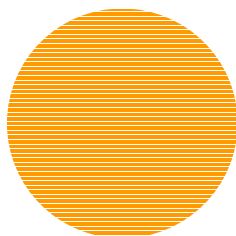


Newsletter Date May 2002
Volume 02, Issue 5

Noguts Country Club

Special Interest Articles:

- New Web Address
- Baby Brian
- Discussion Board



Individual Highlights:

Discussion	2
e-mails	2
Sponsors	2
New Story	5
Curdin	3

May2002 Newsletter
www.noguts.us

New address for the Country Club

We now have a new web address for the Noguts Country Club. For the past year we have had trouble trying to move the site to a new server, all we got was grief from Vera Sign, the keeper of the URL's.

We found that NOGUTS.US was open and available so we, with the help of our sponsors, trusting in the Lord, and some kind people that have made donations to the site, we took the plunge and registered it.

The move will cost us about \$150.00 upfront, but we think it will be worth it as we will be able to put the discussion board back on the site.

In case you are wondering the US is the designation for web sites in the United States, but I prefer to think of it as a collective "US", "NOGUTS US" tells it all.

We will still have the .com site for a while but it will be phased out over the next year. Later in the newsletter I will give a list of new e-mail address that should be used to contact me. If you could make the changes in your address book (if you have me in yours) I would appreciate it. The e-mail on the .com site will only be working for about 6 months.

BABY BRIAN

We have posted Baby Brian's picture and story on the [web site](#). We received quite a few e-mails and each was forwarded to Brian's Mom and Dad.

We want to thank each one of you that took the time to write.

We have received an e-mail with an up date on Brian and

you will find it posted later in this newsletter.

We also have an e-mail from Stefan posted, so if any of you can help him it would be appreciated.

Thanks again to all that taken the time to help others.



Don't forget you must send for a user name and password in order to use the Discussion Board. There is no charge.

Noguts Country Club Discussion Group

We now have a Discussion Group on line at noguts.us. You may post your questions and maybe answer some that are already there.

We have made one change in the way you post. Due to the fact we lost two of the previous boards to people that only wanted to spam with everything from porno to a scheme to take your money, we have a sign up procedure that requires a user and password.

There is no charge for either and all you have to do is send me a blank e-mail to password@noguts.us ,

Be sure to put the word "password" in the subject line.

This must be sent from your working e-mail address in order for me to return your user name and password.

We hope this will help keep down the spam.

E-Mails and why I cannot use the Phone

I have received several e-mails asking me to talk to people with SBS on the phone. Let me explain why I cannot.


First I am not a Doctor. If I should inadvertently say something that worked for me, and the other person tried it, they may have a reaction that would make their condition worse.

As an example, I cannot drink water as it gives me a very bad case of gas. I drink a generic

"cola". If a person that was borderline diabetic and they tried it, it is possible for them to go into shock. I would then be responsible.

It is for this reason I do not use the phone, and I never give specific advice except to check with your doctor. With e-mail I have a record of what I said and if there ever should be a question I can produce it.

Hope this answers the question.



"I am not a Doctor, I am just a person with Extreme SBS"

**No Gate
Country Club**

Thanks to these Sponsors

We want to thank these people that have helped to make noguts.us and noguts.com possible.

Mary Beth	Pete
Frank	Beverlee
Bill	Jim S



We had a late e-mail from Stefan.

I know there is someone out there that can help with some information. If you can help Stefan's address is Stefan Zumbrunn sz@zuhlke.com
My son's Name is Curdin. He was diagnosed Hirschsprung with approx 5 day's. Unfortunately Curdin had long-segment Hirschsprung - about 30cm of his small bowel has been removed too. He got a pull through operation with 10 days. Since then he is developing fine but he needs TPN. The doctors to not have a great experience with this severe form of Hirschsprung, therefore and also since every child develops differently, they can

give us no estimation about the future.

I'd like to here about babies with a similar form of Hirschsprung and their progress.

Fortunately Curdin was 3.5kg when born and already has 3.9kg. His stool is also already quite solid and only slightly greenish. This all looks like good progress - but we still do not now for how long he will need the TPN and how complicated it would be to take him home while he still needs the TPN.

I guess, that are the important facts about Curdin.

Thanks a lot for your support Stefan

*Is there someone that is able to help Stefan and Curdin.
I know nothing about Hirschsprung.*

More on the New Website

I am asking for your help in finding information and Links to post on the web site.

If you find something, or know of something that should be posted please let me know.

There is a feedback form on the web site that will come to me. I am trying to use forms instead of e-mail address, as I do not get as much spam with forms.

Last week I had over 400 e-mails and about 150 of them were spam, so if you could use

the feedback form I would appreciate it.

I now have the space to post your personal stories.

When you write them, if you will do it in a notepad it will make it faster transferring it to the templates. When it is written in a word processor, I have to type it over. If you want to use a word processor please save the file as text with no line breaks or formatting and I can do a direct cut and paste.



Don't Forget The New Addresses

On the <http://www.noguts.us> site you will find e-mail address.

Because of the amount of spam e-mail we are getting we are setting up filters in the mail handler.

You will notice that when you click on an e-mail link, it will put a subject in for you. If that subject is not in the proper place the mail is directed to another mailbox and it may be sometime before we get to it.

Thanks to three of our sponsors the mail server is doing great, and this next week will give it a final test and workout.

One thing to remember. DO NOT send an attachment, unless you use the address attachment@noguts.us, with the subject attachment.

Most of the Virus in e-mail is an exe

file and one mailbox is set to catch ALL ATTACHMENTS and do a scan. If the word attachment is not in the subject it will be deleted.

