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AUTUMN NEWSLETTER 2017 • FIFTH EDITION

Ketogenic Therapies

Newsletter

Matthew's Friends Rainbow Ball

raises over £23,000 for the advancement of
Ketogenic Dietary Therapies in Chronic Conditions

▼ The boy behind the charity Matthew Williams, pictured with his mum and Charity Founder, Emma Williams MBE, his sister Alice and the two women that Emma credits with saving Matthew's life when he was part of the Ketogenic Diet clinical trial at Great Ormond Street hospital back in 2001 led by Professor Helen Cross OBE and Dr. Elizabeth Neal RD.

► Matthew and his mum with Celebrity Chef and Chef Patron of Matthew's Friends, Mr. Tony Tobin. Tony has been with Matthew's Friends since it first began back in 2004 and is heavily involved with the charity – visit our YouTube page and ketocooking channel to see Tony in action. More will be coming from him soon.

Read more about our terrific Rainbow Ball inside...





Ketogenic Dietary Therapies
Information • Training • Research • Support
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TO HELP FUNDRAISING VISIT:

www.matthewsfriends.org/easy-fundraising/



No local ketogenic service available to you?

Long waiting lists?



MATTHEW'S
FRIENDSCLINICS
KETOGENIC DIETARY THERAPIES

Ask for a referral to the Matthew's Friends Clinics

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



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Matthew's Friends Rainbow Ball

30th September 2017 saw 173 people put on their posh frocks and bow ties for the annual Matthew's Friends Ball at Lingfield Park Racecourse.

This year the theme was sparkles and we had a truly sparkling evening in every sense of the word. Chris Oxlade, our Matthew's Friends Ambassador, hosted the evening for us as usual and did a wonderful job of managing the Live Auction. Our fabulous Chef Patron, Tony Tobin, again generously donated a fine dining meal, but this time at his own home as a special 'intimate evening' for 8 people. So popular was this Lot that he ended up generously giving away two of these very special evenings!

Actor Shane Ritchie is in Panto this year in Woking and generously donated tickets to the show and a personal 'meet and greet' with him afterwards and we are delighted that Independence Homes for Adults with Epilepsy won this fantastic prize, some of their service users are going to be in for a lot of fun that evening. Independence Homes were also successful in winning the Daisy Vintage Ice Cream van which was kindly donated by one of our original Matthew's Friends Mums, Wendy Meteyard, her daughter Francesca was on the diet the same time as Matthew many years ago.

So many people generously donated raffle prizes and auction prizes that there are too many to mention but we would like to just say a huge thank you to all that supported us. The amount we raised - £23,032 - is truly wonderful and will go towards the advancement of medical ketogenic dietary therapies.

Special thanks go to our main sponsors of the evening, Nutricia and VitaFlo, as well as our fab film-makers Red Goat Productions and amazing band One Eyed Jack, who had everyone on their feet rocking the night away! As always, AvenSys AV did a fabulous job, not only supplying awesome Audio Visual, but sponsoring the Silent Auction and Virgin Atlantic flights.

The evening was also made very special by having a table of 'originals' join us this year - these were some of the first Mum's and Dad's that joined us when Matthew's Friends first started.... most of their children are now off diet but as we say; 'once a Matthew's Friend, always a Matthew's Friend'.

It was lovely to see so many of them, in the same room, at the same time! We also want to thank Angela Parker, Claire McDonnell-Liu and Abbie Cary who shared their stories on film for everyone there. If you visit our Facebook page and YouTube channel - you will be able to view these films for yourselves, as well as our website for further news and photos from the Ball. Thank you to all our sponsors, donors, contributors and guests for a very special evening!

Please put our next Ball date in your diary - 8th September 2018 - a VERY special celebration of Matthew's 24th Birthday on that day!



FUN AT THE LONDON AQUARIUM

We kicked off the Summer holidays for these fabulous little ones with a fantastic day at the London Aquarium! Co-funded with Nutricia, the makers of Ketocal, keto families of St George's Hospital, Great Ormond Street Hospital and Evelina Children's Hospital in London came together for a special meet up and to enjoy the fun of the Aquarium.

