GLUT 1D SPECIAL FEATURES INCLUDING INSIDE

IN THIS ISSUE

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

SUMMER NEWSLETTER 2016 • SECOND EDITION

Ketogenic Therapies

Newsletter

Neil and Mo Demonstrating

Matthew's Friends

KetoCollege is launched

The 9th and 10th of June 2016 at the Felbridge Hotel, East Grinstead saw over a 100 people attend the first of our Ketocollege training programmes for health care professionals.

Aimed at those new to ketogenic therapy, we welcomed medical professionals from all over the UK as well as from Ireland, South Africa, New Zealand, Italy, Spain, and Belgium. It was a very busy two days with our delegates experiencing the low carbohydrate lifestyle while they were with us. All meals and snacks were low carbohydrate with our sponsors and exhibitors providing plenty of tasty keto treats which all seemed to disappear quickly enough!

Our mentors provided some excellent talks and workshops for the delegates, together with EKM (Electronic Ketogenic Manager) tutorials, live cooking demonstrations and speciality subjects, such as the diet being used for Glut 1, PDH and Brain Tumour. The feedback has been incredible and we are already planning our next Ketocollege for June 2017 which is having to be extended from 2 to 3 days. If you would like to register your interest then please email us at **ketocollege@mfclinics.com**

Professor Joerg Klepper presenting on Glut 1.

Delegates taking information from the Matthew's Friends Stand to use in their clinics.

Matthew's Friends KetoCollege

Harry's story

In August 2014 our beautiful, healthy 4 month old baby boy, started having seizures. There followed a terrifying month of hospitals, brain scans, MRIs, lumber punctures, blood tests and fear beyond anything we could ever have imagined.

When the diagnosis of Glut 1 Deficiency Syndrome finally came, it was something we had never heard of before. With the support of the dietician at St George's Hospital, at five months old our little man started the ketogenic diet on a 2:1 ratio.

The transformation was immediate. Pre-diet he tended to stare blankly off into space, didn't make eye contact, was extremely floppy to hold and was having upwards of 100 myoclonic seizures a day together with some absence seizures. Overnight his seizures stopped and he is now a happy, lively, alert 2 year old. He has recently started to take his first independent steps and he has a limited but growing vocabulary – his animal sounds are pretty impressive, particularly his roaring and neighing! We receive regular support from an NHS physiotherapist and speech and language therapist and both they and the development paediatrician are really pleased with his progress.

We were very lucky that he was diagnosed so young. For the first five months of his life, until we started the ketogenic diet, his brain wasn't being fed

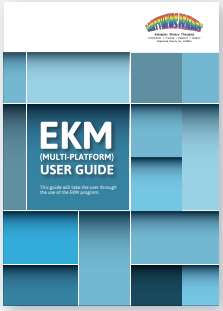
so it does feel like he is a few months behind on his development compared to his friends. BUT crucially that gap doesn't feel to be widening, and whilst five months behind might seem a lot at this age, it hopefully won't when he reaches school age.

Harry's first MRI scan on diagnosis also revealed abnormal white matter in the front of his brain. This was a huge source of anxiety to us for many months, as it could have meant he had an additional white matter disorder.

However, his repeat MRI four months after starting the diet showed that the abnormal white matter was reducing and improving. The expectation is that it will continue to improve and hopefully disappear completely – this is something our doctors had never seen before with Glut 1 patients and it is real proof of how the ketogenic diet is benefiting his brain.

When we started the diet there didn't seem to be many babies on it, so finding inspiration for baby food keto recipes was tough. Mo from Matthew's Friends was amazing and I set up a blog at **www.lastnightsomedairysavedmylife.com** to chart my journey and hopefully help other families in the same situation. Now, almost two years on there are lots more babies starting the diet and there's even a weaning recipe book from Nutricia which is great progress!

Harry enjoys his food, with Mo's bread, garlic mushrooms, celeriac and kale 'potato' cakes, bacon crustless quiche, tuna & avocado balls, olives and fishy-cakes his particular favourites.



