



## **RING14**

### **A Mother's Guide to Good Health & Seizure Control**

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This booklet has been a long time in the making. I am a mother of a Ring14 child in Pennsylvania. Our daughter, Chloe, is now 10 ½ years old, and what a 10 ½ years it's been. We have learned so much during this time, and it's my intent here to try and share some of what we have learned with you. I imagine we have not yet met every obstacle that a Ring14 child can encounter, but we have met many. This is for all Ring14 families. Perhaps you may garner some tidbit of information here that might help with your child's overall health.

When Chloe was diagnosed, at about age 2, there were very few known cases, and not that much information. Fortunately, The International Ring14 Association in Italy had already begun much work on studying and helping Ring14 children, but here in the United States, at least in the Pittsburgh, Pennsylvania area, the doctors didn't really know anything about the condition. There was some information out on the web from a couple of different entities including Italy, but other than that, there wasn't much.

So we began a learning process. Much learned the hard way, through numerous medical crises. Now 8 ½ years later, with Chloe experiencing much improved health, I am documenting the various means by which we have been able to aid in our child's overall wellness. We are by no means out of the woods, and we are still continuing to learn as well, but we have picked up many tips along the way which have greatly improved our child's health.

I recognize that each of our children have different health concerns. I can only speak of the one's we have experienced and worked through. **I AM NOT A DOCTOR. I AM NOT A NURSE.** I am simply a mom offering ideas that have helped improve our child's health.

Along the way, we have had some wonderful medical help. Our child is fortunate to have an excellent neurologist/epileptologist, a medical marvel of a special needs pediatrician, and the most helpful and accommodating general pediatrician. We've also been so blessed to have probably the best home healthcare nurse anyone could ask for, with decades of experience and a heart as big as the moon. We've had some beautiful medical, nursing and therapeutic people involved along the way as well. We have been fortunate, and we've tried to learn from them.

Chloe is also so fortunate to have a loving, kind and patient Daddy who provides her so much strength and support. She's also so lucky to have the best big brother ever, one who helps her along and is fun to beat up on too!!

A few sections in this booklet are written by Sheila Ferguson, mom to Brooke in Oklahoma. Brooke just turned 20 years old, and Sheila has tremendous knowledge in caring for a Ring14 child/adult. She has contributed valuable information about bone density (Osteopenia / Osteoporosis), girl's hormonal changes, and educational advocacy.

The international Ring14 president, Stefania Azzali, has contributed information in several sections in this document. The Association Ring14 in Italy was founded 10 years ago to assist our children with anomalies on the 14<sup>th</sup> chromosome.

Ring 14 children have compromised immune systems. Everything we can do as parents and caregivers to strengthen their immune system increase our children's chances at better health. Paying close attention to nutrition, hydration, supplementation, environment, medications, bodily functions, and other health indicators is essential to this goal.

Perhaps there is something you can take away from this booklet that will better your child's condition. It's a compilation of our experience and the help of the fine medical and therapeutic people that have been in our child's life. It is my prayer and my hope that you will find aid here.

5/16/12

## **TABLE OF CONTENTS**

### **Nutrition/Food**

- Organic Food
  - Meat/Fish
- Vegetables/Fruits
- Gluten Free Diet
  - GABA
- Other Foods That Help
  - Foods to Avoid

### **Fluids**

- Water
- Coconut Water
- Juicing

### **Ketogenic Diet/Modified Atkins Diet**

### **Supplements**

### **Gastro Intestinal Issues**

### **Osteopenia/Osteoporosis**

### **Respiratory/Pneumonia/Aspiration**

### **Seizures**

#### **Seizure Triggers**

- Food/Hydration
  - Sleep
- Temperature/Weather
  - Heat / - Cold
- Elimination ~~ Peeing & Pooping
- Over-The-Counter Medications
- Medications In The Hospital
  - Stress

### **Anti-Seizure Medications & Therapies**

**Vagal Nerve Stimulator**

**Seizure Calendar**

**Video Taping Seizure Activity**

**Oxygen**

**As Your Child Grows**

**Vaccinations**

**Health Indicators**

**Puberty**

**Types of Physicians**

**Other Medical Issues Related to Ring 14 Children**

- Mobility

- Fine Motor

- Speech

ABA Therapy

Developmental Delay

**Advocacy**

**Other Forms of Therapy/Services**

**Even More Treatment Types**

**Two Newer Non-USA, Non-FDA Approved Seizure Control Methods**

**Unproven Medical Techniques**

**Siblings**

**More Information on Ring14**

**Conclusion**

Our child's #1 health problem associated with Ring14 has been seizures. Much of this booklet deals with improving the child's overall health AND helping with seizure control.

## **NUTRITION/FOOD**

You're probably wondering, of all the things to talk about first, why food? Though it seems like a simple subject, we have come to learn how important a healthy diet is for a Ring14 child (or any child). We've learned what our child should eat, and what she should NOT eat. Here in Pittsburgh, we are very fortunate to have the most wonderful holistic-type pediatrician who deals solely with children that have a huge variety of difficult to treat medical conditions. I call him "the best kept secret in Pittsburgh!" In our case, he actually does a complete blood analysis of my child every year to determine nutritionally and supplementally (vitamins/minerals) where she is deficient. He then recommends foods and supplements to support her body's needs.

We have also learned that there are foods our child should avoid AND foods that are very beneficial. We strongly believe that there are seizure-trigger foods. Foods we definitely avoid. We have also learned that there are foods that enhance healthy brain function. It's essential that the child have a nutritionally balanced daily diet. Supplementation can be given in the form of Peditasure or Pediatric Boost which contains important vitamins and minerals for brain and body development. It goes without saying how important it is that the child not be hungry or go to bed hungry, but in a non-verbal child this can be difficult to assess. We often give a final Peditasure before bedtime to assure good rest and a nice full tummy.

The phenotype of our Ring14 children is to be thin, sometimes too thin. Regularly have your Pediatrician check and compare your child's weight and height to the norm chart. If you see that your child is consistently underweight, and consistent food consumption is insufficient at increasing weight, you may want to consider having a feeding tube placed. The tube

can be used to supplement feedings by adding healthy calories and can also be used as a method to giving medicines and fluids.

Increased seizure activity consumes a great deal of energy and often causes exhaustion, thereby reducing normal food and fluid intake. Dehydration can also follow increased seizure activity.

Even if your child can consume food and drink orally, there are still a number of benefits to having a feeding tube. Please keep in mind that having a feeding tube in no way prohibits your child from eating and drinking orally. But, when your child is ill and unwilling or unable to sufficiently eat and drink, the feeding tube can be a Godsend. Here are several advantages to a feeding tube:

- \* Increased calories
- \* Increased weight gain
- \* Reduces dehydration
- \* Reduces potential of Osteopenia
  - \* Aids in constipation issues
  - \* Aids in increased urination
  - \* Aids in dispensing medication
- \* Increased hydration and calories may reduce seizures

If you think a feeding tube can benefit your child, see your Pediatrician for more information.

Our daughter eats orally, and she also has a feeding tube which was placed last year, at age 9 (more on that later). What follows concerns oral foods.

## **ORGANIC FOOD**

As much as possible, clean/pure/organic food is, in our opinion, the best. Foods free of chemicals, pesticides, and processing, with additives that you can barely pronounce, are much healthier and easier for the body to process. Our kid's little bodies seem to have to work so much harder than the average body, so organic helps get in those good vitamins and minerals. It can get a little costly to try and eat mostly organically, but as much as we can afford, we try and purchase natural and organic products for her. If you have the land, time and desire, growing a vegetable garden that is pesticide and chemical free is another alternative. Freezing and canning your own "clean" food can help cut down on costs.

## **MEAT/FISH**

If able, we recommend purchasing hormone-free meat and chicken and wild-caught fish.

## **VEGETABLES/FRUITS**

As much as possible, organic fresh fruits and vegetables are the safest.

## **GLUTEN FREE DIET**

Thanks for the dear doctor I mentioned above, and all the comprehensive blood work he's done on our daughter, it was determined that she has a slight gluten intolerance. She does NOT have Celiac Disease, but as it turns out, wheat is just messing with her system, slowing it down and clogging it up. Thus, she's been on a gluten free diet now for about three years.

Pretty much, a gluten free diet is a diet free of wheat. Most of the food you find that is gluten free in the grocery store has been certified gluten free and is produced in a facility or on machinery where no wheat is present. We have seen a great improvement. In general, I think it is more difficult for some bodies to process wheat, and hers happens to be one of them. It is my OPINION (no facts to support this), that most of our kiddos could benefit

from gluten free diets. It's at least worth a couple of weeks to try, just to see if it makes any difference. There's no harm that I can think of in eliminating wheat for a week or two week trial. There are plenty of tasty cookies, treats, pasta, breads and cereals available that are gluten free.

Recently, scientists have published a number of studies linking Celiac Disease or mal-absorption problems to genetic syndromes and neurological problems. Some Ring14 children have been diagnosed with Celiac Disease or mal-absorption problems. Often this goes undiagnosed by physicians, so parents have to pay particular attention.

Your child may have Celiac Disease or mal-absorption problems if he/she has any of the following symptoms:

- \* constipation or diarrhea
  - \* swollen belly
  - \* low weight
- \* low iron in the blood
  - \* low immunity
  - \* poor sleep
  - \* agitation

Gluten may be the culprit. A gluten-free diet can solve many of these issues, possibly resulting in lowering antiepileptic drugs and improving sleep and mood.

Check with your physician if you notice any of these symptoms.

Should you decide to change your child's diet to gluten-free, be sure to have the physician check medication levels after the child is on the diet to assure that the levels are in the therapeutic range. Along with blood levels, the physician will also need to do specific testing on feces as well as gastroenterological testing (stomach, intestines and associated organs). The diet may alter medication absorption, so please take care to have all these levels checked.

## **GABA**

We have learned a bit about GABA, which is gamma-amino butyric acid. GABA is sometimes referred to as the “brain’s own anti-anxiety medication.” GABA influences personality and the ability to handle stress. People with a GABA deficiency may experience headaches, anxiety, irritability and seizures. There are great foods that help increase GABA, foods which we feed our daughter and feel have helped in her health, possibly even with some seizure control. They are:

- \* Almonds
- \* Bananas
- \* Broccoli
- \* Brown Rice
- \* Oranges (Citrus Foods)
- \* Rice Bran
- \* Spinach
- \* Whole grains

Other GABA increasing foods are beef liver, halibut, lentils, oats (whole grain), and walnuts, and there are surely more that we haven’t yet tried.

## **OTHER FOODS THAT HELP**

There are other foods that we regularly feed our daughter to promote good health:

- \* Blueberries ~ I have heard them called “brain berries!” We put them in yogurt, cereal, and mix them with other fruits. We give blueberries daily.
- \* Purple Grapes ~ We cut up grapes in order to avoid choking. Contain great antioxidants.
- \* Prunes / Prune Juice ~ Our daughter eats prunes every day of her life! We have found that they greatly help her constipation (more on that later). We cut in small pieces and mix with a bit of bottled water and then warm in the microwave. She gobbles them up. I can’t stress

How much they have helped her with constipation. We also mix with other dried fruits like apricots and dried blueberries.

\* Yogurt ~ We have found that a healthy tummy appears to decrease seizures and help with overall health. We give our daughter about ½ a container of yogurt every day. Yogurt contains pro-biotics which promotes a healthy G.I. track.

\* Salmon ~ Good for heart and brain health, in moderation.

\* Rice Milk ~ Instead of cow's milk if it is difficult to digest for your child

\* Mangos ~ Help immune system

\* Pinto Beans ~ Good antioxidant

\* Sweet Potatoes ~ Skin in particular is great beta-carotene

\* Kale ~ Good for the eyes

\* Cherries ~ Help with sleep (melatonin)

## **FOODS TO AVOID**

There are certain foods which we believe can be seizure triggers. I imagine if you Google it, there may be loads more not contained in this document, but here are just a few that we never give our child:

\* Peas

\* Shell Fish (shrimp, lobster, crab, etc.)

\* Peaches

\* No dyes ~~ we recommend not giving foods that contain dyes, especially red. We give no dyes for fear of seizure trigger

\* Processed foods

Our holistic doctor also recommends staying away from eggs, milk, chocolate and nuts. In our daughter's case, we do give her eggs, a bit of milk, chocolate, walnuts and almonds.

In summary, we do think it's very important to pay close attention to the foods we are giving our Ring14 child and the effect they may have on her.

## **FLUIDS**

Getting plenty of good fluids is just as important as getting good food. Some seizure medications have dehydration as a side effect, causing headaches, fatigue, irritability and constipation.

In our child's case, we went through many hospital trips due to dehydration. Dehydration was a common outcome of increased seizure activity due to an inability, after mounting seizures, for our daughter to get sufficient hydration orally. We have literally spent months and months and months of our lives doing nothing but syringing fluids orally into our child. In the end, we still ended up in the hospital due to dehydration. We don't want to see this happen to any child or any family, so here is how we have learned to handle this situation:

For the first 9 years of our daughter's life, she did not have a feeding tube. Because of so much seizure activity over so many years, it got to the point where our child would gain a pound or two, but after a few days of seizures and, therefore, inability to sufficiently eat and drink, she would lose the gains. We always felt that it was two steps forward and four steps backward. This literally went on for years. Finally, at about age 9, we had a feeding tube placed. Through the tube, we are able to supplement her oral eating and drinking. We initially did not want to have the tube placed, but in hindsight, it's one of the best things we could have done for our girl.

Chloe takes one to two feeds through her tube a day. She is on Pediasure which contains loads of great vitamins and minerals and contains 240 calories per can. She also loves the taste and drinks orally before bedtime.

She has gained over 20 lbs. in about 1 ½ years, so at this point we fluctuate her feeds based on how much other fluid and food she has had each day. At a minimum, she gets one Pediasure tube feed a day.

## **WATER**

In addition to the tube feed(s), we push bottled water throughout the day. We give her about 3 to 4 bottles of water each day (approx. 17 ounce bottles). Most of the water is given orally, though we do use the tube periodically throughout the day to assure good hydration. We recommend bottled water as opposed to tap due to chemicals, etc. contained within some city's water systems. We are on a well and have a filter system, but we still only give her good bottled water. Chloe also does have a bit of juice a few times a week and some milk, usually Rice Milk.

Our 60 lb. girl takes approximately 70 ounces of fluids a day. You may need to adjust for your child's size, and you may want to get your doctor's recommendation on fluid intake.

Early on in our daughter's life, we noticed a good bit of hand and feet mottling, or discoloration. Some of this was due to inadequate fluid intake. At this point, it is very infrequent that we are seeing the mottling, and we attribute this, in part, to good fluid intake.