These happy faces show just how much they enjoyed their day! We love bringing keto families together... as featured in our Summer edition, with the Leeds families' bowling trip.

If your Ketogenic centre would like a special keto family get-together day, please ask your dietitian to contact us!



PLAYING GOLF FOR THE SPECIAL OLYMPICS

“My son started having spasms at 3 months of age and as I was a first time mother, I was not quite sure what it was.

I rushed him to the doctors office during an episode. He was having over 50 a day. They told me to go to hospital to do an EEG..... Anyway to make a long story very short... he was diagnosed with infantile spasms, a very rare seizure disorder. We tried the ketogenic diet and after 3 days his spasms stopped. At that time, I was told that the medication had a 10 per cent death rate. My boy is now 21 years old and he is the sweetest boy. He is delayed but doing great and has a happy life.

This is my son Chaz!! Playing golf for the special Olympics!!”

Natalie (Chaz’s mum)



Emma says.....

“Such a great little story to receive in my mailbox, I love getting these messages and the photos of all these great kids doing so well. Once again, a shining example of how food can make such a positive impact on what can be such a catastrophic epilepsy disorder and now Chaz is playing golf in the Special Olympics – what a superstar”.



Save the date

**MATTHEW'S FRIENDS WILL BE HOSTING THEIR ANNUAL KETOCOLLEGE PROGRAMME
19TH – 21ST JUNE 2018 - CROWNE PLAZA FELBRIDGE HOTEL, EAST GRINSTEAD, WEST SUSSEX, UK**

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

BDA CPD APPROVAL PENDING



No.1 Supporter and fundraiser of easyfundraising!

Angela Tickner was presented with her Keto Star t-shirt at the Matthew's Friends Ball, as our No.1 supporter and fundraiser of Easyfundraising!

Congratulations and thank you Angela, you've proved that just by clicking through the Easyfundraising app or website, it's easy to fundraise by internet shopping from home!



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'Soft Options'

Recipes suitable for both classical and modified diets.

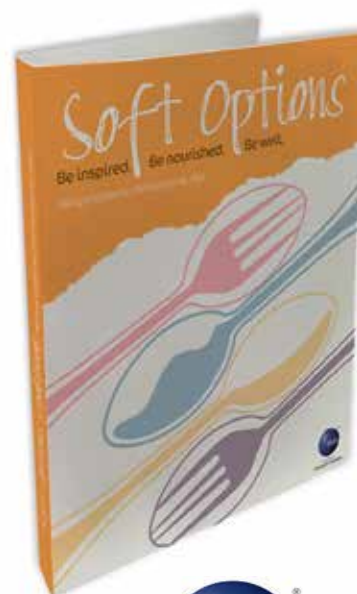
VitaFlo® International have been working with your dietitians and an independent Speech and Language Therapist (SALT) to provide ketogenic food options for those who may have swallowing difficulties. This booklet is called 'Soft Options' and has recipes suitable for both classical and modified diets. Most recipes will also work as standard classical or modified ketogenic recipes too, just no need to purée!

The recipes are in fork-mashable, thick purée or thin purée. Where possible the recipes have been taken to each consistency. We have developed a mix of recipes, although predominately savoury ones, and we have kept the carbohydrate to a minimum as this is always easier to add in if required.

Always check with your dietitian what is suitable for you or your child.

The recipes will be uploaded to VitaFlo's www.myketogenicdiet.com

Please join the: MyketogenicdietUK&IRE facebook page or subscribe to <https://www.youtube.com/channel/UCdVGPzGa6xeelsk38g31-xg>



Innovation in Nutrition



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New Adult Service in Ireland

The medical ketogenic diet is now a potential treatment option for Irish patients with epilepsy which has not responded to other treatments. This national service has recently been established, supported by Matthew's Friends Charity, in St. James's Hospital, Dublin, led by Dr Colin Doherty, Consultant Neurologist and Laura Healy, Specialist Dietitian.

From studies in adults, we know that about a third of patients can achieve >50% reduction in seizures, when compliant with dietary changes, as well as marked improvements in alertness, energy levels and wellbeing despite no change in anticonvulsant medications.



What is involved?

- Ketogenic therapy involves a considerable change in food choices, cooking meals, weighing ingredients, using specific recipes and planning for eating outside the home. If oral feeding is an issue, specially formulated ketogenic tube feeds can be used.
- Ketogenic therapy requires a detailed assessment before starting the diet and a range of blood tests which are repeated at regular intervals. To undertake a ketogenic therapy without supervision of a registered dietitian and consultant neurologist can be dangerous.
- Ketogenic therapy requires careful monitoring and adjustment to optimise control of seizures and manage side effects. This involves keeping accurate records of food intake, seizures, blood ketones, blood glucose and body weight and sharing this information regularly.
- Ketogenic therapy requires support both moral and practical from friends and family.

How can I access the service?

If you would like to consider a trial of ketogenic therapy please speak to your Consultant Neurologist, Epilepsy Nurse Specialist in the first instance to see if this diet is suitable for you.

They can refer you to Dr. Colin Doherty, Consultant Neurologist, St. James's Hospital, Dublin for assessment.

Further information on Ketogenic Dietary therapy is available online at www.matthewsfriends.org





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Ketogenic Dietary Therapies
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SEASONAL RECIPES

As Autumn is now here and Winter fast approaches, the season for staying indoors all warm and cosy approaches and so does various festive holidays, which usually all revolve around food! Planning is the key to making any festive foodie occasion easier to manage – so visit our recipe pages and cooking channel to plan ahead what you would like to have stored in the freezer or pre-made.

Forward planning will make your life so much easier and treats can be included on the diet. Your dietitian will help you with this. In the meantime, we hope you enjoy the latest offerings from our wonderful ketocook Mo.

To 'ASK MO' then please email: ketokitchen@matthewsfriends.org

Visit Matthew's Friends [#KetoKitchen](#) YouTube channel for Ketogenic recipe demonstrations and tutorials!



FRANKFURTER RISOTTO

INGREDIENTS

- 14g Butter
- 35g Mushrooms
- 50g Frankfurter – MORRISONS VACUUM PACK
- 28g Olive oil
- 80g Cauliflower
- 16g Sweetcorn

You will also need some GIA garlic paste and $\frac{1}{4}$ KNORR chicken stock cube dissolved in 50mls of hot water.

METHOD

- Grate the cauliflower, chop the mushrooms and slice the frankfurters.
- Fry the mushrooms in the oil, add the butter to the dissolved stock cube and cook for one minute.
- Stir in the sliced frankfurters, sweetcorn, Gia paste and grated cauliflower, cook for a further 2 minutes.
- Season to taste.



MO'S TIPS

You could add some dried herbs.
I used frozen sweetcorn.

CLASSICAL 3.70:1 RATIO

CHO: 5.04g

FAT: 52.71g

PROTEIN: 9.21g

KCAL: 531

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

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

FRANKFURTER FLAN

INGREDIENTS

- 124g Eggs
- 63g Italian mozzarella – MORRISONS
- 105g Frankfurter – MORRISONS VACUUM PACK
- 21g Almond flour – HOLLAND & BARRETT
- 9g Double cream
- 40g Mature cheddar cheese
- 5g Psyllium husk – TELEPHONE BRAND SAT-ISABGOL

You will also need a tiny pinch of salt.

METHOD

- Pre heat oven to 180c / fan 160c / gas 5.
- Grate the cheddar cheese, RESERVE 110g of the egg, frankfurters and the cheese.
- Melt the mozzarella in a microwave for 30 seconds, stir and then melt for a further 30 seconds.
- Beat in the cream, psyllium husk, almond flour, pinch of salt and 14g of egg, until a dough is formed.
- Roll out to fit a 6 inch pie dish or flan ring. Slice the frankfurters, place on the pastry with the grated cheddar.
- Pour the reserved, beaten egg over and then bake in a pre heated oven for 25 – 30 minutes.



