



**Children and Adolescent
Cancer & Blood Diseases Center**

MARIA FABERI CHILDRENS HOSPITAL
WESTCHESTER MEDICAL CENTER
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Boston Children's Health Physicians
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Patient Family Advisory Council (PFAC) Newsletter

Fall 2018

*Pediatric Hematology, Oncology and Stem Cell Transplantation
Children and Adolescent Cancer and Blood Diseases Center*

The Patient and Family Advisory Council is a committee initiated in 2017 that partners family members with Division staff to identify ways to improve the patient experience and ensure family-centered care. Members of families both actively in treatment as well as those who have completed their therapies use their experiences to develop innovative processes and contribute to the Center's goal of providing state-of-the-art compassionate care.

If you have a desire to share your suggestions or experiences and participate in initiatives that will impact the lives of the families battling cancer and blood disorders, contact us today.

You do not need to be a PFAC member to share your input, however, we always welcome new applicants!



One Parent's Advice. . .

Success at School

My son Sean was diagnosed with ALL-Leukemia almost eight years ago. He was seven. He was in 1st grade. Initially, there were no real problems with school, remember, he was seven. But as Sean got older, school became more of an issue. His attendance was terrible. His retention was terrible. His handwriting was terrible. School was terrible.

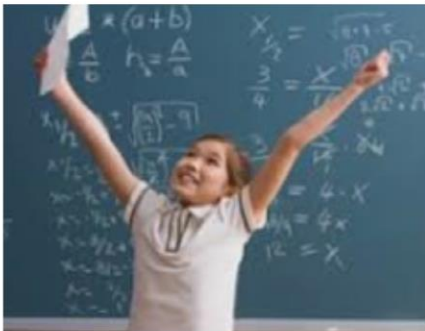


So here are some of the things that we did:

CONTACT YOUR LOCAL SCHOOL DISTRICT Because of his years of treatment, Sean missed a lot of school. If attendance becomes an issue, you are entitled to home instruction. Each district has its own policy regarding home instruction. They are paying for it after all. For example, Sean's district required a student to be absent 10 consecutive school days before a home tutor can be assigned. Other districts require even less - 5 consecutive days or even 2! Contact your district office to find out your district's policy.

SPECIAL EDUCATION OPTIONS Although Sean was tested for developmental delays / learning disabilities, he never qualified for an Individualized Education Plan (IEP). Sean did qualify for 504 - Other Health Impaired (OHI) which affords him extra time for assignments and state testing. He also is allowed to wear a hat in school, snack when necessary and miss gym due to fatigue. These accommodations seem like common sense but having them in writing is helpful. Start the process with your child's teacher or guidance counselor.

TUTORS Teenagers can tutor your child. Even when Sean returned to school full time, he needed help. Many high school students need community service hours and tutoring can be a great gig. Even if community hours are not on the table, teenagers are usually pretty desperate for money. We paid \$25/hour for one-on-one homework help at our home. A lot can be accomplished in an hour and honestly, it was the best money we spent.



Every service that Sean received required time and effort to get approved. Paperwork needed to be submitted along with medical documentation. Your social worker can assist with providing the proper required medical documentation. Remember you are your child's advocate and there are services out there to help your child succeed in school.

Psycho-Social Corner



Our psycho-social team is very excited to be a part of this Newsletter. We aim to present topics, reflections and resources that are useful to our patients and families. Since it's Fall, let's talk about Back To School! School is a significant part of a young person's life. It's where they learn the academic and social skills to succeed in life. As your children are either resuming home instruction or returning to school, keep in mind that we are here to help you get what your child needs to be successful

Here is information/resources we find most useful:

What is a 504 Plan? A 504 Plan is designed to provide supportive accommodations that will ensure your child's academic success and access to the learning environment. It may include use of extra time on tests, use of an elevator, etc. Services will be assigned by the Committee on Special Education (CSE).

What is an IEP? An Individualized Education Plan (IEP) provides the same accommodations as a 504 Plan, but is a better option if your child's disability requires more intense educational interventions. It may include an aide, educational supplements, etc. Assigned through the CSE.

Neuro-psychological testing Skills and abilities are evaluated through this program. It measures areas as attention, problem solving, memory, language, I.Q., visual-spatial skills, academic skills, and social-emotional functioning. Services will be designated through an IEP.

Monkey In My Chair Program www.monkeyinmychairprogram.org A collaboration between teacher and parent, this program helps a child stay connected to their school environment.

Edutopia <https://www.edutopia.org/topics> Is a comprehensive website for all types of education related issues for all students.

Sending your child back to school during or after the traumatic treatment of cancer can be a daunting task. Feelings of fear and joy co-mingle. . .but there is a lot of support for both parent and child. Always ask for help and your providers will be there!



Food for Thought



Healthy eating is so important for your children and should be a major priority for all parents and caregivers, even more so when caring for a child with cancer or undergoing treatment. Eating well can help kids in countless ways - from being able to better cope with any side effects of treatment to just feeling better during a challenging time.

Several key issues that we as parents can assist with include:

- **Keeping hydrated** - kids can lose fluids due to diarrhea or vomiting or just not feeling up to drinking and eating. Make sure your child has plenty of fluids, especially water. Some children might find water more palatable if it's served as a spritzer - approximately ½ all natural 100% juice and ½ seltzer. *(Let your child pick out their favorite cups, straws, bottles, etc. This will go a long way towards helping them stay hydrated!)*
- **Healthy Protein Sources** - *think lean meats and fish*, if your child enjoys or at least tolerates them. In addition, eggs, beans, lentils, chickpeas, are great protein sources too. Take the opportunity to boost up protein whenever you can - from adding beans to salads, spreading hummus on sandwiches as a spread instead of mayonnaise, to eating hard boiled eggs as an afternoon snack. If there is no nut allergy, add nut butters to any meal. Our family favorite is a toasted whole wheat English muffin, spread with melty natural peanut or almond butter, then topped with berries, sliced bananas, raisins, dried cranberries or sliced apples.
- **Whole Grain Carbohydrates** - there are many wonderful choices to fill up children's tummies! Whole wheat, bean/lentil pasta or soba (buckwheat pasta) or, if your child really just prefers white flour pasta, that's fine - just plan on bulking up the nutrition with the toppings. I've always served pasta with a large amount of vegetables cooked in the pasta water for the last few minutes of pasta cooking time. (Boil penne for 7 minutes and then add several cups of your favorite vegetables, such as broccoli, and cook for an additional two or three minutes). If your child enjoys beans - add them too. It's a great way to add additional fiber and protein with your carbohydrates. If your child's stomach is feeling queasy soup may be more tolerable. Our family loves the Italian Stratiaccella - egg drop soup which contains chicken broth, pastina and an egg drizzled into the simmering broth for the last few minutes. If your child likes greens, add in a few handfuls of spinach or whatever vegetable they enjoy most!