## **COCONUT WATER**

Another form of water that we give our child which has increased hydration is coconut water. Particularly on hot days, we like to use coconut water. It is our understanding that it is far more hydrating than regular bottled water.

## **JUICING**

In keeping with the organic mindset, we do periodically prepare our own juice for our daughter. We have a good juicer and can really load her up with great vitamins and minerals in a yummy way. Again, we try to use organic as much as possible. We juice apple, grape, carrot, and beet juice and combinations of these fruits and vegetables, as well as others. If you've

not tried before, you can offer this to your child orally or utilize the feeding tube if your child has one. It's our belief that there are great health benefits from juicing.

If juicing is impractical for you, there are many great organic juices available.

### **Give Plenty of Good Fluids Each Day**

## **KETOGENIC DIET/MODIFIED ATKINS DIET**

The Ketogenic Diet, otherwise known as the Modified Atkins Diet, is a diet in which you significantly reduce the amount of carbohydrates in a diet and simultaneously increase the amount of fats. Proteins are calculated into the diet as well. The Ketogenic Diet is often used as an add-on method to aid in seizure control.

In our daughter's case, she went on the diet on two separate occasions, both for four months each time. We tried the diet in an attempt to reduce or eliminate seizures. In our particular case, it was not effective, but that is not to say that the diet is ineffective for everyone. I do personally know of other non-Ring14 cases where the diet has eliminated seizures entirely.

The diet is initiated in the hospital under the care of a dietician and neurologist. Based on the size of the child, a formula is employed to determine the exact amount of carbohydrates, fats and proteins to be consumed each meal. Exact calculations are performed by the caregiver for each ketogenic meal. The diet is heavy in fats and somewhat in proteins, and carbohydrates are very minimally allowed.

If your child is completely tube fed, the diet can be much easier to prepare and your dietician will help set the exact formula.

If your child predominately eats orally, the diet can be trickier to implement but entirely possible to manage. The dietician will teach the parents how to calculate meals and there are some nice meals plans and ketogenic books available.

In our case, our daughter loves carbohydrates. Withdrawing them, almost completely from her diet, was torturous, and she pretty much went on a food strike. It was no fun for her or for us. We did not see the seizure control benefits because she simply would not eat the ketogenic foods that were prepared for her. So, unfortunately, I cannot speak of first-hand success. However, having said that, if you think your child can adjust to such a low carbohydrate diet, it is certainly a seizure control method to consider.

I have learned that other Ring14 families have tried this diet with their children. One family, in particular, found great success with the diet, eliminating their child's seizures for over a year! The younger the child, the more success you may have, particularly if the child is at an early stage of eating and has not yet formed food preferences.

## SUPPLEMENTS

I mentioned earlier that we have been blessed with a wonderful holistic pediatrician for our child. Through him and his regular blood work analysis of our daughter, he recommends certain supplements, vitamins and minerals specific to our child's needs. He recommends, what we consider, the finest of vitamins and supplements. Here are a few that our child has either been on or is currently on and their benefits. Understand that each child has different needs and deficiencies, so you will want to **get your doctor's recommendation.**

- \* Multivitamin ~ we use Kirkman multivitamin with D
- \* Acidophilus ~ a Kirkman product ~ promotes great G.I. health
- \* Pro-Omega +D3 ~ from Nordic Naturals ~ great for brain and heart
- \* Zinc rub ~ from Kirkman ~ Chloe is not currently taking, but has in the past when there has been a deficiency
- \* Aloe Juice ~ from Market America ~ to aid in G.I. health and reflux ~ Chloe is not currently taking

\* OPC3 ~ from Market America ~ a super antioxidant that promotes overall good health ~ Chloe is not currently taking

\* Coenzyme Q10 ~ a Kirkman product ~ taken under doctor's direction

**Please check with your child's doctor before starting any vitamin, supplement or additive to assure no adverse effects**

## **GASTRO INTESTINAL ISSUES**

Some Ring14 children have more substantial GI issues than our daughter has had. I can only speak to the period of time in which my daughter did have a degree of problem. This section will not be all inclusive in that I am writing only of a short period of time in which my daughter had some issues and what we did to remedy. There are other children who have much more involved GI issues, and I am not as experienced in this regard.

Our daughter did have moderate GI problems for about a year at which time she would suddenly throw up. We did modify some of her food at that time to help remedy this, eliminating chocolate, milk and bananas. We have since added all three back into her diet to a degree. But, something that we did do for her that we think was helpful is that we added Aloe Juice into her diet each day. It had a calming effect on her GI system and seemed to help mitigate vomiting. We purchased through a company called Market America. We think it is one of the better Aloe Juice brands on the market. This is a small tip, but one that may prove helpful to your child. However, before trying, **we do recommend asking your doctor**. He/she may or may not recommend for your child's specific issues.

## **OSTEOPENIA/OSTEOPOROSIS**

If a child is inactive and/or does not consistently consume enough quality calories, osteopenia (and future osteoporosis) is a very real threat. Osteopenia/Osteoporosis, simply put, is the deterioration of bones and found most commonly in the elderly and handicapped. Children with genetic disorders may metabolize calcium and other minerals differently than typical children which could potentially lead to this disorder. This can be a real concern for Ring 14 children.

If your child is diagnosed with osteopenia, they should be followed closely. You may want to ask your doctor to have a DEXA scan done on your child to get a bone density baseline. A DEXA scan is similar to a full body x-ray/bone scan. Every few years the DEXA scan should be repeated to make sure that the bones are maintaining their density. If the bones are deteriorating, there are oral medications available, such as Boniva. However, since many Ring 14 children have GI issues, Boniva and other such medications may not be advised. There are also medication infusions, such as Pamidronate, that can help with rebuilding bone density but it can cause a deterioration of the jaw bone. Pamidronate is given via IV for four hours a day for three days in a row, every three months.

Given side effects to the oral and IV medications, it's probably best to just make sure that you are giving the proper amounts of calcium, vitamin D, and vitamin K. Although vitamin supplements can be a big help, it is best to try to get most of these essential vitamins and minerals from a balanced diet. In particular, **DO NOT** give your child vitamin K supplements without the recommendation of your child's doctor. Vitamin K supplements are known, in some cases, to cause additional health related problems for some children. Always seek your doctor's advice. A little bit of exercise daily also can help.

Sources of vitamin D are found in sunlight, some foods like dairy foods and some leafy green vegetables, supplements and vitamins and in liver and kidney functions. I have written about kidney function further in this document, but note that kidney disease may be a precursor to osteopenia. Vitamin K is also essential in treating osteopenia. For the purpose of maintaining strong bone health, be sure to only offer vitamin K foods to your child. High vitamin K foods include swiss chard, kale, broccoli, mustard greens, brussel sprouts, spinach, blueberries, kiwis, grapes, and asparagus.

In Chloe's case, a 10 year old child, she recently suffered an ankle sprain requiring an x-ray. It was determined that she has some degree of osteopenia, and is currently scheduled for her first DEXA scan. Given that Chloe did not have a feeding tube placed until about 1 ½ to 2 years ago, early life calcium, vitamin D and vitamin K consumption was likely insufficient, particularly given other health issues that prevented her from always eating sufficiently.

Sheila Ferguson, mother of Brooke, a 20 year old child/adult, reports that Brooke has osteoporosis, despite her family's best efforts to provide a good diet. Brooke now has a feeding tube, and her family diligently provides calcium/vitamin D.

