment option for epilepsy! We thank our social media manager Trevor Gordon as well as volunteer Claudia Marcela for your support and enthusiasm to this endeavor. Also, a reminder that MFC has Practice and Evidence Based (PEN) approved tools through the Dietitians of Canada that are available to use for education!

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**



HAPPY 1ST BIRTHDAY

Lewis and his family had an extra-special celebration on Valentine's Day this year... Lewis' 1st Birthday! Lewis' parents, Jordyn and Steven, decided to raise funds for our charity through a Facebook Fundraiser, to mark this special occasion...

"After suffering a traumatic brain injury at birth, Lewis has cerebral cortex brain damage, global developmental delay, cortical visual impairment and awaiting a cerebral palsy diagnosis along with a few other things. He also suffers from epilepsy, having focal seizures but most recently has been diagnosed with West Syndrome (infantile spasms) which has been veryyyy difficult to treat with his doctors not knowing how to treat it, every spasm he has causes more neurological damage than he already has. We found out through our own research that this diet could help without trying our probably 6th antiepileptic drug, and it's been like our miracle cure up to now!"

Without the help of this amazing charity and Lewis' dietitian at Ninewells Hospital Dundee, we may have not been celebrating. The reality is that this diet and the work this charity does is second to none and this year we would love to be able to give something back to them!! "

Donations flooded in from their family and friends, totalling a huge £465! We're so grateful to the family and thankful for all the donations, that will help us support more children like Lewis.

Matthew's Friends are very happy to part-fund the NHS Grampian post of Tracy Cameron, paediatric ketogenic dietitian, based at Ninewells Hospital Dundee, since October 2017.

VIRGIN LONDON MARATHON 28TH APRIL 2019

This year MF's supporter Dervla Weir has very generously decided to use her place in the Marathon to raise funds for Matthew's Friends.

To sponsor Dervla visit:
www.uk.virginmoneygiving.com/fundraiser-display/showROFundraiserPage?userUrl=DervlaWeir&pageUrl=1



Dervla in training mode!

TRACY HAS THE RUNNING BUG!

The running bug has well and truly bitten Tracy Cameron and we are very happy to say that she has kindly chosen to raise funds for us for which we are truly grateful.

Tracy is a specialist ketogenic dietitian at the Matthew's Friends supported service at the Royal Aberdeen Children's Hospital and the Ketogenic Diet Co-Ordinator for the North of Scotland.

Here she is after finishing the Inverness Half Marathon on Sunday 10th March, the first of three half marathons she has committed herself to run for Matthew's Friends, she is already signed up for the Dundee Half Marathon in July! Go Tracy!!

Please follow the link to give Tracy and Matthew's Friends your support! <http://www.justgiving.com/Tracy-Cameron6>



Tracy after the Inverness Half Marathon

If you would like to get involved and help us in any way, please contact the Matthew's Friends office on **01342 836571**, or email **enq@matthewsfriends.org**. Every penny helps us to make the difference to the many families and Ketogenic centres we support. Please help us to continue our work and extend our services through 2019 and beyond, thank you.