

The "Sun" day Times

A Crigler-Najjar Family Newsletter

***Feel free to contact the Hiscock's via the internet anytime at hiscock@optonline.net or 19 Chipmunk Lane Norwalk, CT 06850**



Happy New Year From The Hiscocks

Over the past year, several new CNS families have gotten in touch with other families via the Internet. The Internet has been a valuable tool to communicate with others. In addition to parents communicating, afflicted children are corresponding with other children from different countries. Being such a small group, most families find comfort in talking to other families about this disease. If you do not have computer access, we hope this newsletter enlightens you with a bit of news, personal stories, and events in our special little circle.

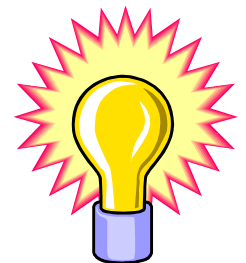
Fund Raising

Cory Mauck, of Kansas (CNS-2), began a whirlwind campaign to get a Crigler-Najjar Association up and running. This non-profit association has been set up under the Kingsway Foundation. The goal of the CNA is to raise money in hopes of finding a cure. In the immediate future, the CNA needs to design literature informing prospective donors about our cause. To raise sufficient funds, it will take effort from all CNS families. If you have questions about how you can help, you can contact Cory at mauckc@msn.com.



A Global Effort

We heard from a doctor in El Salvador who was treating an 8 month old boy with CNS. The boy had lived in the hospital since birth, as his family did not have a light for him at home. Floyd and Katie Martin made a light for Numan and Fed Ex picked up the shipping costs. People generously donated money to the Martins to help pay for the materials. Thank you to all who were involved.



F.Y.I.

Light Bulbs

Katie Martin conducted an informal study of the light intensity of name brand bulbs versus generic bulbs using a light intensity meter. She found that name brand bulbs (Philips) were more intense and lasted longer than generic (Interlectric) bulbs.



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A WORD FROM THE PAST



A Meeting Place

Eight CNS families attended the annual auction for the Clinic for Special Children in Strasburg, PA. A total of twelve CNS patients attended this auction, which is held every September.

I just recently decided to look up Crigler-najjar on the web to see what I could find; and to my surprise, I found several articles and a couple of newsletters from families who have children with Crigler-najjar. I found this intriguing, especially the pictures, because my son, Scott, who was born in 1968, also had the enzyme deficiency. To my knowledge, he was the FIRST baby with the syndrome to use the phototherapy for management of the disease. I always considered him a pioneer in the field. He was born in California, diagnosed at

Children's hospital in LA; and that is where he was first put under the lights. In the beginning, it was simply regular fluorescent bulbs. We got him out of the hospital when he was six weeks old (on Christmas eve). He used a bank of four fluorescent bulbs for quite a while. Later, as more research was done, he ended up with "special blue" lights. As he grew, the time he spent under the lights increased. (As a teenager, it became difficult for us to get him to cooperate.) By the time he was 18, he was sleeping under a bank of 12 lights. He did receive a liver transplant when he was 18 years old. There have been a few complications with regard to his life after transplant; but basically, he has done very well. He is now 33 years of age. He went on to marry and have a son, but is now divorced and maintains custody of his 7 year old son. I have a great deal more I could share with anyone who might be interested, but for now, I'll say so-long.

Recipe for Crigler-Najjar Syndrome

by Miriam Martin

- 10 cups sunshine
- 9 c. phototherapy
- 7 c. needle pricks
- 4 ½ c. doctors visits
- 1/3 c. surgeries
- 2 c. pills
- ¼ c. ultrasounds



Combine the above ingredients with tons of love and understanding. Slowly add peace and acceptance. Please omit blankets, nighties, and bitterness.

(John & Miriam have 3 CNS children).

Ruth Churchman



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A YELLOW RAISIN IN THE SUN

I read the book *God's Golden Children* with great interest. Many of the personal stories sounded exactly like my own. For so many years I was so alone.

Some of the stories talked of teasing and made me cry, it brought up old memories. I learned to set aside my hurt feelings with humor. I cried for these kids because I knew how they felt, the words could have come out of my own mouth.

I am now 40. I never expected to live this long, but I was saying that at 16 and then 21. At 3 months of age my mother took me to Denver Children's Hospital, my bilirubin was 50 and the doctors did not know what to do. They told my mom that she needed to prepare for my death, as I would die before I reached 6 months and the only other option was exploratory surgery and possibly a liver transplant, which was about 50 % successful. They also added that there was a high chance that I was already mentally damaged (some think that I am) due to high bili levels and that she needed to accept this fact. The baby in the bed next to mine died. So she took me home to die. "I could watch you die at home easier than I could in a hospital where the other babies were dying." From an early age my mom prepared me for death by relating what she had been told, first that I would die within the 1st 6 months and then later before I turned 6 years old. So not knowing what was wrong with me, I expected to drop off any time along the way before 18, maybe in my sleep.

My mom withdrew from me to protect herself, my younger sister told me this just recently. Mom does not know that I know this. It explained why I always felt weird at home, like maybe I was adopted? We never got along very well. Not to mention I was extremely ornery.

When I had not died by 23 and had found a young lady who was interested in marriage, I thought I should find out why I was still alive and what I was afflicted with. The various physicians that I saw were uninterested or just clueless. I went to Oklahoma Teaching Hospital, where a group of doctors agreed to submit my case before their specialist board. 20 specialists came up with, "Well it's not hepatitis." I found a liver teaching book written by Sheila Sherlock, and went about eliminating my disease one by one. The only one left was Crigler-Najjar, which stated that type 2 was responsive to Phenobarbital. When my bili levels dropped from 17-25 down to 7-9 using

Phenobarbital 30 mg twice a day, the board agreed that I had CNS Type 2.

Phenobarbital gave me an attitude problem, so after 5 years or so I quit taking it. Several years later, I found an internist who agreed to try some other meds. In my charts he wrote that I was well read and knew more about the liver than he did, which is doubtful. I tried some medicine made from bear bilirubin, which caused higher levels, then Rifampin, an antibiotic mostly used on Tuberculosis. Rifampin produced the same results as the Phenobarbital, so I have been on it about 5 years.

Fatigue is always a problem and at times I am really itchy, but otherwise I just am happy to be alive, enjoying my family, a wife and 3 kids; Chelsey 16, Lindsey 15 and Jordan 13. All appear to be CNS free. Trish and I went through adoption classes last year to qualify to adopt 2 little kids, but they were finally placed with their foster family. I work as a Product Support Engineer and coach 2 soccer teams every year.

One bit of advice for those who are fatigued and feel like staying in bed all day (as I myself feel) Get up and get busy, do something for someone else, live life to its fullest. The older I get the harder it seems to be to stay motivated, but it sure beats being depressed and non-productive.

So now you know a little bit about me. Did I mention that I grew up in South Africa? More about that in the next newsletter! May God Bless you all and keep looking for a cure!

I am starting an organization called the Crigler-Najjar Association to raise money for a cure for CNS1 in America. Get involved. You can email me at mauckc@msn.com for more information.

Cory Mauck