MO'S TIPS

This makes 4 good portions and can be served hot or cold. Because it is very low carb you can add some vegetables or salad to complete the meal to suit your ratio. I found that rolling pastry between baking parchment makes it easy!

Each portion ($\frac{1}{4}$ of the flan) gives: 20.2g fat / 13.9g protein / 0.5g CHO

MKD: 2.07 g CHO

FAT: 81.18g

PROTEIN: 55.68g

KCAL: 962

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

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

SPOTLIGHT ON BREAD LIKE PRODUCTS...



KetoCare has produced the first high fat ketogenic “bread” that is now available on prescription.

Without adaptation, the KetoClassic Savoury is suitable for both a 3:1 and modified diet as well as nearly 30g of fat per portion and less than 5g of carbs. It is perfect for breakfast, lunch or dinner, working with both sweet and savoury options. From sandwiches, pizzas, cheese or eggs to cream and strawberries or even just toasted with butter, it's a simple, stress free and delicious meal or snack.

The KetoClassic savoury also has a 9 month ambient shelf life making it incredibly convenient whilst a wholesome and nutrient rich addition containing only natural ingredients. For samples or prescriptions, simply get in touch with your keto dietitian.

Lo-Dough

Lo-Dough produce lo-carb, gluten and dairy free bread like product – not a wrap, but not bread either, but extremely versatile with only 2.2g of carbohydrate per serving.



The cost (£28 for 14 pieces/£14 for 6 pieces/ £5 for 2 pieces with free UK delivery) may currently be a little prohibitive for some, but is quite useful to keep in the cupboard for those days when you really want something like a sandwich. Good for packed lunches too. It is proving very popular and Matthew's Friends have samples to give away (subject to stock).

If you or your child are on a medically supervised ketogenic therapy then contact us for your free sample at enq@matthewsfriends.org and if you want to find out more about this product then please visit the website at the following link... <https://lodough.com/>

MAKE YOUR OWN!

Mo has made some wonderful bread recipes including her bread rolls and golden flaxseed bread – all these can be useful.

BREAD ROLLS

INGREDIENTS

- 160g Almond flour flurry – HOLLAND & BARRETT
- 110g Egg white
- 25g Psyllium husk
- 1 teaspoon of salt
- 2 teaspoons of BARKAT baking powder
- 190g boiling water
- 15g white wine vinegar.

COOKING INSTRUCTIONS

- Pre heat oven to 180c/fan 160c/gas 5.
- Mix the almond flour flurry with the psyllium husks, baking powder and salt.
- Add the egg white and vinegar, mix well.
- Pour in the BOILING water and mix until a dough forms.
- Divide into 6 equal portions and then shape in to bread rolls. If you dampen your hand with water this will help with the shaping.
- Brush with a little beaten egg yolk and bake in pre heated oven for approximately 40 minutes until cooked through.
- Leave to cool on a wire rack.



EACH ROLL IS:

- 1.8g Carb • 7.2g Protein
- 14.9g Fat

GOLDEN FLAX BREAD (USED IN LUNCH RECIPES)

INGREDIENTS

- 33g Ground almonds
- 80g Eggs
- 37g Butter
- 40g Flaxseed – eg. Virginia Harvest Golden Omega Milled Flaxseed
- You will also need 1 teaspoon of BARKAT baking powder (do not use others which are high in carbohydrate) and 2g of white vinegar.

COOKING INSTRUCTIONS

- Pre heat oven to 180c / fan 160c / gas 5.
- Soften the butter; beat in the salt, vinegar and golden flaxseed.
- Beat the egg then mix in with the almonds and baking powder.
- Put in to a lightly greased loaf tin 8" x 4" and cook for 20 minutes.

Mo's tip: Cooking it in this size tin makes a flatish loaf. When it is cold each portion can be cut through the middle making the slices nice and firm for toasting or making sandwiches or you can divide the mixture between 4 muffin cups and bake.

1 muffin will then equal a quarter of a loaf as used in the lunch recipes.