If you send everything in plain text it should be ok.

I am sorry to do this, but I cannot afford another crash of the computers.

I have had three crashes because of a virus opening in an HTML file with an attachment

The way it is now set up we will be sending the newsletter in a PDF file and it should open in any version of the Adobe reader.

All the newsletters are scanned and then converted to PDF to make sure they are safe.



“Remember: all attachments send to: attachment@noguts.us with Attachment in the subject line.”

STORIES

One of the things that stand out in almost every letter I get is that everyone enjoys the stories and how each and everyone is able to cope with SBS, TPN, and the other problems in this life.

I have a number of letters that are asking about ostomy, I cannot answer them, as I do not have one, I am reconnected even though it is only 12 inches active intestine.

If any of you have an ostomy and could write about how you cope and what you do to make your daily life easier, we would like to hear from you.

One person was writing for help as he was having problems going out to dinner.

I also get a lot of letters about TPN. If any of you are on TPN I would appreciate some stories about how you plan your treatment and day.



“We now have room for more stories about you and how you cope with SBS.”



Brian's Update

Sorry I haven't had a chance to update everyone what is going on with my son, Brian Jr. On April 29th, Brian went back into surgery (# 4) to be reconnected. When they were in, they discovered Brian had 36cm of small bowel left, instead of 28cm, which is amazing to us!!!!!! Well now, yesterday, May 10, Brian went in for surgery #5, not a major surgery, but still another.

Brian had a broviac put in him and had a circumcision. As of right now, Brian is not feeding orally he is still on TPM. Oh yea, he also got a Gtube put in, so they can put him on a slow continuous drip!! Starting Monday, May 13th, they are going to start feeds. So we pray to GOD, we can get a balance going. Oh yea, we got Brian's direct liver scores. At one time they were all the way up to 8.3, and now it is at

2.3. So every Friday that shows us that, his liver is getting better, not getting worse. Which was my major concern. I was so scared hearing about all the babies that did NOT make it, because TPM destroys the liver. And they would die of liver failure. That is still something I have to worry about, but for the time being everything seems to be working for Brian, instead of against. Well that's about all for now.

Talk to everyone soon!

Jeanette & Brian (senior)
Brian Jr. is now 2 months and 6 days

Brian's update

One of the new Stories

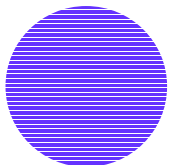
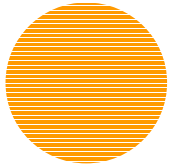
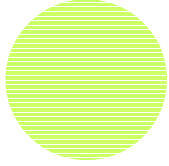
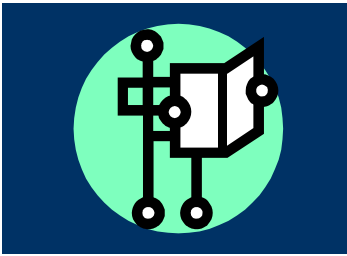
My daughter, Chelsea, was born at 26 weeks and weighed 1 pound, and was 11 3/4" long. She had NEC and had surgery at 1 month old. They removed her large intestine and she currently has 30% of her small. She has had numerous surgeries, to many to count. The last one was when she was 3 1/2. She had obstructed bowel. They were going to do a procedure called the Bianca (spelling??) where they divide the intestines in half and then connect them to make them longer. They said that was not necessary. She has had numerous hospital, approx 50, stays since that time for dehydration, central line infections, g-tube problems. She will be eight in July, and currently weighs 30 lbs and is 42" tall. The doctors are now exploring the growth hormone route to see if it will help her get on

the growth chart. She is a very happy go lucky child, very smart, and has no problems with controlling her bowel. She just has to go a lot. She now has no button and takes all food by mouth. She drinks Peptamen Jr every day and I let her eat what ever she wants. She will catch up on her own time. I'm just glad she is here. So what if she can wear some 6-12 months clothes. She just stays smaller longer.
She will catch up.

Lisa - Mom



*"A NEW STORY
FOR NOGUTS.US
PERSONAL
STORYS."*



We're on the Web!

See us at:

www.noguts.us

WHO WE ARE

Hi and welcome to The No Guts Country Club. My name is Jim Combs, just so you will know I am a real person. Let me say up front that I am not a Doctor. Every thing I say is from my experience in the last ten years with **Short Bowel Syndrome**, in fact I have what is called Extreme Short Bowel Syndrome. I have about 12 inches of active small intestine. I cannot give, nor do I want to give the impression that I am giving out medical advice (please read my **disclaimer**).

Our Purpose I n Life...

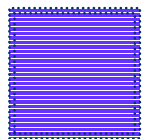
I have heard it said that God has something in this life for everyone to do. Maybe this is my work in life. I will have to admit that I would have preferred something to do that did not have as much pain attached to it. The No Guts Country Club is a place that everyone with Short Bowel Syndrome can call home. With the help of the Lord, I am trying to provide information, or the way to find information, on Short Bowel Syndrome. I have tried to provide something for everyone with

I believe there is no one, except The Lord, that is better than a good Doctor that you can talk to, and one that will listen and give you better answers. Keep in mind a good Doctor will tell you if he or she does not know the answer to your question. Now explore the No Guts Country Club and let me know what you think of it. If you are in a hurry you can click here and go to the Club:

<http://www.noguts.us>

SBS regardless of the cause; there is also information for friends and family. Some of the information listed in these pages is the work of years of searching for information on my part, and others have provided some of it, I pray that these pages will provide comfort, encouragement, and direction to those that find themselves suddenly at, what looks to be, the end of their world.

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TO: