

In this issue

Page 2 • Ketogenic and Modified

Page 3 • Able X • Status Epilepticus Study

Page 4 • Queensland Specialist Immunisation Service

Olivia & Lorelei's Story with Epilepsy and Dietary Treatment

We are the Page family. My husband Kenyon and I are proud parents of Olivia (10), Lorelei (10) and Edward (3). Our girls are identical twins, who were diagnosed with Juvenile Myoclonic Epilepsy. They have extreme photosensitivity, myoclonic jerks, absent seizures and a tendency to self-induce their seizures by waving their hand in front of their face or getting up close to a white wall. By the time we started the Modified Ketogenic Diet (MKD), the girls were having 130+ seizures a day (each).

We have tried numerous medications without success. Dietary treatment had never been on our radar, until Olivia had a vomiting bug. During the week long illness, Olivia had not eaten much and we realised that her seizures had significantly decreased and this lasted for about 6 weeks. After casually mentioning the improvement to our Neurologist, we discussed the ketogenic treatment and we were referred to the Ketogenic Clinic at the Mater Children's hospital. After being on the waiting list for a good length of time, we found out that the funding for the clinic had been cut and it looked as though the girls wouldn't be able to access this treatment.

Not long after the cut in funding, we were contacted by the dietician working with the Ketogenic Clinic to discuss another option called the MKD. It did not include a hospital stay and seemed to be less restrictive than the classic version of the treatment. We had our initial clinic appointments to discuss how the diet worked, what it would look like, blood tests that needed to be completed and side effects that we could expect. We were one of the first families to try this version of the Ketogenic Diet, so therefore there wasn't a lot of information about recipes or foods and we had to find our own way in some respects.

After our blood work was completed and we had been to our final information appointment, it was time to decide when to start. I was desperate enough to start my girls the very next day, even though my husband was away at the time. To say it was tough is an understatement...it was horrific! The girls reached ketosis very quickly, their bodies weren't used to making ketones - there was a lot of food refusal and vomiting which lasted for almost 10 days... however the food refusal went on for longer. The start of the MKD took its toll on the girls and myself, emotionally and physically but within weeks we could see signs of improvement - their behaviour improved, cognition was better and the seizures were reducing. Within a month or so, their photosensitivity seemed to have dulled and we were seeing a 98% reduction in daily seizures.

We have had to become creative with the food, almost marketing the same ingredients (cauliflower is an amazing food!) in different combinations. I tried to replicate their favourite recipes without much success and in the process I have had to throw out a lot of food. We still have battles over foods that the girls would really like to try or eat, but we have found a way to make the MKD a part of



our family. We BBQ a lot in summer and include salads or low carb vegetables and roast pork in winter with lots of crackling! We have found solutions for kid's takeaway, like chicken nuggets and we eat out with family and friends. We are not dictated to by the diet; we find solutions so that our girls feel that they are included. This doesn't mean that they don't feel like they miss out, they do and they constantly remind us but we try to talk about what a healthy diet means to everyone and hopefully they will see its benefit for themselves in the future.

In most cases, the treatment is weaned after the 2-year mark, we did try to go through this process however it was unsuccessful so we continue on with MKD at this stage. This treatment is very difficult, expensive and time consuming but well worth the effort and heartache for the success and the quality of life the girls and we as a family have gained. Although we are not seizure free and still medicated, this treatment has been a huge success for us.

Things we have found helpful:

- When starting the diet, we tried to keep the food simple and whole. It gave us a good start to introduce other foods and see how each of the girls would react.
- We eat out at our local leagues clubs, RSL's or Pub's. There are always options for a steak and salad or roast with low carb vegetables. I seem to always carry some mayonnaise or most restaurants have it also.
- We still have "sometimes" foods, like low carb chocolate bars, low carb bread or even ½ an icy pole (depending on the brand).
- The girls love the nut free chocolate brownies on Ditch the Carbs - <http://www.ditchthecarbs.com>.