EKM user guide

We are very pleased and excited to announce the launch of the new version EKM (Electronic Ketogenic Manager)! Release Date: 31st May 2016

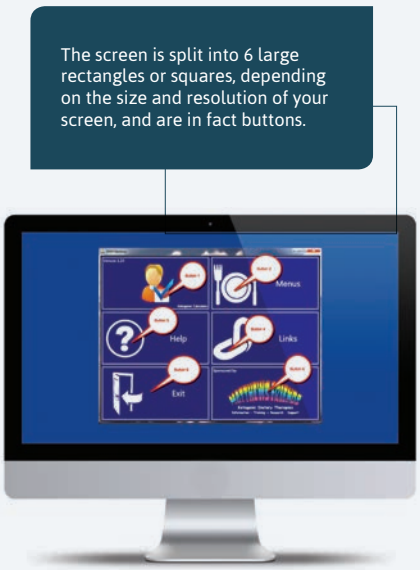
Through our charity fundraising and donations, we have been able to fund these updates and changes to EKM and benefit all patients on a prescribed Ketogenic therapy, including the introduction of EKM-Mobile.

Patients, parents, families, carers and managing dietitians can access these FREELY, thanks to Matthew's Friends.

The major re-write of EKM (Electronic Ketogenic Calculator) in 2016 has enabled the program to be used within the following operating systems and platforms:

- Mac desktop OS X
- PC, Windows version 7 and above (Vista not recommended)
- Android: phone and tablets (non-Intel platforms recommended)
- iPad and iPhone; iOS

Therefore the majority of desktop and portable devices are supported by this new release of EKM.



A free User Guide has also been designed and is available to download from the Matthew's Friends website or you can order a hard copy from **enq@matthewsfriends.org**

GLUT1 deficiency syndrome: Diagnosis and new treatments

Dr Archana Desurkar

Consultant Paediatric Neurologist, Sheffield Children's Hospital & Matthew's Friends Glut 1D Clinics

Synopsis from the keynote lecture at the Annual BPNA conference, Sheffield, 2016

Glucose Transport Deficiency Syndrome (GLUT1DS) is a rare treatable metabolic condition with wide phenotypic presentations. This presentation discussed clinical presentations, challenges in the diagnosis, current evidence base for treatment, challenges in treatment and touched upon new emerging treatments.

There are two families of the glucose transporter proteins in the body. One transports glucose actively such as in kidneys and gut and the other by facilitated passive diffusion. GLUT1 is the exclusive transporter protein for glucose transport to the brain, by passive diffusion. GLUT1 DS is caused by deficiency in the glucose transporter protein caused by absence or loss of the gene encoding for this. (SLC2A1)

Symptoms in GLUT1DS are caused by energy crisis in the brain caused by insufficient glucose availability. Glucose transport in the brain is not a rate limiting step as 50% glucose transported to the brain is transported back to plasma. This also means that in patients with already compromised glucose transport, this safety margin is compromised too. Prevalence of GLUT1DS is 2.6 patients per million population.

GLUT1DS was first recognised in 1991 by De Vivo, in 2 children with refractory infantile onset epilepsy who had acquired microcephaly and evidence of hypoglycorrhachia (low CSF glucose) and rapid response to ketogenic diet therapy. This classical phenotype can also be associated with complex movement disorder in about 70% and developmental impairment of variable severity occurs in two thirds. Classical presentation in infancy consists of abnormal eye movements , head bobbing, complex absences, cyanotic spells and later other types of seizures such as myoclonic and generalised tonic-clonic seizures may evolve.

A study evaluating SLC2A mutations in 57 mutation positive patients noted that 84% had classical presentation and 15% had non-classical presentation.

It is now also recognised that there are non-classical presentations of GLUT1DS that can be grouped into following categories:

- Paroxysmal dyskinesia/ dystonia without epilepsy
- Paroxysmal movement disorder with epilepsy
- Developmental delay with movement disorder, without epilepsy
- Slowly Progressive spastic paraplegia with Paroxysmal Exertional Dystonia (PED) (DYT9)
- Normal psychomotor development with carbohydrate responsive symptoms, PED

Different types of epilepsies can be associated with GLUT1DS. About 10% of early onset absence epilepsy (those with epileptic absences under 4 years of age) and 5% with myoclonic astatic epilepsy may have GLUT1DS . However, a study of 15 family members with SLC2A1 mutation identified variable epilepsy phenotype in these.

Non-classical phenotype with PED was demonstrated in this presentation with several patient videos.

Movement disorder consist of usually choreoathetosis with dystonia, predominantly affecting legs, typically provoked by activities such as walking, running or climbing hills. They can last from 15-60 minutes and can be unilateral or bilateral.

Movement disorder can co-exist with epilepsy. Similar to epilepsy phenotype, nature of movement disorder varies with the same mutation.

There are some rarer presentations such as alternating hemipelgia of childhood.