In both Chloe & Brooke's cases, we parents feel that earlier placement of a feeding tube would have been very beneficial to our children's bone health. Through the tube, we could have more consistently (no matter the child's other health issues at the time) provided better nutrition.

## RESPIRATORY/PNEUMONIA/ASPIRATION

**In some Ring14 children's cases, pneumonia is the child's first health crisis. For new parents of a Ring14 child, you may want to pay close attention to this area.**

Pneumonia is the leading cause of death in Ring14 children. Fortunately, in our case, our daughter has not had respiratory, pneumonia or aspiration problems; however, she is not the Ring14 norm in this regard. Most Ring14 children have respiratory and pneumonia problems. In fact, many first infancy medical crisis are due to pneumonia.

There are several possible causes, but in particular immunity deficiencies (particularly IGA and IGE) play a significant role. Because of low immunity thresholds, parents may want to assure that the child is kept away from anyone who may have a cold, virus or other illness.

Many of our children have difficulties with eating and/or drinking, particularly if there has been seizure activity. Aspiration and/or reflux are potential problems and can also lead to pneumonia.

Pneumonia may present without fever.

Consult an Immunologist or Pneumologist if necessary, and be sure to tell them of the high incidence of pneumonias with Ring14 children.

Antibiotics are often used to treat pneumonia.

You may want to ask your Lung Specialist and/or Neurologist to prescribe in-home oxygen for medical crisis situations and a pulse oximeter to monitor your child's oxygen levels, again during at-risk times as well as during sleep. Many of our children tend to have seizure and other issues around sleep. The pulse oximeter can monitor oxygen saturation rates and help indicate when oxygen is required.

## **SEIZURES**

I feel like I could write volumes on this subject. This rates #1 of the biggest health problems our child has faced. We have been working to manage her seizures since she was 6 months old. This is a common age of seizure onset among many Ring14 children. In our case when the seizures began, we didn't even know what we didn't even know. One minute, everything would appear fine, and the next we were in an unimaginable crisis situation, a situation that nothing can prepare you for. Some 10 years later, we have learned so much about managing and mitigating seizures. We've learned about some seizure triggers, such as food, stress, sleep and even temperature. And perhaps more importantly, we've learned of ways to help control and possibly even eliminate some seizures. I am going to start with some of the seizure triggers that we have encountered. From there, I will discuss some control methods.

### **SEIZURE TRIGGERS**

Every time, meaning hundreds of times, that our child would have a seizure, we would rack our brains trying to figure out if there was something we had done that could have caused it. Was it too much household commotion? Was it something we fed her? Was it this or was it that? What we believe at this point is that there are some things within our control that could have triggered this or that seizure. We've also realized that there are other times when we have no known logical explanation as to why a seizure occurred. All of our 't's were crossed and all of our 'i's were dotted. There is only so much as parents and caregivers that we can control. There will be times when we are tired, preoccupied with our other children, busy with work or the house or whatever. We cannot control every seizure. There are, however, some management techniques that have proved to be very helpful to our child and have significantly reduced (even eliminated for a time) seizures. Here I will start with seizure triggers, meaning things to remain cognizant about and have an active hand in monitoring.

## **TRIGGERS:**

- \* Food & Hydration
- \* Sleep
- \* Temperature ~~ Weather
- \* Elimination ~~ Peeing & Pooping
- \* Over-the-Counter Medications
- \* Medications in the Hospital
- \* Stress

## **FOOD & HYDRATION**

I've already spoken in-depth about both subjects. To reiterate, both are significantly important to the health of the child and both, in our opinion, with good management have a direct impact on seizure control.

## **SLEEP**

I can't stress enough the importance of good sleep for the child. Good sleep includes nice body position (good alignment), sufficient napping as necessary, a comfortable, full belly and uninterrupted sleep if possible. A soothing bedtime regiment sets the stage. A gentle waking routine is important as well. Our child tends to have seizures during sleep, particularly in early morning when she is soon to awake. Monitoring her breathing and even gently waking her can help ward off some seizures. Lack of sleep, in our opinion, can stress the child's system and perhaps lead to seizures.

Many Ring14 children have seizures around sleep, either falling asleep, in the middle of sleep, or upon awakening. To assure safe sleep, monitoring may be needed as well as utilizing a pulse oximeter to assure proper oxygenation. There are a number of devices on the market, including video monitoring, that may help assure safe sleep for your child. As a family, you will need to determine what works best for you and your peace of mind.

## **TEMPERATURE/WEATHER**

### **HEAT:**

We often talk about moving South to the nice toasty warm weather, but we think if our daughter had her druthers, we'd be in Alaska! Why? The heat is brutal on our child's body. It is our opinion, with some agreement from the medical community, that our child's internal temperature gauge is not operating correctly. She simply cannot withstand hot weather and quite literally melts in the heat. We have had occasions while in a nice warm 80 to 90 degree climate, where our child has had seizures on the beach or at a park. Her system just can't handle the heat. So if it's a hot day or we are in a warmer climate, we:

- \* Hydrate, hydrate, hydrate and then hydrate some more
- \* Provide shade (tenting on the beach, cover on the wheelchair)
- \* Mist her body with a cool mist fan
- \* Apply good sunscreen
- \* Wear a hat and cool clothing
- \* Wear sunglasses as we feel the bright sunlight is taxing on her eyes
- \* Don't stay out in the sun too long if we see her melting

If these things don't work, get in a cool, temperature controlled/air conditioned place.

We also have found that it is best for seizure control to not keep the bedroom/house too warm and to not over blanket our child. We suspect that keeping her body too warm contributes to seizure activity.

## **COLD:**

While too much heat is a real concern for our Ring14 children, temperatures that are too cold can also be an issue. Because many of our children are under weight, they can be sensitive to the cold. You can often tell if the child is too cold by checking their hands and feet. If they feel cold to the touch or are discolored, warm the child with socks, gloves, clothing, blankets or raise the heat in the home. If the child is speech impaired, they may not be able to communicate this, so the parents need to pay close attention. Keeping the child too cold may lead to colds, bronchitis or pneumonia.

## **ELIMINATION ~ PEEING & POOPING**

This is perhaps not the most enticing topic, but it is hugely important to seizure control. I rate this just as important as good food and plenty of hydration. It is our opinion that proper elimination is vital to seizure control. I have much to say on this subject as our child has had significant urinary tract problems. It is our suspicion, again unproven and not yet medically determined, that she may not be on the only Ring14 child with urinary tract concerns, concerns that can be affecting seizure control. At the very least, it may be something you wish to keep an eye on.

**POOPING:** It is vitally important that the child defecate at least once a day. The body needs to detox regularly. If your child is immobile, they may have even more difficulty eliminating. This information is not direct from the medical community, but we have seen over and over again that if our child does not regularly defecate, that seizures follow. It's our belief that lack of elimination causes impurities in the system that can affect seizure activity. At the very least, lack of defecating just plain upsets the gut. To increase daily defecating, your doctor may prescribe Miralax or another similar product that promotes elimination.

Our daughter does have a script for Miralax and does take it a couple of times a week. However, what I have found that works like a charm is giving her prunes each day. We give her five or six prunes a day, and that combined with some walking helps her pretty regularly eliminate. If your

child will not eat prunes or prune juice for feeding tube, you can also try high fiber foods like bananas, canned pumpkin and other fruits. For us, we have found that the prunes work very well. We cut up, add some water and warm. She gobbles them up.

Combined with this, we also give our child Acidophilus and yogurt each day, which I discussed above. Acidophilus is essentially a pro-biotic that promotes gut health.