Krischelle Page

Ketogenic and Modified Ketogenic Diets

The Ketogenic (Keto) and Modified Ketogenic Diets (MKD) are both high fat, low protein and low carbohydrate diets used for difficult to treat forms of epilepsy. They work by using mostly fat to fuel energy production in the body, instead of glucose.

What is the difference between the Ketogenic Diet and the Modified Keto Diet?

The Modified Ketogenic Diet is less restrictive than the Ketogenic Diet. It allows unlimited amounts of protein foods and fats are encouraged. Food does not need to be weighed and recipes do not need to be precise. Carbohydrate foods are counted and spread throughout meals with the aim to keep within the daily limit. Ketogenic diet on the other hand requires accurate weighing of foods ensuring precise proportions of fat, protein and carbohydrates.

Who can be helped by the Diet?

Both diets can be considered for children and teenagers with uncontrolled seizures and where other therapies have failed. They are very restrictive and require a great deal of preparation and planning. As a result, this therapy, whilst it may be beneficial for adults, is often not as successful due to a high rate of non-compliance.

Important Facts

Both diets require a referral from your neurologist to a trained dietician and should be strictly conducted under medical supervision. Blood tests will be required. It is also important to note that not all people will respond to this treatment option and therefore monitoring its effectiveness is essential.

Resources

The following is a list of resources that a number of Epilepsy Queensland clients have found helpful when undertaking either the Ketogenic or Modified Ketogenic Diets:

Websites

- Matthews Friends - <http://www.matthewsfriends.org/>
- Charlie Foundation - <https://www.charliefoundation.org/>
- Carb Zero - <http://www.vitaflo.com.au/products/disease-specific-nutrition/ketogenic/ketogenic-product-range/carbzero/>
- Ketocal - <http://www.myketocal.com/>
- Ditch the Carbs - <http://www.ditchthecarbs.com/>
- www.carsonharrisfoundation.org

- www.atkinsforseizures.com
- www.livestrong.com
- www.hopkinsmedicine.org

Pinterest

This way of eating is accepted more these days and there is a huge amount of resources on Pinterest. Be careful to check all the carb amounts and add the fats required.

Forums/Facebook

There are a number of forums and Facebook pages for Ketogenic Diets, be careful as some of these are for weight loss but others have good recipes and ideas.

- Modified Atkins and Keto Diet for Epilepsy (Australia) - <https://www.facebook.com/groups/114406348747695/>
- Australian based, fantastic network if parents, who are on the diet, weaning the diet, failed the diet, and simply survived the diet. Very real and current hints and tips, menu plans, recipes.
- Ketogenic parents ROCK - <https://www.facebook.com/groups/ketogenicparents/>

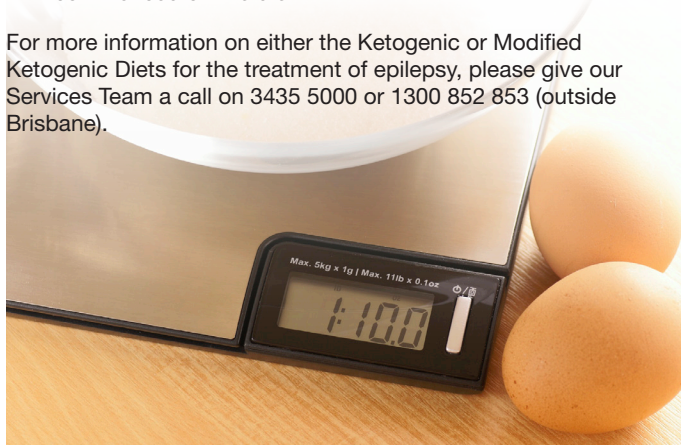
Recipe Books

Ketocal recipe book (supplied with ketocal product), your local pharmacist can order this (requires a GP script).

Other Resources

- Your Dietician
- Calorie King is a recommended app for carb counting once commenced on the diet.