Treatment of GLUT1DS is with ketogenic diet therapy as this bypasses the metabolic block in the energy metabolism and provides an alternative source of energy to brain. It is well documented that epilepsy responds to the diet swiftly within a few weeks in a majority. PED also responds well. However impact on cognition and movement disorder is variable. A recent study evaluating impact of KD on cognition indicated significant gains in visuo-motor perception and sensory motor speed. KD should be started as soon as possible and continued at least through adolescence.

However, it is also now clear that not all patients improve on KD, paroxysmal disorders may continue despite continuing KD and maintaining KD through adolescence may be challenging. This prompts consideration for new therapies.

Triheptanoin (C7) is an artificial ester made from castor oil beans. Being an odd carbon item molecule, it generates two separate compounds that will fuel the TCA cycle (anaplerosis)

Currently published data of use of C7 open label trials was presented. One study demonstrated improvement in cerebral metabolic rate, decreased amount of epileptiform activity and improved psychomotor functioning in medium term treatment. It was also found to be well tolerated. Another open label study evaluating C7 in patients with uncontrolled movement disorder demonstrated significant improvement in a short term case control study. Upcoming sponsored randomised trials of C7 for epilepsy and movement disorders were also briefly discussed.

Essentially, diagnosis of GLUT1DS requires a high index of suspicion. A practical approach to diagnose GLUT1 was also presented. Finally, registering GLUT1 patients into the international registry to promote further understanding of the condition and research was highlighted. **(www.G1registry.org)**

ATAHOTEL EXPO FIERA | 7TH & 8TH OCTOBER

For meeting registration please visit http://www.biomedia.net/Glut2016

Information on Hotel Rooms and Room Rates: **http://www.biomedia.net/materiale/Glut2016_room.pdf**

General information on the city and transport: **http://www.biomedia.net/materiale/Glut2016_info.pdf**

TRAVEL This link gives you vital information on how to travel to and from the airport: **http://www.atahotels.it/en/expo-fiera/dovesiamo**

The Glut1 conference programme: **http://www.biomedia.net/materiale/Programma_INFO_GLUT1_agg.pdf**

Julie from Matthew's Friends has made a site visit to obtain additional information for families that are wanting to attend this meeting and bring their ketokids with them and we have sent the information to all the Glut 1 families on our database. However, if you have NOT received this email please contact us and we will send it to you.

Dietitians and Health Care professionals are also welcome to email us for this information on behalf of their patients. Please contact us on **glut1UK@matthewsfriends.org**

The difference our Keto Support Line makes -
which is available 365 days a year

Dear Emma,

I just thought I'd drop you a line to let you know that Leo is now off the keto diet all together. He managed 21 months but it was clear at Christmas that he'd had enough. We were always aiming to begin weaning soon anyway, he just decided slightly ahead of our schedule!!

I just wanted to let you know how grateful we are for all your support, both personally from yourself and from your team! We have always known there was someone at the end of the phone if we needed advice, support or in my case a damned good cry with someone who just 'got it'!!

Although Leo is not seizure free it has given us so much of our little boy back.....a little Boy for a time we had lost. We can never express how thankful we are for that and we know that it is very much down to charities like yours to help families just like us.

We've had a roller coaster ride and we are still searching for our miracle, thanks to the diet though we are definitely on the right path!!

Sending love and best wishes to your family and amazing team of colleagues!

Kate and Adam Braniff

Emma says:

Running the support line is the very best part of what I do as I get to speak to incredibly special families every single day. Over the years I have spoken to thousands of families from all over the world and you never know what the next call will be, some are wonderful stories and some can be truly heartbreaking.

I remember feeling very alone when I did the diet with Matthew and I don't want another family to ever feel that way. This is why the support line is open every day of the year, 2 minutes on a phone call could save a huge amount of worry for a family.

I can't always answer the phone straight away, especially if I am with Matthew, but families can always text me and I will get back to them as soon as possible.

The Matthew's Friends support line number is
0788 4054811.

Olivia's Story

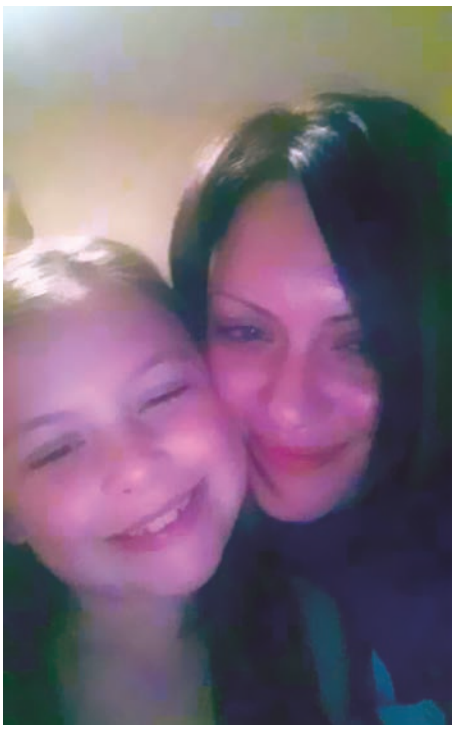
Olivia was 18 months old when I first saw her seizures. Her brother Bailey had just been born and life was pretty hectic with a toddler and a newborn.

At first Olivia was just twitching a little and falling down more than usual. I took her to the health visitor, who mentioned that she thought Olivia had flat feet causing her to fall and that we should see a specialist. We waited months for the appointment to come around to be told her feet are completely fine. At this point Olivia's little twitches were becoming more frequent and we noticed her eyes rolling. We mentioned this to our health visitor and different doctors a few times with no answers. I was actually in an appointment for myself one day and I decided to mention Olivia and finally the doctor stated that it sounded like petit mal seizures and she would refer us.

We needed a doctor who knew more about epilepsy and we asked to be referred to a paediatric neurologist. I spent the months we waited for our appointment researching. Trying to figure out the different names of the seizures and what characteristics they had ... trying desperately to find out a possible diagnosis. It was at this point I was making myself physically and mentally sick. Google was turning up horror stories about medications and really debilitating forms of Epilepsy. I was finding the not knowing and waiting really difficult at this time. We finally got our appointment with the neurologist and I went into the appointment with a huge list of tests that I wanted her to put forward for. I told myself if this doctor won't put her forward for them then we are referring again. I honestly did not need to take the list out of my pocket. Every single test and more was mentioned by him and I left that appointment knowing we had found a marvellous doctor. We were trying Ethosuximide at this point and Olivia was again getting worse, it was really scary so we weaned this medication after only a few increases.

Olivia had a bout of sickness where she refused to eat for 5 days. During this time Olivia became completely seizure free. I was baffled, my first thoughts were a food intolerance. She had not eaten anything so some type of ingredient must have been causing the seizures. We had an appointment with a temporary neurologist who was filling in and I explained what had happened. We were told Olivia's body had gone into starvation mode and was mimicking the ketogenic diet. I'd done some research on it and I instantly knew that she just had to be on this diet.

Olivia's MRI and lumber puncture was coming up and we were hopeful of answers. We had the tests done and we left the hospital with a giant bag of Lamotrogine as Olivia had been having lots of seizures at this point. I stood in my kitchen holding all this medication and burst into tears. I hated the thought of having to give my baby girl these dangerously strong meds. The thought of it making her worse was heavy on my mind. I got the courage to give her the first 1/4 tablet, 2 minutes after she had taken it my phone rang, it was Olivia's neurologist. His first words were 'Please do not give Olivia the medication we have a diagnosis'. At this point my stomach was doing somersaults. He asked me to Google Glut1 and explained the only known treatment was the ketogenic diet so a dietitian will be in



contact within a week to initiate starting the diet as soon as possible. I have to say that hearing 'don't give her meds' and 'you are starting the diet soon' were the most important words I've ever heard in my life. He also said Glut1 responds very well to the diet. Within days of starting the diet the seizures had almost gone. Within a week the 50-150 myoclonic seizures were 100% gone.

I couldn't believe how lucky we had been to get a diagnosis of a condition that called for the diet as it's number 1 treatment. Olivia is now in normal school she's doing very well and is an extremely keen learner.

Without the diet and the help of Matthews Friends we would be in a very different situation today. Olivia has been so lucky and we are so proud of the achievements she has made in her life so far. She's been through more in 7 years than most adults do in a lifetime. She's brave, confident, smart, and extremely switched on to the benefits the diet has given to her. To say I'm proud is an understatement. She has dealt with the life she's been given with so much determination and courage that I know no matter what life throws her way she has the strength to shine through it. Love you Livi.

Laura Rees – mum to Olivia (Livi)

To read Livi's full story please visit **http://www.matthewsfriends.org/about-us/our-stories/**

Ketogenic Diet Prominent

at the 14th biannual ICNC Meeting in Amsterdam

By Eric Kossoff MD

The 14th Biannual International Child Neurology Congress was recently held in early May in the beautiful city of Amsterdam.

Although traditionally there has not been much in the way of ketogenic diet content at this meeting (compared to American Epilepsy Society meetings for example), this year was an exception.