**PEEING:** This is a huge area of concern for us. One I suspect may be a potential issue for other Ring14 children. Some of this is medically documented, while some comes from our observations of our child.

For a seven year period, from about age 3 to and 9 ½, our child had seizures about every week or week and a half, each time lasting a period of two to four days, becoming increasingly debilitating. We noticed during this time that if our child had an ear infection or some other condition that may have been preemptive to seizures, that if she were put on an antibiotic, the seizures would cease. We noticed this many, many times over a six year period.

During this same time period, we noticed odors and other evidence that suggested the possibility of intermittent urinary tract issues. We tried working with our neurologists over this concern, but since this was out of their expertise area, no help was given in this regard. We tried other medical avenues, to no avail. We felt there was a urinary tract issue, an issue that was partly causing seizures for our daughter.

I tell you all of this because in the end it was determined that our daughter was having serious urinary tract problems throughout this time, which was in fact instigating seizures. In our daughter's case, her ureter (the pipe that runs between the kidney and bladder) was kinked thereby not allowing urine to pass through properly to the bladder. This did cause some kidney damage as well. In the end, our daughter had surgery to repair the ureter.

How does this affect your child? What we came to learn is that not only was the urine not passing fully from the kidney to the bladder, but that our child upon elimination of urine, was not expelling all of her urine fully, otherwise known as a Neurogenic Bladder. Improper elimination is not an uncommon

feature in children with varying developmental issues. The child pees, but some pee remains in the bladder.

I liken it to a rain bucket: some rain water is present in the bottom of the bucket, and when it rains more water is added to the bucket. If you spill the bucket over and dump out most of the water, still some older rain water may remain on the bottom of the bucket. The process continues until the bottom of the bucket is filled with rancid, bacteria producing muck water. It's infected! Just the same as the child who does not fully and frequently eliminate. The urine in the bladder can become infected.

This was the case with our daughter. As an outcome, our daughter has now been put on a **DAILY DOSE of a small amount of antibiotic** to prohibit infection. In addition, we do catheterize her twice a day to assure complete urine removal. **THIS HAS SIGNIFICANTLY** improved not only her overall health but her seizure control!!

Please keep an eye on this with your child if you feel they are not fully eliminating. I always say that we have to control what goes in her and what comes out, and I quite literally mean it. In the end, it helps so much with her health and so much with her seizure control.

## **OVER-THE-COUNTER MEDICATIONS**

For optimal seizure control, this is an area to pay particular attention to. Some over-the-counter medications can lower the child's seizure threshold. For instance, we do not give our child Benadryl as we understand that it can lower her seizure threshold. There are likely other over-the-counter meds that may instigate seizure problems, so we recommend that before giving such meds that you check with your pharmacist and/or doctor.

Also, we do not give our daughter any over-the-counter medications that contain dyes. With Tylenol and/or Motrin, we purchase the dye-free forms. It is our opinion that the dyes can affect seizures detrimentally.

## **MEDICATIONS IN THE HOSPITAL**

We have had many hospital stays in the past 10 years, and have learned the hard way things to keep on top of while at the hospital.

First, if the hospital is giving Tylenol or Motrin to your child, you may want to ask them to only administer dye-free.

Secondly, and even more importantly, is that not all versions of a seizure medication are created equal. If your child is prescribed a **BRAND** medication, for example Lamictal, make 100% sure that if the hospital is administering seizure medications from their in-house pharmacy that they are giving your child **BRAND** Lamictal (again, using Lamictal as an example). In some cases, the hospital only provides generic forms of seizure medication. If your child is brand sensitive, as our child is, **BRING YOUR OWN MEDICATIONS TO THE HOSPITAL**. Clear your meds through the nurses and pharmacy, and make sure that they are only giving your child the medication you have provided.

Your child may be in the hospital due to increased seizure activity, and the goal of the parents and hospital is to help stop and/or find the cause of the current seizure activity. Doing everything possible to eliminate a variety of variables is important to this goal. Some children may have increased seizures by switching from brand to generic or visa-versa.

Additionally, if you are giving your child a medication(s) purchased from another country, make sure to have that medication with you at the hospital. Our child takes two similar medications that we purchase from Canada. They were just recently USA FDA approved.

**IMPORTANT:** although more cost-effective for us to purchase the USA FDA approved versions, we have learned that the medications are produced by different manufacturers in the US. Different manufactures can mean different chemical compounds or additives, which can alter the effectiveness of the medication. In our case, since the medications we purchase from Canada are working so well, we are not planning to purchase from the US manufacturer.

It's very important to pay close attention to the subtleties of varying yet similar drugs.

## **STRESS**

In our child's case, it appears that stress or negative emotion can potentially play a part in seizure activity. Changes in routine or any unusual flurry of activity not common in the household seems to upset our child's system and, in some cases, appears to induce seizure activity. As much as possible, you may want to remain consistent in household routines, consistent with medication dispensing and feedings, and try to keep as calm an environment as possible. In our case, it never fails that when we are planning a party or there's a big holiday event, our child tends to have more problems, even though we try to remain as consistent as possible with every other aspect of her care.

## **ANTI-SEIZURE MEDICATIONS & THERAPIES**

In treating chronic seizures (otherwise known as epilepsy), sometimes one medication is insufficient to fully control seizure activity. That is the case with our child, and I'm sure with many Ring14 children. Often over a long period, the doctors will try varying medications and/or combinations of medications in an attempt to reach optimal seizure control for the child. In our child's case, she is currently on two USA medications and two Canadian medications. This combination of medications is sometimes referred to as a "cocktail." It can take years to find the right cocktail for the child. Fortunately, as of this writing, the current group of anti-seizure medications our child is taking is working very well for her. Unfortunately, there are times when medications appear to be working well, but suddenly stop effectively treating the seizures. This is often when the neurologists will add or remove a medication.

It's always important to know of the medication's side effects. For example, one anti-seizure medication my child was on for about six months suddenly caused acute, life threatening problems. We recommend that you remain aware of potential side effects and note any significant changes with your child. Side effects of medication can include rashes, hives, and increased seizure activity, to name a few. Contact your neurologist with any unusual or alarming signs.

Always be sure to provide plenty of fluids to the child, especially with giving seizure and other medications, so as to fully flush and detox the child's body.

In treating seizures, at this point there are several methods that may be effective. In some cases, like that of our child, a combination of methods is employed:

- \* Anti-Seizure Medication**
- \* Diet (Ketogenic Diet)**
- \* Surgery, if the child is a good candidate, determined through EEGs and other testing**
- \* Vagal Nerve Stimulator**

Our child is on a combination of anti-seizure medications and has a Vagal Nerve Stimulator.

## **VAGAL NERVE STIMULATOR**

In our opinion, a miraculous device for help with seizure control. The Vagal Nerve Stimulator, otherwise known as the VNS, is a small device implanted in the upper portion of the child's chest, and has leads attached to it that are then wrapped around the vagus nerve. The surgery is performed by a Neurosurgeon, but does not involve accessing the brain. The vagus nerve is a long nerve that begins in the brainstem, which is the lower part of the brain, and navigates to the neck, chest and part of the abdomen.

Once the VNS surgery is complete, the neurologist will program the device to intermittently provide stimulation to the vagus nerve at specific strengths and frequencies. Over time, the neurologist, using a handheld electronic wand and laptop, may adjust the VNS settings to achieve optimal performance for the child. The VNS provides stimulation or discharges to the nerve in an attempt to halt any seizure inducing brain activity. Your neurologist will check the battery and settings of the VNS at each appointment to assure it's in good working condition.

