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

SUMMER NEWSLETTER 2017 • FIFTH EDITION

Ketogenic Therapies

Newsletter

Matthew's Friends leading the team on Dietary Therapies for EpiCARE – a European Reference Network for Rare and Complex Epilepsies.



European Reference Networks (ERNs) are virtual networks involving healthcare providers across Europe.

They aim to tackle complex or rare diseases and conditions that require highly specialised treatment and concentrated knowledge and resources. Health systems in the European Union aim to provide high-quality, cost-effective care. This is particularly difficult with rare or low-prevalence complex diseases or conditions. Between 5000 and 8000 rare diseases affect the daily lives of around 30 million people in the EU. EpiCARE is the newly formed ERN for Rare and Complex Epilepsies and is led by Professor Helen Cross OBE, who also Chairs our own Medical Board.

The objectives of the EpiCARE network are:

1. To improve accessibility of detailed diagnostics to individuals of all ages with rare and complex epilepsies across Europe, including clinical evaluation and investigation
2. To develop treatment protocols and monitor standardised outcomes
3. To improve awareness and accessibility to protocols for physicians and individuals with rare and complex epilepsies across Europe for treatment
4. To enhance educational activities and training opportunities across Europe by interchange across the network
5. To enhance opportunities for registries, and collaborative research for the benefit of individuals with rare and complex epilepsies across Europe

With a strategy of collaborative working, sharing of expertise and access to advanced diagnostics, EpiCARE anticipates an increased number of individuals with refractory epilepsy to have an underlying diagnosis as a cause for the epilepsy. By collecting information about where such patients exist, the ERN will be able to collate information on clinical presentation and evolution across the life span, constitute cohorts of these rare conditions and advance the development of clinical trials, utilising innovative trial design for small select numbers of patients.

The EpiCARE group is divided into different working parties and the team for Dietary Therapies will be working with centres across member states to widen awareness and availability of these therapies, with development of European standards and recommendations as to what, when and how dietary therapy should be applied.

Our Founder and CEO Emma Williams MBE, is leading this work party together with Professor Cross, whilst also being involved not only with the steering group of EpiCARE but also sitting on the EpiCARE EPAG (European Patient Advisory Group) supporting Isabella Brambilla who is the Chair of this EPAG group.



Emma says... "This is truly a massive piece of work, but also a very exciting one. I have known Isabella for years during my time with Dravet UK and it is wonderful to be teamed up again with her and other patient groups, to ensure that the patients voice is heard with the development of all these new ERN's. With Professor Cross being the Chair of our medical board, we have obviously worked together for years trying to advance ketogenic therapies so it becomes more of a 'mainstream' treatment instead of a last resort, with education always playing a major factor in this advancement.

To bring together all the European Union countries to collaborate and work together can only be beneficial in making sure we can advance ketogenic therapy across Europe and it helps fulfil one of the main mission statements of Matthew's Friends which is to have ketogenic therapies available to all those who could benefit from them. I know that this project is going to take quite a bit of my time, but knowing how many thousands of families that this could benefit in the future – makes it all so very worthwhile."



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

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#ketokitchen

TO HELP FUNDRAISING VISIT:

www.matthewsfriends.org/easy-fundraising/



Happy Retirement to Helen Grossi RD

Helen began working as a Paediatric Dietitian in 1994, working mostly in Neurology and children with special needs.



During this time she was involved with starting and supporting children on the Ketogenic Diet in Tayside, Scotland and since April 2010 Helen was employed by NHS Grampian as Ketogenic Coordinator for the North East of Scotland, working across 3 Health Boards, Grampian, Highlands and Islands and Tayside.

As well as working with hundreds of individual families, she also trained local dietitians in the use of the Ketogenic Diet and worked hard to increase the awareness and understanding of the Ketogenic Diet amongst all professionals working with children with epilepsy. Helen also joined the Medical board of Matthew's Friends and over the years has been instrumental in the guidance and development of our resources and support services for families and professionals, being one of the course authors for our most recent Ketocollege training programme.

Although we are sorry to lose her from her day to day work, we are delighted that Helen has agreed to stay on our medical board and help us with some of our future projects that are currently being developed. Her wealth of knowledge and passion for ketogenic therapy is just too valuable to let her go..... just yet!

Enjoy your retirement Helen and a huge THANK YOU for all you have done for the progression of ketogenic therapies and it is only right that we leave the last word to just a few of the hundreds of families that you have helped....

Our son Logan was diagnosed with Glut1 deficiency syndrome when he was 2 years old. We were living on a small, remote island at the time. We met Helen shortly afterwards and became confident in managing his classic ketogenic diet independently thanks to her advice and support.