On the Tuesday of the meeting, I presented a 30 minute overview of "What's New?" with the ketogenic diet for the larger grouped audience as part of a session on epilepsy.

I discussed the current state-of-the-art, namely that the KD has now sufficient demonstrated evidence for efficacy to "end" debate, indications are relatively established, and that side effects are being prevented not just identified. Then, I focused on controversies, including the true benefit for adults with epilepsy, use of alternative diets and creative initiation protocols, and whether ketogenic diet "pills" are truly substitutes or just supplements.

Finally, I predicted future developments would also include non-epilepsy uses (cancer), novel genetic indications, and expansion of dietary therapies to developing countries around the world.

On Wednesday, an interesting poster was presented by Dr. Antonina Gavajuc from Moldova about her experience in starting a ketogenic diet center in a resource-limited situation. This was followed by a 90 minute lunch symposium about this very issue. Ms. Kath Megaw from South Africa, Dr. Janak Nathan from India, and lastly Ms. Emma Williams from UK all lectured about their experiences in helping expand the diet throughout the world, in terms of online courses, workshops, direct patient care in rural settings, and setting up parent-led support groups.

Finally, a small roundtable meeting was coordinated by Elles Van Der Louw of neurologists and dietitians specialized in the ketogenic diet from all over the Netherlands. Research ideas were shared and difficult cases were then discussed. The goal of this meeting was to create collaborations and share knowledge.

Overall, this was a very active and successful meeting for anyone attending who was interested in the use of dietary therapies for epilepsy. We look forward to continued ketogenic diet content at the 2018 ICNC meeting in Turkey.

Free - Matthew's Friends Starter Pack

ALL families who have a child or adult who are following a prescribed Ketogenic dietary therapy in the UK and Ireland are eligible to receive a Matthew's Friends Starter Pack, free of charge!

These are available through your specialist Ketogenic dietitian or via our website Shop FREE keto items section, where you will find other really useful items, such as a vegetable spiralizer, Natvia icing mix and da Vinci syrups, for when you are starting out.

We source varying items to support families and availability of each item is subject to change. Visit **www.matthewsfriends.org** today!

(this image is a guide - the Starter Pack contents may be subject to change without notice, due to stock and funding availability)

CONGRATULATIONS TO OUR LATEST Keto Stars

Nominate your 'Ketostar' - This could be a person or an organisation who has gone the extra mile to help you with your ketogenic diet. To find out more visit www.matthewsfriends.org/matthews-friends-keto-star/

ROWAN HOUSE Young Epilepsy

NOMINATED BY KELLY WALSH...

"Nathan moved into Rowan house at Young Epilepsy in September 2015. Besides the fact that I was sending my son away to school and giving up 'control' of his medicine and everyday care I had to hand over the keto diet. I was not sure how they were going to manage his diet - and watch everything like I did - while taking care of him and the other boys in the house. Well the team at Rowan House - Rob, Celia, Ben, Madalina and Jo and Andreina took my book of suggested recipes, ordered the necessary supplies and started cooking. Nathan always likes to point out when his routine is altered and not once has he told me that they missed a snack or bedtime milk shake. Nathan even comes home and tells me I need to cook like them! Thank you for taking such good care of Nathan and watching every detail."

DRAGOS STANCIU NOMINATED BY JANE DOWNING...

"Dragos, who worked as an A&E Doctor, was diagnosed with an aggressive type of brain tumour last year. His dedication to an incredibly strict Ketogenic diet has been outstanding. He doesn't particularly enjoy it. But he, with the support of his wife, for the sake of their two young sons have stuck to this difficult diet. He has been commended by his specialists, including a unique nutritional study being undertaken in the UK, for his attitude and ability to follow it.

Knowing how important food and variety was to Dragos I have been truly astounded by their dedication to what is clearly a challenging diet."

THIS MONTH'S FEATURED INGREDIENT

Berries are called superfoods for a reason, they are low in carbohydrates but high in antioxidants, fibre, vitamin C and flavonoids. Including berries in your diet is a simple and delicious way of eating fruit, especially topped with cream, added to sugar free jelly or in keto ice cream.

If you feel you're lacking in vitamin C, reach for the strawberries. Just 9 provide you with your whole recommended daily allowance and the many tiny seeds in blackberries make them a fantastic source of fibre. You can find lots of recipes using berries on the Matthew's Friends KetoCooking channel and in our recipe collection on our website at **www.matthewsfriends.org**

URGENT NEWS: COYO Dairy Free Yogurt – Be Aware

It has come to our attention recently that the nutritional content of COYO yogurts have changed. These yoghurts are very popular with some Ketogenic patients - please do check ALL labels regularly, as they can be changed without warning!