Should a seizure occur, the parents/caregivers are provided a strong magnet that is used to swipe over the skin at the location of the VNS implant. This turns the device on and dispenses a discharge to the vagal nerve at a stronger intensity in an attempt to stop the seizure in progress.

Our daughter is now on her second VNS. She had the first for about 6 years, and as regularly observed by the neurologist, the battery life was waning, so a new battery or VNS was implanted. Before our daughter had the VNS, we often had to use rectal Diastat to stop seizures. Since our child received the VNS, we have not had to use Diastat at all. We do, however, always have a current prescription of Diastat on hand, just in case.

We always have the VNS magnet with us, no matter where we go. We keep it near the bed at sleep time and take with us whenever we leave the home. If our child is outside, the VNS magnet is with us outside. We have it with us at all times as a precautionary measure.

If you are interested in learning more about the VNS and if it would be beneficial for your child, check with your neurologist. As parents, we highly recommend it.

### **SEIZURE CALENDAR**

A number of years back, we started keeping a seizure calendar (seizure log) for our child. This was originally recommended by Chloe's neurologist, and has proven to be quite helpful. We use a standard monthly calendar and jot down the times and dates of each seizure. We also indicate any potential reason for the seizure (e.g. illness, irregular bowel movements, stress, heat, etc.). This way the child's seizure activity can be easily tracked and reported to his/her doctor. Using this method, potential trends (e.g. irregular bowel movements, dehydration, etc.) may become more evident, and the parent/caregiver may be able to make appropriate changes.

As I said, we use a standard calendar, but there are plenty of nice seizure calendars that you can get off the web by simply googling "seizure calendar." One nice one is "seizure tracker.com."

### **VIDEO TAPING SEIZURE ACTIVITY**

We have not done this with our daughter, but one of our neurologists did mention it in the past, and we do think it is a good idea. If your child is having frequent or unusual seizure activity, videotaping the seizures and replaying for your child's neurologist may help the doctor more appropriately treat the seizures.

## **OXYGEN**

For some seizure patients, oxygen may be required if they either stop breathing or their breathing rate deteriorates during a seizure. In our child's case, she does stop breathing to a degree and her coloring changes (bluish) during a seizure. Since she has the VNS, we first swipe the VNS with the magnet and then immediately administer oxygen.

If it appears that your child may need oxygen during or after a seizure, get with your neurologist and have them prescribe. The doctor can also provide a Pulse Oximeter for in-home use so that the parent/caregiver can monitor the child's oxygen saturation.

We have a company that actually delivers oxygen to our home, and has also delivered it to varying sites in the US when we have been on vacation.

We have found that for our child administering the oxygen during the seizure and keeping the oxygen flow on for a period of time after a seizure is best for her. It re-oxygenates her system and, we think, aids in her recovery.

## **AS YOUR CHILD GROWS**

With the VNS and G-tubes, it's important to note that as your child grows taller, the VNS and G-tube need to be regularly monitored by your child's doctors. The leads on the VNS may not be long enough as the child grows, and it's my understanding that growth has an effect on G-tubes.

Also, as your child gets taller and heavier, modifications around the home or car may be necessary, as well as larger mobility equipment. When we purchased our farmhouse when our child was 2 years old, we never dreamed that stairs may be a problem down the road. Now, at age 10, we have just installed a stair lift.

## VACCINATIONS

I bring this topic up only to trigger thought in parents. Your pediatrician has a schedule of vaccinations for children at each stage of growth/age. I am not advocating for or against vaccinations. I suggest though that parents read through all of the material around each of the vaccinations, particularly regarding side effects, and weigh the pros and cons. Also, you may want to more closely evaluate the vaccination schedule to assure that it is appropriate for your child.

In our case, our child has most of her vaccinations, with the exception of one. I will admit, though, that early on I do not feel that we paid close enough attention to side effects and schedule. At this stage, we do more closely evaluate. Again, this topic is simply brought up to raise parent's awareness.

## HEALTH INDICATORS

There are a few simple, yet important health indicators to remain aware of with our children:

- \* Fingernails ~~ often good indicators of overall health ~ deep nail ridges may indicate lack of nutrients. Curved, spotty, pitted, and yellow nails are also indicators of health issues.
  
- \* Hair ~~ dry, scaly, limp, and thinning hair can be signals of poor health elsewhere in the body.
  
- \* Dental Health ~~ since many of our children have limited or no speech, dental health is even more important. If the child has a painful cavity, they may not be able to adequately convey to you. Brush at least two times daily. We use Tom's toothpaste with our daughter because it is natural. Twice yearly dental check-ups are needed. Gums and tongues are also health indicators.

## **PUBERTY**

Puberty is another issue for our children. We have not yet had to tackle this area as our daughter is still a little too young. Much of the information here comes from Sheila Ferguson, mother to Brooke (age 20). In female children, going through puberty not only means that they are going to have acne, maturing bodies or mood swings, but it can also mean an increase in seizure activity. Even if the child's seizures are well controlled, because of hormonal imbalances, increases in seizure activity can occur. Confer with your neurologist about medication adjustments during puberty. Increased seizure activity may occur in male children as well, though it's possible that puberty may potentially decrease seizure activity in boys.

As far as menstruation, we all know that our kids are unable to keep themselves clean and dry, so hygiene is a big issue during this time. You may elect to place your child on birth control pills to decrease the amount of flow and number of days; however, in Sheila's experience, these pills only heightened her child's mood swings and caused anxiety. According to Sheila, Depo-Provera can cause osteoporosis, and she DOES NOT recommend. Given osteopenia/osteoporosis concerns for some Ring 14 children, there needs to be very careful consideration before anything that can cause further bone deterioration is given to the child.

Two other methods of stopping menstruation are endometrial ablation and hysterectomy. A hysterectomy is a more invasive procedure, so the endometrial ablation, which is less invasive, provides a valuable alternative. For intellectually disabled women with inadequate menstrual hygiene, unresponsive to other medical therapy, you may want to consider either one of these as the surgical treatments.

As always, the best thing for one child (adult) may not be the best for another, so always confer with the proper professional (OBGYN) to determine what is medically, ethically and mentally best for your child and their quality of life.

## TYPE OF PHYSICIANS

Your child may need to see the following types of physicians:

\* **Pediatrician**

\* **Diagnostic Pediatrician** -- We highly recommend having a diagnostic pediatrician or diagnostic pediatrician practice involved in a Ring 14 child's case, especially for difficult to diagnose conditions. In our case, it was the diagnostic pediatricians who were able to confer with specialists in a variety of areas to finally determine that our child had urinary/kidney problems as well as the need for feeding tube placement. We have found that the specialists, for the most part, are predominately concerned with their expertise area. Diagnostic pediatricians are able to coordinate the efforts of many specialties to determine and remedy health problems with the child.