For more information on either the Ketogenic or Modified Ketogenic Diets for the treatment of epilepsy, please give our Services Team a call on 3435 5000 or 1300 852 853 (outside Brisbane).



Seventh Annual Queensland Epilepsy Symposium Thinking outside the box!

Friday 25 November 2016
RBWH, Herston



Join us for some stimulating dialogue...

www.epilepsyqueensland.com.au

Bookings essential!



More than 120 contributors from 22 countries have provided content for ABLE XSeries. The courses are self-paced and free. The courses are tiered to fit with Years 1, 2, 3 of any health, medical, or related degree. They can also be used for workforce education and can be accessed here: <https://www.edx.org/xseries/intellectual-disability-healthcare>.

ABLE XSeries

This online course series is free and open to anyone interested in improving healthcare for people with intellectual disability.

A certificate is offered on completion. If you need proof for an employer, school, or other institution that you have successfully completed the online course, you can purchase a verified certificate from edX (USD\$99).

ABLE101x – Through my Eyes focuses on the stories of people with intellectual disability around the world, and their families and supporters. Over four parts, students will look at the barriers and enablers to healthcare for people with intellectual disability, their experience of specific syndromes and communication difficulties, and how they stay healthy. Students will listen to family members speaking about complex care, rare syndromes, early death, and planning for independence. The final component focuses on the history of treatment, the impact of rights' movements on healthcare delivery, common health conditions, and health promotion. <https://www.edx.org/course/through-eyes-intellectual-disability-uqx-able101x>

ABLE201x – Well and Able examines the specific physical health issues that affect people with an intellectual disability including, oral health, syndrome specific health issues, health communication, especially for non-verbal patients, sexual health, and interactions between tertiary and primary healthcare systems. There is a special section on complex care including issues associated with aging and spasticity, and the health impacts of epilepsy. <https://www.edx.org/course/well-able-improving-physical-health-uqx-able201x>

ABLE301x – Able-Minded focuses on the mental health issues of people with intellectual disability. Students learn about the complexities of diagnosing mental health issues in people with intellectual disabilities and the types of disorders, assessments, screenings, and treatments used. There is a special focus on the legal and ethical complexities in health practice with patients who often require substituted consent. <https://www.edx.org/course/able-minded-mental-health-people-uqx-able301x>

We loved working with the QCIDD team and would like to thank Miriam Taylor in particular.

Epilepsy Queensland is proud to have participated in QCIDD's "AbleX" initiative. This XSeries Program has been designed to influence, empower and educate a wider population to improve the health and healthcare of people with intellectual disability.

Worldwide, 60+ million people with intellectual disability experience poor health, die prematurely and receive inadequate healthcare. You will gain an understanding of the barriers and enablers for people with intellectual disability, their families, and their healthcare providers.

In the courses, you will learn about best practice in the field of intellectual disability healthcare and gain knowledge to improve health outcomes for this disadvantaged group.

Hear the voices of people with intellectual disability around the world, their families and healthcare practitioners:

- What is their experience – what barriers do they face and how do they overcome these?
- What are their healthcare needs and how can good health be promoted?
- What health conditions do they commonly experience and how can these be assessed and managed?
- What influence do other factors such as ageing and epilepsy have on their health?
- What mental health issues do they have and how can these be recognised and managed?
- What are some of the ethical and legal issues that are of particular relevance to them?

What is an XSeries?

An XSeries is a group of courses that add up to a rich understanding of an area of study. Once you pass the entire series, receive a personalized XSeries Certificate that shows you put in the work, understand the material, and you have a shareable certificate to prove it!

Status Epilepticus Study

Thank you to everyone who has participated in the Status Epilepticus survey thus far. We have had a fantastic response and we would like to hear from more people who either have epilepsy or have a family member who has epilepsy, especially those who have experienced status epilepticus.

To take part in the online survey please go to <https://www.surveymonkey.com/r/39NKBRN>.

Clinical trial for fenfluramine for Dravet syndrome convulsive seizures

Lady Cilento Children's Hospital's Neurosciences is a site for a clinical trial for fenfluramine.

If you have a child with Dravet Syndrome convulsive seizures, and are interested in being considered for the trial, please email services@epilepsyqueensland.com.au. In the subject line say "Interest in the fenfluramine trial" with your contact details in the body of the email.

LCCH cannot discuss inclusion/exclusion criteria otherwise, until a patient has been deemed suitable for screening, and the parents have signed the consent.

WHAT'S ON...



'UNDERSTANDING EPILEPSY' WORKSHOPS BRISBANE

- Are you up to date with current epilepsy terminology and treatments?
- Does your respite organisation manage seizures appropriately?
- Does your school and respite organisations have an up to date management plan for your child?

Epilepsy Queensland is holding monthly workshops in our Woolloongabba office on:

20 October
24 November

We can also tailor training to suit your needs and are happy to travel to you.

'UNDERSTANDING EPILEPSY' WORKSHOPS GOLD COAST

Epilepsy Queensland holds monthly workshops at Benowa:
30 November

SUPPORT GROUPS

Brisbane Adult Support Group

5 November

Northside Support Group

11 November

EVENTS

25 November • 7th Annual Queensland Epilepsy Symposium

5 December • AGM & Awards Ceremony

13 February 2017 • International Epilepsy Day

26 March 2017 • Purple Day

For further information on any of the above events please contact Epilepsy Queensland on 07 3435 5000 or 1300 852 853 (Regional Queensland) or email epilepsy@epilepsyqueensland.com.au.

Do we need to update our mailing list?

We hope you enjoy reading the Livewires newsletter. However, if you no longer wish to receive Livewires, please let us know by calling 07 3435 5000 or 1300 852 853 (Regional Queensland) or emailing pr@epilepsyqueensland.com.au.

We would also greatly appreciate being advised if you have received multiple copies at the same household, so we can update our records accordingly. Thank You!



Telling your story is a great way to raise awareness about epilepsy. We are keen to raise the profile of epilepsy and increase community understanding and acceptance of epilepsy every single day. You can help so much by volunteering to tell your story in our publications and the media.

Please contact pr@epilepsyqueensland.com.au if you're interested in assisting or just want to have a conversation about what may be involved.



Queensland Specialist Immunisation Service

The Specialist Immunisation Clinic offers Queensland children and young people with complex immunisation needs, access to greater protection against life-threatening vaccine-preventable diseases.

Children who may need to see an immunisation specialist at the Lady Cilento Children's Hospital include those who have underlying complex medical health problems, complex immunisation needs and those who have previously experienced a significant adverse event following immunisation. The team of immunisation specialists include senior medical, nursing and allied health staff.

If you are concerned about your child's immunisation status you should discuss this with your local GP or specialist for a referral to the Specialist Immunisation Clinic. For general immunisation advice call 13HEALTH.

Read More:

QSI services: <http://www.childrens.health.qld.gov.au/home/lcch/patients-families-visitors/queensland-specialist-immunisation-service/>

Vaccination Matters: <http://vaccinate.initiatives.qld.gov.au/>



FOLLOW US ON



[facebook.com/epilepsyqueenslandinc](https://www.facebook.com/epilepsyqueenslandinc)



[@epilepsyqld](https://twitter.com/epilepsyqld)



po box 1457, coorparoo bc qld 4151
phone 07 3435 5000 • 1300 852 853 (regional queensland)
fax 07 3435 5025
email epilepsy@epilepsyqueensland.com.au
www.epilepsyqueensland.com.au
ABN 42 025 269 961

Opinions expressed in this publication are not necessarily those of Epilepsy Queensland. Questions and concerns about your condition, its treatment and management should be directed to your doctor.

Information on products should not be regarded as an endorsement or recommendation of these products.

© Epilepsy Queensland Inc. This publication is subject to copyright laws. No part may be reproduced by any process without prior written permission from Epilepsy Queensland.

