

# KID'S CONNECTION



## BACK TO SCHOOL EDITION

### September is Chiari Awareness Month!

Chiari Awareness Month is all about helping others to understand Chiari. Send us a picture telling us what Chiari means to you! You could show us a painting you make about Chiari, a blanket, or anything else that tells us about it.

It's that time of the year! Summer is coming to an end, school supply shopping starts soon, and you have to get used to waking up early in the morning. Hopefully you are excited to start going back to school. You will have the chance to learn new things, see your friends every day, and start playing school sports. Going back to school is exciting, but it can also be stressful. Here are some tips for making the transition back to school easier:

- Start getting used to going to bed and waking up earlier a few weeks before school starts.
- Buy binders and folders of a different color for each class. This will make it faster to gather your supplies before school.
- Use a calendar or planner to keep track of all of your homework.
- Talk to your teacher about your class. Tell your teacher if you have trouble with a certain subject, like math, so they can help you understand it better.
- Make sure that all the medicines you need are in the nurse's office.
- Don't forget to pack your lunch or bring lunch money on the first day!

### Search for School Supplies

B G H Y T F D B W Q V E Z D C  
 K N W D O T F X T U T P D Q L  
 E L T L G G C N X V Y K K H A  
 Y R D B D R Q K W E R N F Z H  
 C E N B B Q C R Y X O V B Y P  
 R Q Y E P A B Q K F T J I Q U  
 Z O Z W P R A F R E A A A B P  
 A U X K P B Y M W R L L A B J  
 E V C C F E C W U A U U P B I  
 E A P T K X N X Q S C S H V U  
 B R E P A P W C G E L C A H A  
 M A R K E R S B I R A K L R Z  
 F M I T W Z Z T H L C U K Y O  
 P J J S D B R T D W D C H F R  
 Y P X G L Q L Q K R W E W K N

Backpack  
 Eraser  
 Markers  
 Pen

Calculator  
 Folder  
 Paper  
 Pencil

If you have any questions, ideas for the newsletter, or just want to chat, feel free to contact either of us!

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**We all have questions when we are going through surgery or feeling sick. I had the chance to meet with a Child Life Specialist named Heather Troyer about these questions. Her job is to make it easier to understand why you are sick, come up with fun things to do when you are sick, and help you and your friends to understand Chiari or Syringomyelia. If you have questions that weren't answered, please email me at [kidsclub2@asap.org](mailto:kidsclub2@asap.org), and I will try to get them answered for you.**

**Can you explain to me what Chiari Malformation and Syringomyelia are without making them sound so complicated?**

**Heather:** Chiari malformation is when the part of your brain that helps control balance is positioned lower than what it should be. It is sitting down by your spinal cord. Syringomyelia is an opening that is filled with fluid that forms in your spinal cord. Your spinal cord is what connects your brain to the nerves throughout the body.

**What happens during a Chiari surgery?**

**Heather:** A Chiari surgery is called a Chiari decompression. This helps to make more room for the part of the brain that is lower than it is supposed to be. There should be lots of room, and when there is a Chiari malformation things are squished. Surgery can help lessen headaches. After the patient is fast asleep using special medicine the doctor will make an opening at the back of the head to make more room for the brain. After that is done the doctor will put stitches in the head so it looks like it did before. After surgery the patient may have their head wrapped in a big band aid to help it heal better.

**How do I explain to my friends why I can't do some of the things that they can or why I don't feel well?**

**Heather:** You can tell your friends you had brain surgery on the part of the brain that helps with coordination. You may be a little sleepy and slower at first until your body gets back to normal. You may not feel well after surgery because of the medicine you have to take so you won't have as much pain.

**Who can help me when I miss school and have trouble with my homework?**

**Heather:** The school teachers are available while you are in the hospital to get your homework and help you. When you are home you can have a parent or friend bring your homework to you until you are able to return to school.

**Kaylee:** The school has ways of helping you. Ask your guidance counselor about a 504 plan, which sets up a plan for when you miss class or have trouble with homework for a long time. When you are sick many days a week, the school should give you a tutor, whose job is to explain and help you with your assignments.

**What should I tell my parents when they ask how I am feeling? Sometimes I don't want to tell people that my head or back hurts.**

**Heather:** When your parents ask how you are feeling be honest and tell the truth. Your parents want to help. They will be given instructions from the doctor that will tell them how to help you [and] can give you medicine when you are in pain. If you don't tell someone you are in pain it could get worse and you may have to be in the hospital longer.

**I'm afraid of doctors and hospitals. What can I do to not feel so scared when I have to go to one?**

**Heather:** To help you feel safe in the hospital you can bring a favorite toy, blanket, stuffed animal or pillow from home [or] your own pj's. Keep a notepad with your thoughts, feelings, and questions and be sure to share them with your nurse and doctor.

**What fun things can I do when I don't feel well?**

**Heather:** When you don't feel well you can listen to music or watch a movie until you feel like doing more activities. It is also good to sleep and [get] lots of rest.

**Are there any ideas or aides I can use to get through a school day?**

**Heather:** If you are having a hard time getting through a school day, be sure to tell your teacher right away. You may need to go to the nurse and lay down. Just remember to take it easy until your body is ready.

**Kaylee:** You can also ask your school if they have occupational therapists. Their jobs are to make school easier when you're sick.

**Sometimes people don't understand why I'm sick because I look fine on the outside. How do I explain it to them?**

**Heather:** You can tell people that your brain is in charge of controlling your whole body and your brain had to be worked on. So even though you look fine, your body is not as strong as others. It is nothing you or anyone else caused, it just happens sometimes.

**Sometimes I get really scared that I'm going to die, or something really bad is going to happen to me. How do I deal with those feelings?**

**Heather:** If you ever worry that you are going to die or something bad is going to happen, it is important to talk to [an] adult you trust. Holding in feelings may make you feel even worse.