\* **Physiologist** -- Specialist in physical therapy, among other areas

\* **Psychologist** -- May be able to help with wrap-around or other services

\* **Neurologist** -- Specialist who deals with seizures or other brain issues

\* **Neurosurgeon** -- Brain surgeons -- Responsible for VNS surgery

\* **Immunologist** -- Specialist who deals with disease immunity

\* **Urologist** -- A surgeon who deals with function of kidney, urinary tract, and genital structures

\* **Nephrologist** -- Specialist who deals with kidney and urinary tract issues

\* **Cardiologist** -- Specialist who deals with heart-related issues

\* **Pulmonologist** -- Specialist who deals with respiratory/lung issues

\* **Gastroenterologist** -- Specialist who deals with the digestive tract

\* **Orthopedist** -- A surgeon who specializes in bone and skeleton problems

\* **ENT** -- Ears, nose, throat specialist

\* **Ophthalmologist** -- Specialist who deals with visual pathway, including eyes and brain

\* **Dentist**

## **Other Medical Issues Related to Ring 14 Children**

Aside from seizures, there are other areas of health that may need to be tended to for your child. Many Ring 14 children suffer with significant respiratory issues. In our case, our child has not had significant issues so I cannot speak to this.

**VISION:** Some Ring 14 children have retinal pigmentation which may present early in the child's life. Vision problems can occur and may be significant. See an ophthalmologist early in the child's life. Other eye issues can develop overtime. Regular screenings are advised.

**HEARING:** Our child has had several hearing screenings, beginning at an early age. Her hearing is fine; however, you may want to check with your pediatrician concerning a hearing test. Given that speech delay is often a common Ring 14 trait, doctors may want to assure that there are no hearing problems.

**MOBILITY/FINE MOTOR/SPEECH:** Delays and problems with all three of these areas is not uncommon for Ring 14 children. Our child is now 10 ½ and really does not have much speech at this point. Mobility is an issue for many Ring 14 children and varies. There can also be fine motor issues. If your child is under 3 years old, you may have an Early Intervention program in your city/state that can provide therapy to your child. Some schools also provide therapy. If you feel these are areas of concern, get with your pediatrician for help with assessing and obtaining therapy.

### **MOBILITY:**

Ring14 children learn to walk very slowly and may require infant Early Intervention in order to strengthen and expedite crawling and walking. Some Ring14 children have even more difficulty in this area and may require assistive devices, such as walkers and long term physical therapy to aid in mobility. Some of our children begin to walk on their tiptoes. If your child is tiptoe walking, notify your Pediatrician so that appropriate therapies can be arranged.

Mobility issues vary. Some children are able to walk, jump, climb steps, and ride bicycles, while others have more difficulty in this area. If your child

requires assistance, your Pediatrician may recommend that your child see a Physiatrist, a physical therapy doctor.

In some cases, Ring14 children may have foot or heel cord problems, potentially requiring orthopedic devices or possibly heel surgery. Among other factors, this can occur when there is limited mobility or an unusual gait. Again, a Physiatrist can best recommend the right course of action. The Physiatrist will also monitor any back issues, including potential scoliosis.

### **FINE MOTOR:**

Some Ring14 children have sensory issues. This varies from child-to-child. If you are seeing repetitive, harmful, or other sensory problems, consult an Occupational Therapist. OT's employ varying techniques, but one is called "brushing." This can be quite beneficial for a child with sensory motor and even repetitive motion issues. OT's also assist in helping children master hand skills, as well as help with eating and swallowing issues.

### **SPEECH:**

Often the Ring14 children do have some understanding of speech, but many are unable to verbalize their needs. This can be very frustrating for them, showing itself in traits that appear somewhat autistic, such as aggressiveness, hyperactivity, behavioral problems, repetitive behaviors, and aloneness. Fortunately, many of our children have had success in learning to communicate in other ways, such as through the PECS system (a picture system), IPAD speech applications, and sign language. Most Ring14 children require very intensive speech therapy (20 hours/week) as they tend to learn more slowly. Check with your Pediatrician and/or school district to arrange therapy. Fortunately, a number of Ring14 children, even after having much seizure activity, do in time obtain some verbal speech.

## **ABA THERAPY**

Applied Behavioral Analysis, otherwise known as ABA, is a scientific approach to understanding behavior and how it's affected by the environment. Behavior analysis focuses on how learning takes place in the environment. Positive reinforcement is one of these principles. When a behavior is followed by some sort of reward, the behavior is more likely to be repeated.

ABA Therapy has been shown to help correct a number of behavioral problems, including aggressiveness and hyperactivity, and help teach communication and social skills.

This is a very intensive therapy, about 30/40 hours a week, that eventually tapers in weekly hours. Parents are taught ABA therapeutic approaches in order to reinforce in the home. ABA Therapy may be offered in your local school or special needs school, or you may be able to obtain through an outside agency. Check with your Pediatrician, your school district, and/or outside autism programs in your area.

## **DEVELOPMENTAL DELAY**

Development delay is unfortunately a common characteristic of Ring14. Learning language, reading, writing and other areas may prove very difficult. Our children require intense, repetitive instruction in most things in order to somewhat master. It is very important that the Ring14 child's environment be stimulating and engaging, with much interaction with the child by his/her teachers (parents, teachers, nurses, therapists, volunteers, siblings, extended family and friends). Repetition and reinforcement are key.

## ADVOCACY

For the most part, doctors and hospitals have the best of intention in treating a child. Keep in mind, though, that the doctors and other medical staff often have heavy patient loads and are pulled in many different directions. We have had loads of specialists and numerous hospital stays in the past 10 years with much great care. However, there have been occasions when some doctor's treatment plans either seemed unnecessary or inappropriate for our child. There have been many other occasions when we simply didn't quite know WHY the doctor wanted to do this or that test or procedure on our child.

It's so important to understand that we, the parents, are our child's voice. The doctors and medical staff work for YOU. Respectfully, ask questions. Make sure you fully understand and agree with a plan of care. If you are unsure, get more information. None of us want our child put through painful tests or procedures unnecessarily. If you disagree with a plan of care, you can ask for more clarification from the doctor, and you can deny the test or procedure if you strongly feel that it's not in your child's best interest. Naturally, we all want the least painful, least invasive treatment plan for our child.

We have had occasions where we initially did not agree with a procedure, but did come to learn, after further discussions with the doctors, that it was for the best for our child. In those cases, we have gone through with the procedures. There have been other times, when after careful consideration we completely disagreed with a plan of care and denied the test or procedure. There have been times when we have requested a different doctor if we felt the rounding hospital doctor was not the best doctor for our child. There have been times when the doctor's plan was the correct course of action, and there have been times when we, the parents, were correct in our decisions.

As in any profession, there are truly fabulous doctors and nurses, and then there are the mediocre. Number of years in a field is not always the best indicator of a truly fabulous doctor. Some may have many years, and some may have few. If you feel uncomfortable with a doctor or feel they are not a good fit for your child, you do have the right to ask for a different doctor. You do not need to settle for mediocre when it comes to your child's care.

In our case, our daughter has an outstanding neurologist. We recently learned that she is moving from our children's hospital to a neighboring state's hospital. We have chosen to retain her and see her in the neighboring state. There are other fine neurologists at our local children's hospital, but we feel that she is so exceptional, that we are willing to follow her.

For doctor's appointments or hospital stays, we advise that you have the following information with you:

- \* Medications your child is currently taking
- \* Allergies, including medication allergies
- \* Past surgeries
- \* Past hospitalizations
- \* Physicians following your child's care

If your child has had a hospital stay or test, you may also want to ask for a copy of any scan, test results, notes, etc. for your at-home medical records. Having your child's documentation at home may negate the need for obtaining medical records through the hospital's Medical Records Department.

In addition to advocacy in the medical setting, you may find yourself needing to advocate on your child's behalf in the educational setting as well. It's very important that you educate yourself with the "Individuals with Disabilities Education Act." Under the "Individuals with Disabilities Education Act" in the United States, an Individualized Education Plan (IEP) is required to meet the unique educational requirements for a child with a disability. Whether it is best for your child to be in a special school for disabilities, a regular public school or to even be home schooled, you have the right to help determine what is best for your child.