She put us in touch with another family affected by Glut1 deficiency which helped us to come to terms with Logan's diagnosis. She was available by phone, text and e-mail even during her days off. Consequently, Logan received the best possible care despite living hundreds of miles from the nearest children's hospital. He remains seizure free and has stopped all medication. His speech and motor development accelerated on his ketogenic diet and at the age of 5 he now leads a normal life. This is a testament to the impact of Helen's care and we don't know how we would have coped without her.

Regards, Richard & Lorna Brunt

Where do I start, without Helen's help and guidance in all that is keto, I don't think we could of managed at all. She came to the rescue so many times, always at the end of the phone no matter what. She constantly helped us adapt and create new recipes to suit Iona (who was extra fussy). But with her help and guidance we managed the diet for 5 years with great success.

I can't thank her enough, keto changed our lives for the better, I know if Iona could speak she would thank her to. Maybe a big cuddle too.

All the best from the Ramsay-kings. Xx

We would like to wish Helen a wonderful retirement and thank her for her support and hard work through our keto journey, in the beginning when everything was so overwhelming, and throughout all the changes and tweaks we required. The ketogenic diet has meant that we got our smiley and cheeky little girl back when we were losing her to epilepsy. We will always be grateful.

Jenny, Bruce and Beth Calder



**Matthew's Friends KetoCollege Australia
took place in Melbourne on Thursday 30th
and Friday 31st March 2017!**



Borne from discussions at the 2016 Global Symposium for Ketogenic Dietary Therapies, held in Banff, Canada, Professor Ingrid Scheffer AO of the University of Melbourne and our own Medical Board Chair Professor Helen Cross OBE, Great Ormond Street Hospital and the Institute of Child Health, teamed up to bring the KetoCollege programme to Australia.

The first day was led by Matthew's Friends Clinics UK Specialist Ketogenic Dietitian Liz Neal and Dr Anita Devlin, Consultant Paediatric Neurologist from the Great North Children's Hospital and MF Medical Board.

The day consisted of presentations from leading Ketogenic teams at Austin Hospital Melbourne, The Royal Children's Hospital Melbourne and Children's Health Queensland Hospital, Brisbane, covering topics such as Preparing for Ketogenic Therapy, Enteral Feeding, Fine Tuning and Weaning and Nurses role in Ketogenic Diet, as well as workshops for dietitians for both Classical and Modified Ketogenic diets.

Following both workshops, Matthew's Friends Keto-cook Mo and Chef Neil demonstrated tasty dishes to show simple dishes that can be created with ease.



The second day concentrated on the medical presentations, covering overviews of the different versions of Ketogenic therapies, basic science and mechanisms of action, neuro-metabolic disease (Glut1DS & PDH), monitoring and side effects, Ketogenic therapy for Adults and for Infants, Supplementation, Medications and over the counter products and management of emergency situations.

During the breaks delegates were able to peruse the information stands of the sponsors of the meeting – Nutricia and Vitafo, who shared their product information and samples of prescription items available for Ketogenic patients.

Our own Matthew's Friends stand was manned by volunteer Dave Fountain, providing free resources and information, along with Matthew's Friends New Zealand President Susan Hill, attending along with her student dietitian daughter Nicole.



Grateful thanks go to all of our KetoCollege Mentors, contributors, sponsors and delegates for an inspirational meeting.



CLASS OF 2017 AT EUROPEAN KETOCOLLEGE HELD IN UK

In June, we embarked on our third Ketocollege Training programme endorsed by the British Dietetic Association and the Royal College of Paediatric and Child Health.

After the success of last year and of our Australian Ketocollege held in March, as well as responding to the feedback we had received, this year we decided to incorporate a third medical day as well as the two specific dietetic training days.

Again this proved very popular as we welcomed over a 100 delegates and speakers from 16 different countries. We also had 2 special guest Mentors join us this year by way of Professor Eric Kossoff and Associate Professor Mackenzie Cervenka from Johns Hopkins in Baltimore.

We are pleased to announce that they have now joined our team of permanent Course Authors for this training programme and will be reviewing the information given out at our Ketocollege each year to make sure it is accurate with the latest information and evidence available.

We are delighted that they have joined our professional mentoring team and they are already set to join us again next year. We also had some of our Matthew's Friends Canada team join us, with MF President Jennifer Fabe also presenting at the course on the different ways of implementing the diet including the 'slow and low' method that she has pioneered in Canada.

The Canadian team will now be developing Ketocollege for Canada and we look forward to sharing more news from them in the not too distant future.

It was an absolute pleasure to meet so many new ketogenic teams that are starting services not only in the UK but also around Europe, we even welcomed a team from China! Education is such an important part of our work, as the more people are educated about ketogenic therapies then the better the treatment will be for the patient.

To have so many enthusiastic people in the same room all wanting to develop new ketogenic services was just wonderful to see and is always part of the Matthew's Friends mission, to make the diet available, accepted and promoted as a REAL medical treatment for those who need it.