NUTRITIONAL DATA FOR WHOLE LOAF:

- 3g carb • 25g Protein
- 72g fat

DIVIDED INTO 4 PORTIONS VALUES ARE:

- 0.75g Carb • 6.25g Protein
- 18g Fat

Matthew's Friends funds an extension to Scottish Service... Meet Tracy Cameron!



Tracy graduated from Robert Gordon University in Aberdeen with a BSc Nutrition and Dietetics in 2009 and has seven years experience. She began working as a Paediatric Dietitian in Tayside, Scotland in 2011.

She has worked with multiple specialities including gastro, oncology, cystic fibrosis, and children with complex needs. In 2012 Tracy took an interest in the Ketogenic Diet and worked alongside Helen Grossi for five years.

Tracy enjoys running and recently completed her first half marathon. She also enjoys cooking and often brings Ketogenic goodies to the office for her colleagues to try!

In August 2017, Tracy started working in the part-time post of Ketogenic Diet Coordinator for the North of Scotland. This post covers inpatients and outpatients across a wide geographical area of five health boards including NHS

Tayside, NHS Grampian, NHS Highland, NHS Orkney and NHS Shetland (green & purple area of map). At present our caseload includes 19 infants and children across the North.

In addition, Tracy is excited to work part-time in a new post supported by Matthews Friends to manage the Ketogenic Diet in NHS Grampian. This new post will concentrate on increasing the Ketogenic Diet knowledge of Paediatric Dietitians in this area and will continue to provide a high quality, patient centred service.

The Ketogenic Diet team accept referrals from the North of Scotland Children's Neurology Network and offer care to children from birth. The Coordinator post relies on the support of experienced and knowledgeable Dietitians working across the health boards to ensure children and adults on a Ketogenic Diet receive care at a local level; therefore, the dedicated post in NHS Grampian, will allow us to develop the service further.

EpiCARE new ERN for rare and complex epilepsies



Are you involved with a patient group supporting those affected by one of the 130+ rare and complex epilepsies?

If so, your new EPAG (European Patient Advocacy Group) representatives would like to hear from you, as we are in the process of compiling a list of such groups and asking if you might complete a short online survey to tell us if you currently have a patient registry/database, or whether you do not and/or would be interested in starting one? This information will be fed into the eDatabase team who are busy creating a new EpiCARE patient database for all rare and complex epilepsies, to be populated with cases from across Europe, commencing 2018.

If you would like to participate, please complete our short online survey here:

https://docs.google.com/forms/d/e/1FAIpQLSf9YDjg9HE0WCwntgi8HO2gN5pwwlwEG_UrrO2sUtgBHXtHSw/viewform

East Midlands Regional Representative for Matthew's Friends

Claire McDonnell-Liu Bio East Midlands Regional Representative for Matthews Friends. She lives in Leicestershire with her husband, 2 lovely children and 8 hens.

I am proud to support the wonderful Matthew's Friends charity and to promote the ketogenic diet.

When my daughter Leafy started on the keto diet, in Australia aged 2, there were less resources, recipes and information about ketogenic diet options about.

I can't say enough good things about the ketogenic diet! The diet very quickly and dramatically improved all of our family's quality of life. Leafy was having up to 60 seizures a day when she started on her new meals and snacks. Within one week some seizure types had stopped completely, never to return, her behaviour, sleep and speech improved significantly. The seizures continued to reduce, in length and frequency, so that they became months apart.

Leafy is a happy, funny, active little girl and it is all thanks starting the keto diet for her at the right time.

This year I had the nerve-wracking honour of giving a keynote speech at Matthew's Friends KetoCollege and presentation to the Midlands Neurological Grand Round, speaking to NHS Dieticians, Paediatricians and Neurologists on our success and the diet from a family's perspective.



Matthew's Friends work tirelessly to help to make sure that families and professionals have the right support and resources to make keto diet a real option for children with epilepsy and I am delighted to be able to support them in some small way.

If you are interested in becoming a Matthew's Friends Regional Co-ordinator or an Ambassador for us, then please contact emma@matthewsfriends.org for more information. We will be featuring further members of the Matthew's Friends team in forthcoming issues of our newsletter.

More #ketokitchen recipe and tutorial films are in production!



View them soon on our YouTube Channel [MatthewsFriendsOrg](https://www.youtube.com/MatthewsFriendsOrg) #ketokitchen and on our website www.matthewsfriends.org/keto-kitchen

Keep up to date via Facebook and Twitter @matthewfriends. Join our 3,789 current YouTube subscribers for free!

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

A very important aspect of our mission at Matthew's Friends, is to provide information for the health care professionals involved with the care of our children and adults who have epilepsy, Glut1, PDHD and brain tumours.

We provide up-to-date, reliable resources, written by our UK and international Medical Board members and attend relevant meetings to encourage early consideration of Ketogenic Dietary Therapy where appropriate. We know how amazing the Ketogenic Diet can be for many drug-resistant epilepsy patients and we want every chance to be given to access the Ketogenic Diet for those in need.

In recent weeks we have attended the International League Against Epilepsy (ILAE) British Chapter Leeds conference, the ILAE 32nd International Epilepsy Congress in Barcelona, a Complex Epilepsy Study Day in Newcastle, plus the Lily Foundation Family Weekend (for mitochondrial disease support and research).

We will continue to support further meetings in 2018 where resources permit.

NEWCASTLE COMPLEX EPILEPSY STUDY DAY



Newcastle Study Day, chaired by Dr Anita Devlin Consultant Paediatric Neurologist at the Great North Children's Hospital & Matthew's Friends Medical Board Advisor.



Nutricia's Chef Derek and his amazing KetoCal chocolates!



ILAE LEEDS CONFERENCE



Emma with Professor Simon Heales of the Institute of Child Health, London, who presented on Inherited metabolic disorders, seizures and treatments.



MF CEO Emma with James from Dravet UK



LILY FOUNDATION FAMILY WEEKEND



MF Clinics Senior Ketogenic Assistant Val Aldridge with her medical student daughter Robyn at the Lily Foundation Family Weekend.

ILAE BARCELONA INTERNATIONAL EPILEPSY CONGRESS 2017



Emma at the MF information table, ready to chat Keto!



The lovely Anita Kaufman Foundation ladies, who drive "Purple Day" for Epilepsy Awareness internationally!

Fundraising for Matthew's Friends

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



Run Garioch Team – fundraising update.

Well the amazing Run Garioch Team - Team Beth, did it in spectacular style by raising the truly mind boggling amount of ...drum roll please£7864!

This includes charity matching amounts of £500 from Bibby and £3324 from BP. Thank you so much Team Beth and a huge thank you also to Bibby and BP! – Matthew's Friends Charity just could not function without the support of wonderful, dedicated people like you!



Royal Parks' Half Marathon heroes

Huge thanks to our team who ran the Royal Park's Half Marathon for us. They all did amazingly well and we are so proud of them.



Ellin, Connie-Mae and Clare
(from Nutricia)



Jade & Michelle from Red Goat Productions
who make our #ketokitchen films

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 2017 and beyond, thank you.

Christmas Shopping

Please visit our Website shop to purchase our fabulous keto Elves Christmas cards, as well as other fantastic keto items, like our aprons for big and small cooks!



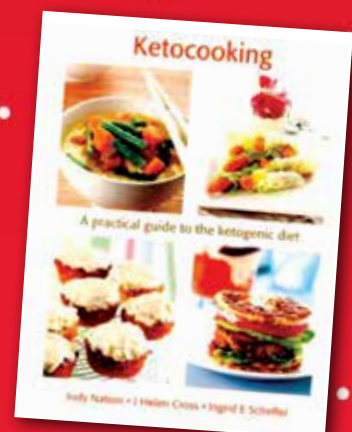
ELVES CHRISTMAS CARDS



APRONS FOR BIG AND SMALL COOKS

Also on sale for November and December only is the Ketocooking book for £10

(usual price £14.99) + P&P
(subject to availability)



Visit our online shop now:

<http://www.matthewsfriends.org/matthews-friends-shop/products/>