Both the chocolate and natural flavours now contain significantly more carbohydrate than previously. Chocolate was 3.8g now 7.6g CARBS with a small reduction of fat from 19g to 17g, natural was 0.5g now 3.9g CARBS with a small increase of fat from 19g to 21g.

To date we have not received a reply from the makers to explain these changes.

Summer Recipies from our KetoKitchen

With summer coming and hopefully the need for picnics, packed lunches and BBQ's, this pastry recipe is proving a big hit with those of us in the office that live the 'lo-carb' life as well as some of our patients on a stricter ketogenic diet. The sausage rolls are lovely and sometimes I add a pinch of mixed herbs or spices as well just to give a different flavour. We hope you enjoy it. Emma (Matthew's Mum).

SAUSAGE ROLLS

Recipe Origin: Chef Craig Rodger,
What The Fat? book
www.whatthefatbook.com
1.25:1 RATIO

100.19 g fat
72.08 g protein
8.28 g CHO
Kcal: 1223

Ingredients

- 125g Grated mozzarella – MORRISONS
- 42g Ground almonds – MORRISONS
- 16g Double cream - MORRISONS
- 27g Egg
- 200g Sausages – BLACK FARMER PREMIUM - remove skins before weighing
- 10g Psyllium husks

Guidance

- You will also need a pinch of dried herbs, sage is nice but for a stronger flavour you could use a little dried fennel seed.
- Pre heat oven to 170c / fan 150c / gas 4.
- Melt the mozzarella in the microwave then mix in the ground almonds, psyllium husk, egg and cream.
- Mix well to form a dough.
- Roll it out to a rectangle, I divided it and made two 8 x 4 inch rectangles.
- Form a roll with the sausage meat to fit the length of the pastry.
- Fold the other half of the pastry over to make a long sausage roll.
- Cut into portions (I made 8), place on a non stick baking tray, brush with a little beaten egg (optional).
- Cook in pre heated oven for approximately 20 – 25 minutes until cooked through.
- If you make 8, each sausage roll will give you: 12.5g fat / 9g protein / 1g CHO

Mo's tip: These are great for lunch boxes, or turn in to a dinner with vegetables or salad.

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

KETO PASTRY

Recipe Origin: Chef Craig Rodger,
What The Fat? book
www.whatthefatbook.com
1.25:1 RATIO

61.00 g fat
42.72 g protein
6.30 g CHO
Kcal: 745

The photo shows the raw dough and an apple turnover.

Ingredients

- 126g Grated mozzarella – MORRISONS
- 42g Ground almonds – MORRISONS
- 16g Double cream - MORRISONS
- 27g Egg
- 10g Psyllium husks

Guidance

- Melt the mozzarella in the microwave for 30 seconds, stir then melt for a further 30 seconds.
- Beat in ALL other ingredients until a dough is formed.
- This pastry can be used to make pies (sweet or savoury), sausage rolls and bases for quiches or pizzas. Batching up will be easy! The dough will weight 216g so just divide in to 54g portions which will be enough to make most recipes. Just add the values of the fillings to suit your ratio.

Two ways of using:

- With one 54g portion, I made an apple turnover by adding 40g raw cooking apples, sliced, added some sweetener and then cooked for approximately 20 minutes in a pre heated oven: 180c / fan 160c / gas 4.
- This made a turnover with: 15.2g fat / 10.6g protein / 5g CHO – serve with cream if you need more fat.

With another 54g portion I made 8 pastry cases which could be used in many ways.

e.g. Make cream cheese filling or smoked salmon.

Mo's tip: I found that rolling between baking parchment makes it easy.

Makes great party food!!

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

Hello from Matthew's Friends NZ

We kicked off the second quarter of 2016 thrilled to announce that Christchurch Hospital will be opening their very own paediatric Keto Clinic – very exciting news, especially for our epilepsy families down South.

This will be the first time that ketogenic therapies have been offered locally in the South Island and means services will now be available for the Auckland, Wellington and Canterbury regions. It is great to see the wheels (gradually!) turning nationally, and we look forward to supporting the Canterbury families as they begin their ketogenic journeys.

I would like to take this opportunity to introduce two of our NZ keto kids, Mitchell from Wellington, and Ben from Rotorua, who both have Doose Syndrome (MAE). The families first met in 2010 when the boys were age 6 (pictured, Mitchell on the left and Ben on the right) and have remained in touch since. Both are now in the process of weaning off the diet. Congrats, boys!

Meanwhile in the sphere of local medical research, Waikato and Tauranga hospitals are currently recruiting brain tumour patients to take part in a pilot study featuring the ketogenic diet as an adjunctive therapy.

The research looks specifically at patients with glioblastoma multiforme tumours – an aggressive type of brain cancer – who will follow a ketogenic diet whilst receiving chemotherapy and radiation.

The study will look at progression-free survival at eight months, as well as adherence, compliance, safety and nutritional adequacy of the diet.

The study's principal investigator is Dr. Michael Jameson, an oncologist based at Waikato Hospital. While research in this area is underway elsewhere around the world (including through the Matthews Friends clinic in the UK), this is the first study of its kind to be carried out in New Zealand.

An exciting step for broadening the profile and potential applications of ketogenic dietary therapies here. Stay tuned!

Susan Hill
President, Matthews Friends NZ

Matthew's Friends Canada

With the weather now getting warmer in Canada - Matthew's Friends Canada is busy moving along with organizing their first 'Ketogenic Child & Youth Family Retreat'.

This shall be held on September 17th, 2016 at Canterbury Hills in Ancaster, Ontario: An exciting camp-style event that will offer various indoor and outdoor activities for the youth to make lasting memories. We are excited to welcome guest speakers: Dr. Eduard Bercovici (Epileptologist), Emma Williams (CEO/ Founder of Matthew's Friends and Keto Mom), experienced Keto families, Chef Neil Bosomworth (Medical Keto Chef), Canadian Chef Patrick Wiese, ketogenic registered dietitians and social workers to offer a day of practical information about ketogenic diet therapy. Hands-on keto-cooking demonstrations will be conducted by Chef Neil and Chef Patrick that all ages will be able to enjoy! We thank Epilepsy Halton Peel Hamilton for their support of this event.

We are also pleased to introduce our new Canadian patron: Chef Patrick Wiese! 'Chef to many high profile clients and, once personal Chef to Oprah Winfrey, personal Chef to Avril Lavigne, and Executive Chef and Owner of Twisted Kitchen Social Truckin' and Caterin'. Chef Wiese has always followed his "Comfortably Twisted " culinary techniques in taking what we all know and love and giving them just the right balance of fun and frivolous flair to create approachable but enticing menu items.'

Chef Wiese's Keto cooking will be a new and exciting chapter for Matthew's Friends Canada and the Ketogenic Diet patient population. We so look forward to working with Chef Wiese. #chefwiese #MatthewsFriendsCanada

Chef Wiese will also be holding upcoming awareness/fundraising events including his 'Intimate Event Series' (May 2016 onwards) – an evening for small groups to get to know Chef Wiese as he creates and entices you with an amazing 4 course meal experience in an intimate dinner setting.

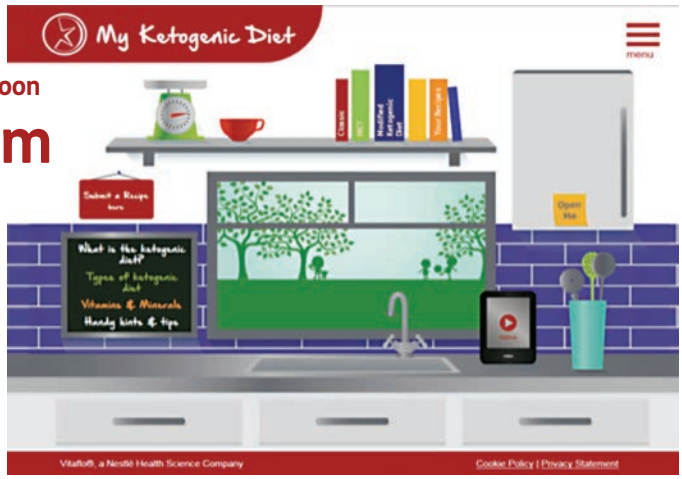
Matthew's Friends Canada is also proud to announce that our English edition library of education tools has been completed. We are thankful to the Canadian ketogenic RDs who helped with this much needed project. These same tools are currently being translated into French and should be ready for circulation by summer. Merci to our Canadian French speaking ketogenic registered dietitians for taking on this great work!