Chair, Professor Helen Cross OBE, presenting on the latest development and research going on with ketogenic therapy



Professor Joerg Klepper

As well as covering Complex Epilepsy for both children and adults, we also welcomed Professor Joerg Klepper from Germany who gave a wonderful talk on Glut 1 Deficiency, how to diagnose it and what the latest information is available for this metabolic condition where only ketogenic therapy is the gold standard at the moment, whilst Dr. Archana Desurkar (Consultant Paediatric Neurologist) did the same for Pyruvate Dehydrogenase Deficiency. Dr. Matt Williams, Consultant Clinical Oncologist from Imperial College London, also gave a talk on where we are at the moment with regard to the treatment of Brain Tumours using ketogenic therapy and the need for clinical trials in this area. The Course Chair was Professor Helen Cross OBE, who presented on the latest development and research going on with ketogenic therapy as well as lecturing on the mechanisms of action. Two days then followed of practical workshops, cookery sessions, case studies and how to manage a patient on ketogenic therapy.

A highlight of the meeting was when one of our Regional Co-ordinators, Claire McDonnell-Liu gave a wonderful talk about her daughter Liv and what the diet had meant to her family and how she managed the diet in the early days. It brought the whole course together and focussed everyone on the only reason why we were all there... for the patients, for the families and for those that will need us in the future.



Professor Eric Kossoff

Just a sample of some of the messages we have received since Ketocollege:

"I cannot thank you enough for organising such a rewarding course. I am only 6 months into my ketogenic journey as a Dietitian and this week has given me the confidence to move forward."

"This course was fantastic from start to finish- your inspiring story as a parent, Eric sharing his modest wealth of knowledge, the highly skilled and experienced doctors and Dietitians who took the time to answer all of our questions in the most simple and understanding manner and not forgetting the cooks and reps who shared invaluable tips for the keto cooking world. It was an absolute delight to come across such a genuinely lovely bunch of speakers and attendees. Every keto college attendee I spoke to had nothing but praise for your ketocollege. There was an undeniable warm welcome as soon as I stepped into that room on Tuesday morning on my own - I certainly did not leave feeling alone!"

"You touched a lot of people's hearts this week and thank you for giving us new keto starters that drive to make a difference."

**NEXT YEARS KETOCOLLEGE WILL TAKE PLACE ON THE 19TH – 21ST JUNE 2018
To register your interest please email ketocollege@mfcclinics.com**

A visit from our Canadian Team!



It was wonderful to welcome some of our MF Canada team to Ketocollege this year, where MF Canada President, Jennifer Fabe, was giving a talk.

They will be taking the Ketocollege programme back to Canada and making it relevant for their requirements in Canada. Pictured with our Chef Patron Tony Tobin, is Cynthia Milburn, Jennifer Fabe and Nicole Turner. Our time together was far too short but we are so proud of all the work they are carrying out in Canada advocating the use of ketogenic therapies and raising awareness.



Congratulations to Abigail and George

The very first patient to be treated in Matthew's Friends Clinics has just got married! Our dietitian Sue Wood and Dietetic Assistant, Val Aldridge had the pleasure of going to the wedding and Mo made the wedding cake – the top tier being a ketogenic cake so that Abigail could have some as well.

Abigail has done so well on the diet and her life has changed dramatically, she was featured in one of our earlier newsletters and if you would like to read her story then visit our website at <http://www.matthewsfriends.org/about-us/our-stories/adult/abigails-story/>

We wish both Abigail and George a wonderful future together.





MATTHEW NEEDS YOUR SUPPORT TO HELP HIS FRIENDS!

Can you help Matthew raise money for all his friends by donating Raffle and Auction prizes for our up and coming Ball on 30th September? We would love to hear from you if you can... please email Julie@matthewsfriends.org or telephone the office on 01342 836571.



CONTACT US
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 01342 836571
www.matthewsfriends.org

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 Find us on facebook

We are delighted TO ANNOUNCE THE NEW ADDITIONS to our already freely available list of resources

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

*Our Colour and Shine Recipe booklets for Young People and Adults are freely available only to Dietitians for use with their patients. Dietitians can contact us in the usual way for a supply of these.

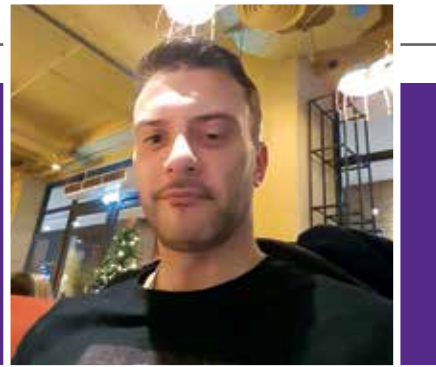
Many thanks to our fundraisers and supporters who make it possible for us to supply this information and our resources freely to all families in the UK and Ireland.

