

# CNS Family Newsletter

Second Edition

November 05, 2001

## Greetings

Hello once again! It seems that the first issue of the CNS Family Newsletter was a big hit around the world. We have been flooded with e-mails and letters of new CNS folks wanting to share their experiences and to find out more about living with CNS. We will continue to publish this newsletter, so please continue to write and send articles.

Kathleen, Timothy, & Thomas Hiscock



## In the News

The Sunday News in Lancaster, PA recently published an article about the annual auction for the Clinic for Special Children.

Ric Devere and his family enjoyed a trip to Hawaii compliments of Dreams Come True. Mark Burnell, a Jacksonville Jaguar quaterback, sponsored this wish to Ric, who who has CNS.

Maria Louisa Lujan, of New Mexico, underwent a successful partial liver transplant in April in Nebraska. Maria is doing well and enjoying her new life with pajamas and **no lights!**

## Read all about it

*God's Golden Children*, a collection of stories and experiences of CNS patients, will be available at the beginning of the year. A big **THANK YOU** to **Katie Martin** for initiating and organizing this project. You will receive an e-mail or a circle letter as to where and how to purchase the book.

We currently have **58** CNS patients on our mailing list or correspond with via e-mail. The youngest is 2 weeks old and the oldest is 51 years old.



## Past Events

On September 15, 2001 the Clinic for Special Children held its annual auction. Several CNS families from around the country attended and had dinner at Yoder's with Dr. Michael Blaese of Valigen.

## In Their Own Words

### **Dawn's Gall Bladder Surgery**

Dawn age two, four weeks away from her third birthday, had entered Lancaster General Hospital at 3:00 p.m. to be put on an I.V. for the night and to have blood work done. Her bilirubin level was 14 and her albumin was 3.8. The day of surgery was February 10, 1998. She wasn't to eat anything that morning, and by 12:30 P.M., she was taken to the pre-op room. She surprised us by riding down on a bed; she was really brave!

The anesthesiologist came to give her medication and a fuzzy worm named "INCH" to take into surgery. After a while, she started to get tired and she giggled and giggled from the anesthesia. It was rather funny, but it made it easier for us parents to see her go through the doors laughing, rather than crying for us.

We waited in the waiting room for one long hour! We anxiously waited until they wheeled her out of the O.R. She looked like she was sleeping peacefully. She woke up a bit later and we moved her back into her room. She had to go potty, which was a chore to get her to sit, so most of it went on the floor. She slept for another two hours, then her anesthesia wore off.

At 5:00, her grandparents came in to visit. She opened cards and she showed them the light switch, since it was different from her light at home. Grandpa fed her chicken corn soup and Jello, although it didn't all stay down.

After her guests left, she was bored and wanted out! We put her in a wagon and we pulled her up and down the hall. In the playroom, she wanted a book, so she started climbing the bookshelf! This was just four hours after her surgery!

We were afraid she would over do it, so we entertained her by opening gifts and by coloring. When Doctor Morton and Doctor Jarwenko, the surgeon, came in, they were amazed at how well she looked. We were told she might be able to go home in the morning.

She had no fever, so the next morning at noon, Dawn was discharged. She had gotten some balloons and proudly carried them out to the van. When she got home, she was happy to show anyone her three little bandages on her belly; the only telltale sign of surgery. We were very relieved to have everything go so smoothly.

Dawn's brother, Eric, who is three, had an ultrasound last spring, and his gall bladder was fine. At the time I wrote this, Joyce, age two and a half, has not had an ultrasound yet, but she will have one in the fall, as she complains of stomach pains, but so does Eric???

Best wishes to CNS families,

John, Miriam, Dawn, Eric, and Joyce Martin

## In Their Own Words (cont.)

### CNS Research in Holland

Research is the one thing we we'll always need with this disease. That is why, after years of talking, there is finally a research program in The Netherlands. This program exists of four visits to the hospital within one year. Each day the patient will be submitted to a diversity of tests. The idea behind these tests is that they, the doctors, want to know in what way Crigler Najjar affects normal life. How does it affect the brain, if it indeed does. How do the patients get along with other "normal" children? How is their memory and concentration? Are they just as smart as "normal" children? For short: How does Crigler Najjar affect a patients normal daily life? I am going for the second round of tests on the 8th of November. It is very tiring. The first time they did an EEG, a hand-eye coordination test, a psychology test (which mostly consisted of word-knowlegde and mathematical insight). This time I am up for an MRI, another psychology test (no idea what it will be, but that part was a kind of fun to do) and a physical examination. It will probably take a whole day again. As I understand it, all Dutch patients will be doing these tests. The doctors hope to get a global idea of what it is like to live with Crigler Najjar and how it affects the patients. There will be a document made up to help others, and the current patients in the future. Maybe the next time they do test like these, they could include the parents as well.

Take care,  
Gabriëlla Kraaiveld



### Prayer in My Pocket

By Ken Burns

There's a prayer here in my pocket;  
I carry it every day.  
God takes time to listen when I take time to pray:  
"Dear Lord, Please give me courage and strength  
to walk alone, so I may turn each stumbling block into a stepping stone."

Submitted by Amy Martin  
age 9 grade 4 CNS 1



## Recent Births

Katie and Floyd Martin welcomed a healthy boy, Matthew, on June 4, 2001.

Jonas and Annie Fisher of Pennsylvania welcomed Henry on Oct. 31, 2001. Henry has CNS.

Best wishes to both families!

## Helpful Hints

### Light Bulbs

Dauphin Electric carries the Philips bulbs for your phototherapy unit. They have the 2-foot F20T12-BB and the 4-foot F40BB bulbs. Find them on the web at [www.Dauphinelectric.com](http://www.Dauphinelectric.com). For prices, email [rherb@dauphinelectric.com](mailto:rherb@dauphinelectric.com). Their phone number is 570-523-3232. Their fax number is 570-524-4280.

Joe Shrock can order phototherapy lightbulbs at a good price. You can contact him at: 11481 S. Stensen Rd. Augusta, WI 54722



## A Note From Us

We can be contacted via e-mail at [\*\*hiscock@optonline.net\*\*](mailto:hiscock@optonline.net).

Many CNS families have been corresponding through the CNS active e-mail message list.

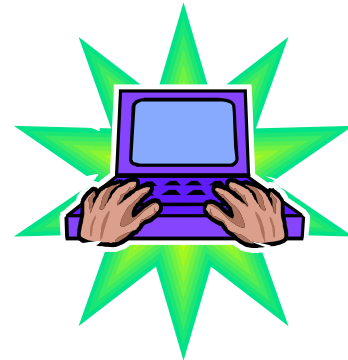
To subscribe: [www.criglernajjar-subscribe@yahoo.com](http://www.criglernajjar-subscribe@yahoo.com)

To post a message: [www.criglernajjar@yahoo.com](http://www.criglernajjar@yahoo.com).

Other popular CNS websites are:

<http://it.geocities.com/criglernajjar/tre.htm>

[www.crigler-najjar.com](http://www.crigler-najjar.com)



If you receive our newsletter through the mail, but you have an e-mail address, please send us that address because it is quicker and more convenient to e-mail the newsletter to you. Current newsletters will also be displayed on [www.crigler-najjar.com](http://www.crigler-najjar.com).

**\*\*This newsletter does not provide medical advice. Contact your health care provider before making any treatment changes.**