Parents are full members of the IEP team, along with teachers, therapists and school administrative personnel. An IEP will be written with the collaboration of all these people. You have the right to agree or disagree with the plan. Remember, you know your child better than anyone else, and

it is very important not to feel intimidated or forced into any plan for your child. Make sure you feel comfortable with the plan and the placement.

There are local and state agencies available to help you to learn the advocating process. You may want to contact them before your first IEP at which time they will train you how to advocate for your child. They are a great resource if things are not going as you think they should. Additionally, other parent of special needs children may be able to help you through the process and provide support.

### **OTHER FORMS OF THERAPY/SERVICES/INSURANCE**

There are other forms of therapy that may prove helpful to your child as well. Particular therapies we have used or are planning to use include:

- \* Aquatic ~ swimming (our child loves!)
- \* Dolphin Therapy ~ swimming with the dolphins
- \* Horseback Riding ~ riding can help regulate and calm the child as well as help with increased mobility and muscle usage
- \* Music Therapy ~ can be very calming and enjoyable and may even aid in speech formation
- \* ABA Therapy ~ Applied Behavioral Analysis techniques can be used to influence a behavior(s) ~ teaching and psychological techniques to modify behaviors and encourage functional skills ~~ commonly used with children on the Autism Spectrum

Additionally, some of our Ring 14 children may be labeled on the Spectrum of Autism Disorders. As of this writing, autism includes:

Autism  
Asperger Syndrome  
Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

In our child's case, she is qualified in our state to receive services with the PDD-NOS label. I define PDD-NOS as "I don't know what it is, but something's different." Though we didn't want our child labeled, she did receive many services through organizations that treat children with autism. For many years, she received "wrap-around" services both in our home and at a local facility. It really was beneficial because it provided even more stimulation and opportunities for her.

Currently the autism spectrum is being more closely scrutinized by the medical community and there may be changes in qualification.

As of now, though, your child may qualify for additional services through your state/local organizations. You may want to check with your pediatrician for help with researching services in your area.

Additionally, there may be other services within your state or local community that can provide opportunities and/or financial assistance for your child. Some organizations may help with both the financial and logistics of purchasing assistive or mobility equipment. Others may be helpful for people with development delays, providing both financial help and opportunities/education/outings. Some areas have wonderful camps or day programs.

Medications, hospitalizations, therapies, etc. can get very costly. Hopefully you have good insurance through your employer or self-employment. Note that insurance may also be available through your state system. Each state varies in terms of eligibility, costs, etc. You may want to check into your state insurance as an add-on to your personal insurance or as stand-alone insurance if you do not otherwise have medical insurance for your child.

## EVEN MORE TREATMENT TYPES

Concerning seizure control, I've always said that we would go to a voodoo witch doctor if we felt that would help our child. I'd say we've come close. It may sound a little kooky, but there are times when you'll try just about anything. I don't know if any of these methods are of interest to you, practical, or even particularly helpful, but I am putting them out there in the event that they may be of interest:

- \* Prayer ~ a personal choice, but one we believe in
- \* Church Healing Services ~ a personal choice, but we have been a part of many healing services
- \* Chiropractic's ~ some suggest that chiropractic's can effect seizures ~ we have not tried, so I cannot comment ~ if you choose to try, make sure you are with a top-notch Chiropractor, one that is well seasoned in working with epilepsy patients ~ you may want to **check with your child's pediatrician or neurologist before visiting a Chiropractor**
- \* Reike Energy Healing ~ Reike is the transfer of energy from the practitioner to the patient to help the body heal itself ~ we did for about a year and I think it was possibly helpful ~ our practitioner indicated problematic areas of our child's body at the time, and she seemed to be right on target
- \* Metaphysical-type Therapies ~ for instance, employing Edgar Casey methodologies ~ I'll be honest, we have tried his castor oil therapy ~ I honestly have no idea if it helped at all, but I don't rule out that it may have been beneficial
- \* Positive Mind Frame ~ whether true or not, we try to keep an upbeat, positive mindset in our belief that our emotions, feelings and energy have an effect on our child

## **TWO NEWER NON-USA, NON-FDA APPROVED SEIZURE CONTROL METHODS**

There are two additional forms of seizure control therapy being utilized internationally, not yet approved for use in the USA. I recall hearing about the first method a couple of years back as a treatment of Parkinson's disease and wondering if it would eventually be helpful in treating epilepsy. As of this writing, European studies have noted some good success in short-term seizure reduction, and even better success in longer-term seizure reduction. This therapy is called "Deep Brain Stimulation."

**DEEP BRAIN STIMULATION:** Deep brain stimulation is a device to reduce seizure frequency by sending electrical pulses, on a regular schedule, to the brain to help disrupt and prevent seizures. This therapy requires brain surgery in order to implant the device.

**RESPONSIVE CORTICAL STIMULATION:** Utilizing MRI and/or a PET scan, the surgeon locates one or two areas of the brain where seizures originate and the Responsive Cortical Stimulator is then implanted into the brain area. The device sends signals when it detects seizure activity, thereby disrupting and preventing seizure onset.

## **UNPROVEN MEDICAL TECHNIQUES**

When considering any new medical technique, always check with your trusted doctor first. We all hold out hope for a cure. Our belief is that one is coming, especially with all the research work going on with the Ring 14 Association in Italy. However, as of this writing, some of the potentially exciting, yet non-traditional methods are not yet safe or effective for our children (i.e., stem cell transplantation). The medical world is moving fast, faster each day, and wonderful medical breakthroughs are unfolding. We continue to hold on to this hope for our children.

## **SIBLINGS**

Having a special needs brother or sister can be challenging for our children. There are times when we parents need to attend to medical or other needs of our Ring14 child, leaving us unavailable to our other children. Typical siblings laugh, play, and argue as is common in any family, but if their brother or sister has special needs, the dynamics do change.

Because of this, The International Association Ring14 has initiated the project “TO BE SISTERS OR BROTHERS OF...” Visit <http://www.ring14.org> for more information on this vital project.

## **MORE INFORMATION ON RING 14**

**Ring14.org** ~ The International Association of Ring 14 in Italy ~ The home of Ring 14 studies

**Ring14usa.org** ~ Non-profit USA branch of Italy’s Ring 14 Association

**Rarechromo.org** ~ Based out of the UK, rare chromosome disorder support group

**Chromodisorder.org** ~ Known as CDO, Chromosome Disorder Outreach, supporting education, advocacy, outreach and support

## CONCLUSION

I hope this booklet leaves you hopeful. There are a number of studies and initiatives taking place to help Ring14 children, both in Europe (Italy) and the United States. There are new techniques, medications, and medical devices available or on the horizon that can prove to be helpful to seizure control in our children. The Association Ring 14 in Italy has developed a BioBank of blood from affected Ring14 children and their parents in order to better study the condition. Much work is taking place. I'm optimistic for a better, healthier future for my child and yours.

It can be very confusing, frustrating, exhausting, heartbreaking and difficult to navigate oneself through a condition that is so medically involved and one in which much is still unknown, especially if this is all brand new to the parent/caregiver. I hope that this booklet helps guide you through some of the challenges you may encounter and that some of the information provides relief for you and your child.

Enjoy and love your very special child. They are your gift and you are theirs.