

AN INTRODUCTION TO KETOGENIC THERAPY & MATTHEW'S FRIENDS

INTRACTABLE (DRUG RESISTANT) EPILEPSY:

1 in 104 people are affected with epilepsy in the UK* and over 50 million worldwide. It is one of the most common serious neurological conditions with approximately 30 different epilepsy syndromes and over 38 different types of seizure.

The majority of cases of epilepsy can be treated successfully with modern anti-epileptic drugs (AED's) used either as single agents or in combination. However, approximately 30% of cases are classed as having drug-resistant or intractable epilepsy, where seizures persist despite the appropriate use of two or more AED's and the possibility of achieving seizure freedom with additional medication is extremely low.

* JEC (Joint Epilepsy Council) 2011 statistics

MATTHEW'S FRIENDS – THE BACKGROUND:

Matthew Williams (24) suffers with a catastrophic form of epilepsy called 'Dravet Syndrome' and his seizures started when he was 9 months old. Emma, his mother, asked if Matthew could try the Ketogenic Diet when he was 2 years old, but she was told the diet didn't work. So she battled on, trying innumerable medications which didn't help Matthews' seizures and which caused devastating side effects. Six years later, Professor Helen Cross began a research trial of the Ketogenic Diet at Great Ormond Street Hospital (GOSH).

Matthew and 144 other children with severe epilepsy were enrolled on the trial. Within 2 weeks of starting the diet Matthew's seizures had reduced by 90% and within 8 months he was weaned off all medication. Sadly for Matthew, the damage had been done. Years of seizures had caused terrible brain damage, his family had broken apart and Emma was now a single mum to Matthew and his younger sister Alice.

Inspired by Matthew, she set up Matthew's Friends in 2004 to provide information, education, training, support and resources for other families wanting to use ketogenic therapies. In 2013 Emma was honoured with an MBE from HM the Queen for services to children with epilepsy.

KETOGENIC DIETARY THERAPIES:

The Ketogenic Diet was successfully used in the treatment of child and adult epilepsy in the 1920's. As AED's became more available the diet was used less frequently with expertise being lost from all but a few centres worldwide. However, there has been a resurgence of interest in Ketogenic Dietary Therapies for children in recent years, due to its efficacy in otherwise intractable cases. The treatment has been clinically validated in a number of studies and a randomised controlled trial from Great Ormond Street Hospital (Neal et al 2008).



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MATTHEW'S FRIENDS TODAY:

Matthew's Friends has a distinguished medical board, chaired by Professor Helen Cross OBE, the Prince of Wales's Chair of Childhood Epilepsy.

It invests considerable funds for clinical research into Ketogenic therapy and its applications, as well as training and educational programmes. It is providing funding for numerous NHS centres around the UK and Ireland. 2011 saw the registration of Matthew's Friends New Zealand and 2014 saw the registration of Matthew's Friends Canada, as well as the organisation being involved with over 20 other countries worldwide in supporting the use of these therapies.

The charity has expanded its remit to help adults that are failing anti-epileptic medication and is also now working in the field of certain types of brain cancer. The contribution that Matthew's Friends makes towards ensuring that these diets are more widely available and properly supported, is internationally recognised by both parents and medical professionals. The charity, which was started from Emma's kitchen table, grew at a phenomenal rate and in 2011 they opened their own Ketogenic Therapies Clinic, employing an expert medical team to

provide the therapy and train other clinical teams. Again, a non-profit making clinic that treats both children and adults where there is currently no NHS provision, so that no family can be denied access to treatment as Emma was with Matthew. The clinic is also pioneering these therapies in other applications and is supporting clinical research in these new areas.

2016 saw the launch of 'Matthew's Friends KetoCollege' which is an accredited training programme to teach medical teams from around the world how to administer and manage ketogenic therapies so as to best serve their patients and 2018 sees the launch of the online tutorials so that medical professionals in resource limited areas of the world can access safe, accurate information led by global experts. The charity also has a series of family introductory films, KetoCooking Youtube channel and online support forums for both professionals and families.

Since the launch of the charity in 2004, Matthew's Friends have invested over £2.5 million into the education, training, research and support of those using medical Ketogenic Dietary Therapies and the charity continues to work hard to change outdated policies, update current guidelines and promote the use of these details to all those who may need them in a safe and responsible way.

THE CHARITY PROVIDES:



A comprehensive website covering all aspects of ketogenic dietary therapies.



Matthew's Friends Ketocollege - A Healthcare Professional Advisory and Training Programme.



Funding for ketogenic centres around the UK and Ireland to provide support to families.



Educational literature, Ketogenic Diet starter packs, equipment and Patient files supplied free of charge to all UK and Irish Ketogenic Centres for their patients.



A telephone support line which is available to families 365 days a year.



Matthew's Friends Clinics - providing Ketogenic Dietary Therapies for all who are currently unable to gain access to local services.



National and International workshops and conferences for both patients and health-care professionals.



NONE OF THIS IS POSSIBLE WITHOUT.....FUNDING

FUNDRAISING

Matthew's Friends do not receive any government funding and are totally reliant on fundraising and donations. By the time our families find us they are usually in a VERY bad way, dealing with a worrying and fraught situation, often fearing for their child's life. Asking them to fundraise at this time to help provide services is not desirable, therefore the small Matthew's Friends team have cajoled and badgered their friends and families to help fundraise over the years. We welcome ALL help and are delighted to provide resources such as a justgiving page for sponsored events, running vests, sponsor forms, t-shirts and anything else that we can for those willing to support us. Please do contact us if you can help.

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