If you would like to find out how you can help Matthew's Friends then please contact Julie@matthewsfriends.org



MEET LEE...

I'm Lee and I'm 38 and had epilepsy since 16. So like everyone else I've been on many different types of medications throughout the years. All with side effects, some worse than others. My seizure types are tonic clonic and myoclonic seizures. My specialists are Lyn Greenhill (Epilepsy Nurse) and Dr Bagary in Birmingham.



I think Lyn is great, basically always giving me options and then she'd implement the plan based on that decision whether it's a new drug or something else.

A couple of years ago we discussed a medicine option of adding Mysaline to my drugs, basically because it's one that my dad uses as he has epilepsy too and he's been seizure free since I was a kid.

I started on half a tablet or the smallest dose to ease it in. I never even progressed beyond the half as I was like a zombie from the start.

I usually work in an office and at the time part of my job was taking calls as well as general office work. I couldn't communicate with people, my brain could not process fast enough to cope with a conversation so I'd not use the phones during that time. This also affected my social life too. It was horrible.

Next I found out that my company was going to be taken over and I'd have to reapply for my job or even look for another. I was not be able to do interviews in that state!

I was stressed and contacted Lyn who said to write an email to explain. It took me 4 or 5 hours to write, I couldn't concentrate. I wanted to make sure I was making sense and not repeating myself. Anyway because of my side effects, they thought it seemed serious so Dr Bagary saw me 2 days later and they started to take me off Mysaline gradually. That was horrible too.

Then we discussed non medicine options like VNS and the Modified Atkins Diet. I did my research and the diet was my choice, basically because it was less intrusive and didn't involve surgery. Neither promised 100% results and I preferred the one without scars!

So I eventually met Jude and the team at the Barberry, they introduced the diet slowly, morning one week, then introduced lunch the next week and evening meal the following week.



I found this helped as it's a lot to take in learning a new way to cook with different ingredients. At first my diet was limited. I'd have cauliflower rice with everything and I then did some research and found all sorts of recipes on the Matthew's Friends website, online and YouTube etc.

I eventually learnt to make my own recipes by using techniques from one recipe to make another. For example I had a recipe for chicken Kiev with keto breadcrumbs made from the puffy pork scratchings and almond flour... I decided I fancied fried chicken one day so used the same mixture but added herbs and spices too. I love creating new recipes it's fun.

As well as the diet I started fitness and I joined the gym and even did a few classes. I found a new passion of mine in yoga which I now do 5 classes a week. I also run and cycle too.

At first I found my early version of the diet wasn't suitable as I'd have jerks while working out so I did some more research.... I found there wasn't much out there on this topic.. most is general keto diet stuff which is fine.... Then there's the fitness topic... everything was talking about carb loading! Then I decided to change up my eating on gym days. I'd make sure I ate an hour or so before or if I couldn't, I would make fat bombs which I'd have about an hour before to get me ready. This helped a lot! I found what worked for me.

My seizures have reduced considerably. Haven't had a tonic clonic in.. well I can't remember.. and the jerks are few and far between.

Last year I signed up for Tough Mudder and as I'd never done anything like this before, I thought I'd do a wolf run as a warm up and test run. This one was only 10k (6 miles ish). I wanted to see if the diet would get me through it and if I was up to it in myself. The wolf run was so much fun. I absolutely smashed it! I felt like I still had a full tank left so could still do more.



Obviously all my fitness plays a big part in getting ready for these events but I believe I'd not be able to get this level without the diet. I'm so much happier now, I can communicate with people normally again. I can compete physically to a pretty decent level and I've lost 4 stone in the last 2 years and gained muscle but most of all my seizures are greatly reduced and I get to live a normal lifestyle.

I've even had interviews and am going for a job as a trainer soon (if my application is successful).

I'm so much more confident now. I'm like a different person. I even motivate others to better health these days too. I just love life right now. Maybe it's all that serotonin!



Emma says.....

Lee's story is just amazing and such an inspiration to others. We are seriously lacking adult services for ketogenic therapy but Lee and many others like him, reflect the fact that adults can really benefit from ketogenic therapy as well as children.

We love receiving stories like this at Matthew's Friends, it just confirms what we already know... that ketogenic therapy needs to be more widely available for both children AND adults, and we will continue to work with our medical professionals in order to achieve this, whilst supporting those patients and families wanting to use ketogenic therapy.

WELCOME TO OUR MEDICAL BOARD Jude Munn BSc RD

Jude has worked as a registered dietitian for 30 years, working in a variety of dietetic specialities in the NHS and she is currently a Specialist Dietitian working for The Neuropsychiatry Dept at The Barberry for Birmingham & Solihull Mental Health Foundation Trust where she has worked since 2005.

Jude has been working alongside the Epilepsy team and she saw her first adult ketogenic diet patient in 2009. The diet showed positive life changing results for the patient and his seizures and hospital admissions were dramatically reduced and his seizure recovery was much improved. Since then the Adult Dietary Epilepsy Service has developed with ongoing positive results. In 2015 Jude and the team expanded their Dietary Epilepsy service for adults and came runner up in their Trust Board Challenge for their work with the Modified Ketogenic Diet in adults.



Jude says...

"I feel extremely fortunate to work in such an exciting field of dietetics where diet can have such a positive impact on health & quality of life. I am very grateful to Emma & Julie for inviting me to join the Matthews Friends Medical Board and look forward to the ongoing journey of the Ketogenic Diet in Adults"

Emma Says...

"Jude has always been so passionate about providing ketogenic therapy for adults and we have worked with her centre over the past few years. We are delighted that she has agreed to join our medical board as we further advance our educational meetings and develop new resources for adults as well as children on ketogenic therapy – her knowledge and dedication to ketogenic therapy will be a valuable asset to our team"

SEASONAL RECIPES

With summer upon us, hopefully there will be time (and weather) for picnics, BBQ's and generally getting out and about.

Mo has come up with some ideas that will help you with this, including a Keto-Knickerbocker Glory! Her bread roll recipe has been such a huge hit via our website, facebook and #KetoKitchen YouTube channel, that we have repeated it here together with some ideas of how you can use the recipe for things like hotdogs and burgers.

Don't forget to visit our website for hundreds more recipes and ideas that can make life easier and tastier whilst on ketogenic therapy.

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

BURGER BUN

INGREDIENTS

- 160g Almond flour flurry – HOLLAND & BARRETT
- 110g Egg white
- 25g Psyllium husks

You will also need 1 teaspoon of salt, 2 teaspoons of BARKAT baking powder, 190g boiling water and 15g white wine vinegar.

METHOD

- 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 burger buns. 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.

CLASSIC 2:1 RATIO

CHO: 11.04 g
FAT: 102.4g
PROTEIN: 43.5g
KCAL: 1140

PLEASE ENSURE YOU CHECK PRODUCT LABELS FOR VALUES.

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.



MO'S TIPS

If you can't get the almond flour flurry, you could use ground almonds, but sieve them first before weighing. You will need enough to replace what doesn't pass through the sieve. The fat content will be less than the flour flurry but protein and carb is the same.

EACH BUN IS:
 17g fat / 7.2g protein / 1.8g CHO

CELERIAC & PARSNIP CRISPS

INGREDIENTS

- 20g Parsnip
- 3g Sunflower oil
- 40g Celeriac

You will also need either a little salt or curry powder for seasoning.

METHOD

- Pre heat oven to 180c / fan 160c / gas 5.
- Cut the parsnip & celeriac as thinly as possible. A mandolin helps to do this.
- Lightly coat the slices with the oil and place on a sturdy oven tray.
- Place in a pre heated oven until golden. Alternatively you can cook these in deep oil if you prefer.
- Serve sprinkled with either a little salt or curry powder.



MO'S TIPS

They crisp as they cool. You can of course use all celeriac if you need to have less carbs. They will keep crisp for a few hours in an airtight container.

TREAT / SNACK 3.42G CHO

CHO: 3.42g
FAT: 3.38g
PROTEIN: 0.84g
KCAL: 47

PLEASE ENSURE YOU CHECK PRODUCT LABELS FOR VALUES.

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.

KNICKERBOCKER GLORY

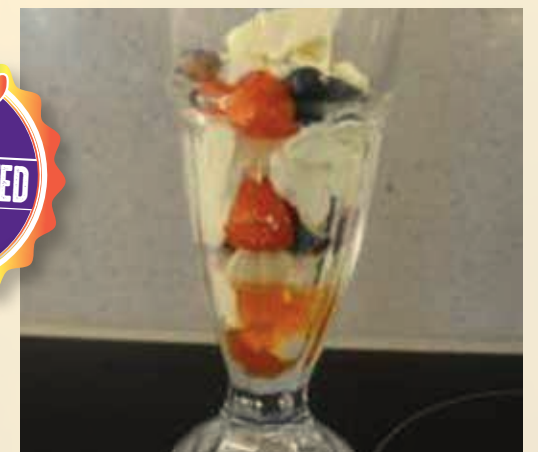
INGREDIENTS

- 96g Double cream
- 10g Blueberries
- 21g Strawberries
- 2g Sunflower oil

You will also need some sugar free syrup such as Da Vinci or Joseph's, some liquid sweetener and vanilla extract.

METHOD

- Start by making some ice cream – whip 50g of the cream with the oil, ¼ teaspoon of liquid sweetener and a few drops of vanilla extract.
- When the cream is whipped to soft peaks freeze until ready. Just pile it in a small plastic dish, do not press it down, keep as much air in as possible.
- Cut up the strawberries and the blueberries too if they are a bit big.
- To serve, whip the remaining cream and layer it with the fruit in a tall knickerbocker glory glass (you can get plastic ones which may be safer).
- I started with half the ice cream in the bottom then layered, ending with the remaining ice cream. Top off with some syrup of your choice.



MO'S TIPS

You can of course layer this in any order you prefer! The ice cream has a very good texture after being out of the freezer for approximately 10 minutes..

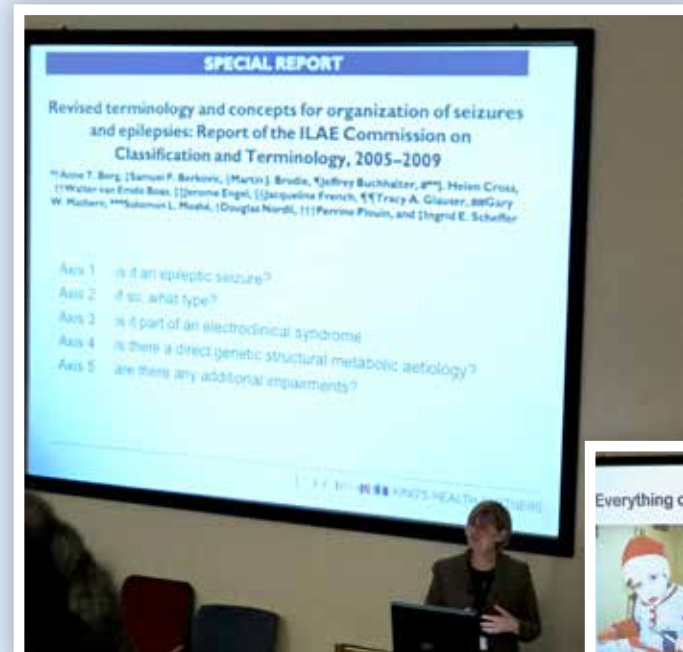
CLASSIC 9.40:1 RATIO

CHO: 3.73g
FAT: 50.6g
PROTEIN: 1.66g
KCAL: 477

PLEASE ENSURE YOU CHECK PRODUCT LABELS FOR VALUES.

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.

TAKING THE MESSAGE TO MEDICAL SCHOOLS...



As part of our ongoing education and information programmes, Saturday April 29th saw Emma and Consultant Paediatric Neurologist Elaine Hughes from Kings, carry out a joint educational session at the National Student Paediatric Society conference.

Elaine gave a brilliant talk on 'Treating Complex Epilepsy - Is it Art or Science?' and Emma followed up with how complex epilepsy can affect the whole family by telling Matthew's story and why more knowledge of this particular area is urgently needed. We were delighted to sponsor this event and make a whole new generation of trainee doctors aware of the more complex epilepsies as well as the treatments currently available, obviously including the ketogenic diet.

We also held an information stand where Emma and Matthew's sister Alice gave out further information on ketogenic therapies. Alice is currently a student at Brighton and Sussex Medical School having just completed her third year.



At Matthew's Friends we are dedicated to the education and support of the trainee medical professionals that are wanting to work in the field of complex epilepsy and ketogenic therapies.

If you would like Matthew's Friends to provide information sessions on Ketogenic Therapies then please contact emma@matthewsfriends.org



BOWLING BONANZA FUNDED BY MATTHEW'S FRIENDS

Matthew's Friends were delighted to fund a recent bowling event for the Ketogenic patients and their families of the amazing Leeds General Infirmary Ketogenic dietetic team.

Pictured in their MF t-shirts are dietitians Kathryn and Rachel, with dietetic assistant Emily who organised the event. We received this message along with the fab photos from the day... "A massive thank you again to Matthews Friends for sponsoring our bowling event on Saturday, it was a big success!"

Alison, Mum to Jade said:

Thank you so much for stepping in to pay for the Leeds ketogenic family bowling day. We had an amazing time, got to meet some wonderful families. What really stood out was the siblings, all similar ages (10-12ish) you could really tell how caring and loving they are with their brothers and sisters on the diet. Was so nice also to talk on a more relaxed level with the dieticians. Thank you!



We are always happy, where funds permit, to support events that bring together keto families! If you would like further information on this then please contact Julie@matthewsfriends.org

Ketogenic Dietary Therapy Service

Christchurch, Canterbury, New Zealand

Written by Charlene Tan-Smith, Paediatric Ketogenic Dietitian, Ketogenic Dietary Therapy Service Canterbury, Christchurch Hospital, Canterbury, NEW ZEALAND.

We are the 'Canterbury' in New Zealand on the other side of the planet to the UK Canterbury! We may be physically a long way away, but we have a special connection and bond with Matthews Friends UK.

The Canterbury District Health Board (CDHB) relatively recently funded a new Ketogenic Dietary Therapy Service which started August 2016, roughly a year or so after Starship Children's Hospital (based in Auckland in the North Island) started the only other Ketogenic service in NZ. Our capture area at the moment is limited to the Canterbury region in the South Island.

We are a small country that does a lot with a limited health spend. Resources are limited, with one Dietitian, two Paediatric Neurologists and an Epilepsy Nurse Specialist. As a result the service has an entry criteria which needs to be satisfied before patients can be referred to the service and go on the waiting list. The sickest patients are being treated first. All patients are screened by the Dietitian before the team decides if the family is a suitable candidate for the intense Dietary Treatment. After acceptance to the service, the family have the option to start in the community or as an inpatient.

"On a personal note, as hard as the work is that goes into the Ketogenic Dietary Therapy itself, and setting up the service from scratch, the results have so far been exciting and rewarding as it continues changing lives... both my patients, their families and mine."



The patients are then monitored closely by the dietitian for 3 months before a decision is made on the effectiveness of the Dietary Treatment. These decisions have to be made in a pragmatic, non-biased and systematic way to make the best use of resources. Even so, as a practitioner it can be hard when the diet inevitably doesn't work for some of the patients and families you have come to know.

My personal journey to becoming a Keto Dietitian began about 6 years ago with a patient Brydie Lauder. (Some of you may be aware this timing was shortly after the devastating earthquakes in Christchurch NZ where we are based). We were unable to provide this treatment to Brydie at the time and sadly we lost her. Brydie's mum has been an untiring fund raiser for the cause.

It was the Brydie Lauders Charitable Trust who helped fund my overseas trip to visit hospitals, up-skilling and part-fund some technology that I use every day for the service. As a result I was able to attend the first Keto Dietitian Forum in Toronto in 2015. There I met Jennifer Fabe president of Matthews Friends Canada and she has been incredibly patient and generous with her time.

We are a small country that does a lot with a limited health spend. Resources are limited, with one Dietitian, two Paediatric Neurologists and an Epilepsy Nurse Specialist. As a result the service has an entry criteria which needs to be satisfied before patients can be referred to the service and go on the waiting list.

Her vast experience and knowledge has helped shaped the way we have organised our service. And we had a great day at the Matthews Friends Family Day!

Also due to the generosity of the Brydie Lauders Charitable Trust I was able to attend the Matthews Friends UK Keto College in East Grinstead in 2016. This was an amazing experience, one I will never forget, and a critical piece to the puzzle of establishing the service here at the CDHB. The training was a solid base that set me off in the right direction and prepared me for further development of my knowledge and thinking. I'm also very grateful to all

the Keto Dietitians who willingly gave their time to meet with me at various UK hospitals to explain their services approaches and management.

There were many people involved in securing funding, supporting and lobbying for the creation of the service, and continue to support us. It has been a privilege for me to work with them all to start such an exciting and life changing service.

I have a supportive manager and we have support from hospital management, Matthews Friends UK, Matthews Friends Canada & Matthews Friends NZ, Hyman Marks Trust, Wedderburn®, Peter Timbs Meat and my supportive team at work & my patient long suffering husband.

On a personal note, as hard as the work is that goes into the Ketogenic Dietary Therapy itself, and setting up the service from scratch, the results have so far been exciting and rewarding as it continues changing lives... both my patients, their families and mine. We are a very young service and look with great expectation to treating many more patients in the years to come.

Thank you to Avonhead School and the Haig family in Christchurch.

Jackson Haig from Avonhead School was recently placed on the ketogenic diet through Christchurch Hospital.

MF NZ was nominated as one of the recipients of funds raised in their recent Mufti Day and Ice Cream Day to help raise epilepsy awareness. This is an excerpt from the lovely letter sent to us with the accompanying cheque:

"Our family wanted to support Matthew's Friends because the diet has been life changing for Jackson. He has had a huge reduction in seizures and is looking and sounding the best he has in the last two years".



This is Jackson holding the cheque made out to MF NZ and with one of his meals on the 'Dinner Winner' plate from his Matthew's Friends NZ Starter Pack.



And lastly for this issue, welcome to Jackson's Christchurch dietitian, Charlene Tan-Smith, who has recently accepted an invitation to join our MF NZ Medical Board.

Successful Keto College event in Melbourne

Our keto health professionals were recently invited to attend the Matthew's Friends UK Keto College held in Melbourne, Australia. Our New Zealand neurologists, dietitians and nurses were well represented, with the opportunity for up-skilling and knowledge sharing much appreciated.