As we continue to raise awareness we have been delighted to be invited by various epilepsy organizations to speak to their clients, staff and support groups. Please let us know if there is any assistance that we can provide you with! We are also looking for more volunteers for projects and to help support raising awareness - you can reach us at **info.canada@matthewsfriends.org**

Make sure to visit us:
Twitter MF_Canada
Facebook Matthews Friends Canada

Vitaflo are pleased to announce their new website coming soon

www.myketogenicdiet.com



What you can expect:

- Great recipes for classical, MCT and modified diets
- Video clips of how to cook the recipes
- Handy hints on how to add fat into the diet
- Opportunity to share your recipes with others

Please remember to check with your dietitian to what is suitable for your prescription.

Chef Neil has been with Vitaflo several months now and has already created some fabulous new recipes using MCTprocal ™ and betaquik®. These can be viewed on the **myketogenicdiet.com** and videos will be recorded and uploaded shortly.

These recipes are:

- Waffles: sweet or savoury
- Brownies
- Pizza
- Quiche
- More in development.....
- Pancakes
- Bread
- Breadsticks
- Tarts

Some patients will have been lucky enough to have tried these fabulous recipes at patient cooking days at:

- St Georges, London
- Manchester Children's
- Queen Elizabeth, Birmingham

More cooking demonstrations are planned around the UK throughout 2016, some are listed below.

Month	location
May	Leeds
May	Plymouth
May	Queen Elizabeth, Birmingham
June	MF KetoCollege, East Grinstead
July	York
July	Addenbrookes, Cambridge

For more information please do not hesitate to contact your dietitian.

ULTRAGENYX ANNOUNCE NEW STUDIES FOR GLUT 1

Ultragenyx Pharmaceutical Inc. is currently developing a Phase III study for patients with Glucose Transporter Type-1 Deficiency Syndrome (Glut1 DS) who experience Paroxysmal Movement Disorders. This study is planned to start by the end of 2016.

In an effort to gather key data to support the development of this study, Ultragenyx is launching a study to evaluate a daily electronic diary used to capture Glut1 DS symptoms for eligible patients.

Families are asked to contact Ultragenyx if they would like more information about these studies. Space is limited so we suggest you register your interest as soon as you can.

Transforming good science into great medicine for rare genetic diseases.

ultragenyx pharmaceutical

1. Electronic daily diary study

- Enrollment will begin mid-July
- Study will include patients with Glut1 DS who are 12 years and older and caregivers who care for someone with Glut1 DS who is 6 years and older*
- Patients may complete the electronic diary at home
- Electronic diary will record information about Glut1 DS symptoms
- A study stipend will be offered
- Please contact Gemma Barrett at Adelphi Values for more details: **gemma.barrett@adelphivalues.com**

Fundraising for Matthew's Friends

We are so grateful to ALL our fundraisers! Please like and follow us on Matthew's Friends and Twitter @matthewsfriends for uptodate news on all our events. Please support us and request an MF fundraising pack today from **enq@matthewsfriends.org**

Well done and thank you

HUGE well done to Eva Clawson, aged 10, pictured here with her friend Poppie (Eva is on the right), who arranged a cake sale to raise funds for Matthew's Friends together with some of our wrist bands and pens. They sold everything and raised a massive £360.27p which is fantastic.

Every penny raised helps towards furthering ketogenic dietary services. We are so grateful to Eva for thinking of us and for doing such a marvellous job.

Nutricia stepping forward for Matthew's Friends...

On July 18th, the Nutricia HR team put their best foot forward and completed a sponsored walk for Matthew's Friends. Team member, Jamie Duncan told us 'We walked from Trowbridge train station to Bath Station along the Canal tow path, a distance of approximately 15 miles. With the heat and a number of water stops we took a total of 8 hours to complete it'. Huge thank you to Nutricia HR for doing this for us and at the time of writing their total is in excess of £300. Well done.

Book your place on the Tunbridge Wells Bike Ride

Sunday September 4th sees the annual Tunbridge Wells Bike Ride take place – this year raising funds for Matthew's Friends Glut1UK fund! There are 3 routes to choose from and 200-250 riders expected to take part. If you would like to enter please visit the website for more information **www.tunbridgewellsbikeride.co.uk**. Matthew and Mum Emma will be at the finish line to welcome the riders home! There will be a tent for our charity supporters and any Glut1 families who would like to come along and join in the fun of the day... there will be stalls and refreshments – a thoroughly enjoyable day out in a beautiful setting!

Our main fundraising event of the year Saturday 29th October – Matthew's Friends Halloween Ball!

Tickets are now on Sale!

Don't miss out, book yours today at **www.matthewsfriends.org/halloween-ball-2016**. Tickets are £58 per person, with a discount if you book a table for 10 or 12.