More details about the event are in the full newsletter write up. Thank you so much MF UK for coming down under and sharing your experience and wonderful staff with us!

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

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.



A huge THANK YOU to Mick and all the team at Shipleys Accountants and Business Advisors. They donate the proceeds from their tuck shop to Matthew's Friends and at the end of the last financial year it was over **£500** and they are still going strong. We really appreciate your support and keep going!



Coffee morning raises €785

BIG THANK YOU to Meadhbh and Peter for holding a coffee morning for us in their home town of Drumcondra, Dublin and raising a massive **€785** for us. Your kettle must have permanently been on! Matthew's Friends not only freely supplies information and starter packs to families in the UK, but Eire too. We also support the new adult service in St. James's Hospital in Dublin.

Libbie Fullman organised Purple Day fund raiser at her school, Great Leighs Primary School Purple Mufti day, Cake Competition and bake sale and raised a rather splendid **£565.66**. Well done Libbie and a HUGE THANK YOU from us all at Matthew's Friends.



Garioch half marathon

5 of us are taking on the Run Garioch half marathon and 2 of us are running the 10K to raise funds for the fantastic Matthew's Friends charity.

Matthew's Friends support and supply information for patients and families who are employing the Ketogenic diet in order to treat drug resistant epilepsy.

The reason why we're supporting Matthew's Friends is because of our own "keto-kid", Beth. Beth has been on the Ketogenic diet since May 2016 and amazingly it has managed to control her epilepsy far better than any anti seizure medication. The Ketogenic diet has made such a massive difference to her life and she is back to being the cheeky, smiley girl she once was. Without the help of Matthew's Friends the daunting task of starting her on the Ketogenic diet would not have been possible.

Donating through JustGiving is simple, fast and totally secure. Your details are safe with JustGiving - they'll never sell them on or send unwanted emails. Once you donate, they'll send your money directly to the charity. So it's the most efficient way to donate - saving time and cutting costs for the charity.'

Vitaflo support

Vitaflo once again supported us for Purple Day raising £250 with their Purple Day Extravaganza, including wearing something purple, a purple bake off, lucky dip and a make your own purple mask 'masquerade' - many thanks to all involved, we really appreciate it.



Hats off (well, cycling helmets off) to The Knight Riders

"Well, we did it! Hooray!! 50 miles cycling around beautiful Edinburgh from 8pm to 3am! The weather was perfect - warm and dry and we are all so delighted at all the support we have had from our friends and family.

Our justgiving page is currently at £865 and we are so delighted to be able to give back to you all at Matthews friends after my daughter Rossi had received such fantastic support from Emma and the whole team. I made use of the 24hr support from Emma on several occasions and can't thank her enough for that. You really did make a huge difference in our lives at a very difficult time and the work you all do is invaluable and so very much appreciated.

Our team - the Knight Riders -(Caroline, C.J, Jenny, Natalie & me!) started at Meadowbank Stadium, cycled up Arthurs Seat, around and through the city to Silverknowes & Cramond beaches, over the Forth Road Bridge and eventually back to Meadowbank to cross the finish line at 3am!! Phew!! Not much sleep was had Saturday night but wow what a sense of achievement!!

Tonya, Caroline, C.J, Jenny and Natalie a.k.a The Knight Riders!

Thank you so much to Tonya and all the marvellous members of the Knight Riders Team. Your amazing fundraising and support of Matthew's Friends is very much appreciated by us all!

The Knight Riders Edinburgh Night Ride Cycle Challenge page
<https://www.justgiving.com/fundraising/7-knightriders>



Once again this event is raising funds for our charity!

THE EVENT TAKES PLACE ON 3RD SEPTEMBER 2017

you can register to take part via www.tunbridgewellsbikeride.co.uk
we hope to see you there!





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For more information contact us:
www.independencehomes.co.uk
 0867 456 765

Ketogenic Dietitians Research Network

The Ketogenic Dietitians Research Network is a newly-established group of paediatric and adult ketogenic dietitians and researchers.

The aims of the group are to:

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



Our dedicated and enthusiastic team are currently working on our first project: a survey of ketogenic diet services across the UK and Ireland. Our next meeting will be on August 9th in Liverpool. All are welcome.

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



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 For further information about our other services, please speak to your managing dietitian.

Kossoff EH, Dorward JL, Turner Z and Pyzik PL. (2011). Prospective Study of the Modified Atkins Diet in Combination With a Ketogenic Liquid Supplement During the Initial Month. J Child Neurol. 26(2): 147-51

KetoCal is a food for special medical purposes only to be used under medical supervision. If you would like to find out more about KetoCal, receive a sample, or get further information on any of our ketogenic services then please contact your specialist ketogenic dietitian.



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

FURTHER INFORMATION AND RECIPES AVAILABLE VISIT:

🌐 **www.matthewsfriends.org**

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