

## **New Beginnings After Childhood Cancer: Returning to Elementary School**

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**Alma Morgan, MEd**  
**November 14, 2006 • 12:00pm ET**

OPERATOR: Hello, everyone, and welcome to *New Beginnings After Childhood Cancer: Returning to Elementary School*, a free telephone education program.

It is my pleasure to introduce your moderator, Peyton Mason.

PEYTON MASON: Thank you and hello, everyone. My name is Peyton Mason. I'm the National Director of Patient Services Programs for The Leukemia & Lymphoma Society. And on behalf of The Leukemia & Lymphoma Society, we thank you for choosing to spend this hour with us today and welcome all of you.

The Leukemia & Lymphoma Society appreciates your participation in today's program, *New Beginnings After Childhood Cancer: Returning to Elementary School*. Today's program is part of the Society's *Focus on Childhood Cancers* educational series and is solely funded by The Leukemia & Lymphoma Society.

We thank our speaker, Alma Morgan, for sharing her time and expertise with us today and for her dedication to serve families touched by childhood cancers.

You all should have received a packet of information that includes brochures about some of the Society's services; a flyer for our publications, *Emotional Aspects of Childhood Cancers* and *Learning and Living* and Alma Morgan's biography. We encourage you to look through the materials at your leisure.

You will also find in your packet an order form for the Society's materials and an evaluation form for you to fill out for today's program. For nurses and social workers, you can receive continuing education credit and we've included an evaluation form marked specifically for you in the packet. Please return that form in the envelope provided to claim your one hour of credit. All other program participants may use the envelope to return your program evaluation.

After our keynote presentation we will open up the program to questions from you. We have over 800 individuals participating today via telephone from all over the country, in addition to several international participants from Iraq, Nepal, Pakistan, Ghana, the Philippines, and Venezuela, and many participants from Canada. We welcome everyone.

If we are not able to get to your question today, you can call the Society's Information Resource Center, the IRC, toll-free. That number is 800-955-4572. Dialing that number will connect you with an Information Specialist who can answer your questions or help you obtain more information. We also encourage you to call the IRC to order materials specific to your needs, such as those on the flyer in your packet. The IRC's regular hours are between 9 a.m. and 6 p.m.

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PEYTON MASON: Eastern Time, Monday through Friday. Again, that toll-free number is 800-955-4572.

We are also audiotaping and transcribing today's live program for future postings on the Society's Web site. The program archive will be available to you to access in a few weeks on [www.lls.org/survivorship](http://www.lls.org/survivorship).

The Leukemia & Lymphoma Society provides critical information and support to all patients, families and caregivers touched by blood cancer. The Society has 64 chapters nationwide, two in Canada, and offers a comprehensive array of free services to patients and families.

The Society's mission is to cure leukemia, lymphoma, myeloma and Hodgkin's disease and provide support for patients and their families. We hope that today's program is a step forward in providing up-to-date information and resources for childhood cancer survivors and their caregivers.

I now have the pleasure to introduce our guest speaker, Alma Morgan. Alma Morgan is an educational consultant in the Hospital Education Program at Virginia Commonwealth University Medical Center for the pediatric hematology/oncology program. She visits approximately 90 plus schools per year, developing educational plans for children initially diagnosed and transitioning back to school following treatment. She also conducts in-services for classmates regarding childhood cancer, sickle cell disease and hemophilia. While the classroom presentations provide support to the child returning to school, Alma feels that they also educate students at a young age regarding chronic illnesses and will help children grow up to be compassionate, caring adults. Prior to her 19 years at VCU Medical Center, she worked as a teacher in the private and public school sectors as well as in correctional and adult education. Ms. Morgan's complete bio can be found in your packet.

Alma, it is now my pleasure to turn the program over to you.

MS. MORGAN: Thank you, Peyton, and thank you to The Leukemia & Lymphoma Society for inviting me to talk about a subject that is truly dear to my heart, educational issues for children with cancer.

Today I feel that we are very blessed with the progress that has been made in the treatment of childhood cancer, which has greatly impacted the opportunities for young people to return to school much earlier in their treatment protocol than ever before. For example, the treatment protocol for leukemia is approximately two, two and a half years. Fifteen years ago children were remaining home and

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MS. MORGAN: receiving their education in the home for the majority of their treatment. Today that's not the case.

Today I have many children returning to school four to six weeks following the diagnosis.

Of course, there are many factors that determine when a child is physically and emotionally ready to return, but overall children are returning to school much earlier than ever before.

I sometimes have to laugh and beg for a little time from my patients, for they're ready to go back to school and I have to say, "Give me time to make contact, make the accommodations prior to your return." I think this says a lot about the progress we are making in the area of treatment as well as the confident and well-balanced children that we are raising.

Just as adults, children do not want to be dependent or invalids, but strive for their life to have meaning and purpose. Therefore I have to ask, why is returning to school so important for these children following the diagnosis of childhood cancer? One, school provides a normalcy that all children, as well as adults, need. Just as adults get up and go to work each day, children get up and go to school. When this is taken from them, they suffer. They suffer physically, socially, emotionally, psychologically and educationally. They no longer have structure and control of their lives. They wake up and say, "What am I supposed to do today? Wonder what my teacher and friends at school are doing? What am I missing in language arts? I wonder if they are going to do something new in math today. Am I going to fail this year or remain with my classmates? I bet I won't get invited to the sleep-over this Friday. Why didn't the guys ask me to go to the movie on Saturday?" All of these are questions and feelings the child has when he is unable to attend school regularly.

That is why I love the topic of today's teleconference, *New Beginnings After Childhood Cancer*. It is definitely a new beginning when the child returns to elementary school following a diagnosis of childhood cancer. His or her life has changed greatly. The child has experienced medical procedures, treatment, side effects and, of course, the medical talk or jargon that we would not wish on any child.

The children with a medical history of childhood cancer have suddenly lost part of their childhood and have been forced to grow up or mature much earlier than their years. They all know about portacaths, about central lines, radiation,

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chemotherapy, side effects of medication and sometimes the experience of bone marrow transplants. Therefore I must ask, how can we as parents, school personnel and medical personnel help these children?

We help them to find the normalcy that they once knew – going to school, participating in extracurricular activities such as soccer, ballet, Scouts, Little League, swim team and others. We guide them back to normalcy. Without a doubt, these elementary age children face many challenges when returning to school. These challenges include both physical and cognitive effects as well as short-term and long-term effects.

I will first address the short-term physical challenges that these children face that will have a direct impact on their classroom participation.

The first one I would like to discuss is fatigue. These children are extremely tired. Their stamina is not what it used to be before diagnosis. They quite possibly have been through numerous surgeries, may have received radiation, and most likely have started chemotherapy, with the induction phase of treatment being the most difficult. Their sleep patterns may have been interrupted with inpatient hospitalization and we all know what it's like to be hospitalized and woken up every few hours for blood pressure and temperature checks as well as the IV monitors and other buzzers going off throughout the night.

When at home and due to napping during the day or due to the side effects of the medication, somnolence may be an issue, in which the child cannot sleep at night. But he may fall asleep in the early morning hours and then have difficulty waking up and getting ready for school. If the child makes it to school, then getting through the school day without a rest period may be difficult.

Also for fourth and fifth graders who change classes, going from class to class and physically participating in physical education class may be a major problem.

Another physical challenge is the nausea and vomiting that is a common side effect of chemotherapy. Sometimes the child may just experience a wave of nausea and can get through the day without any problem. However, there may be other times in which certain smells may make the child feel ill. This is especially true for children who are sensitive to the smells in the cafeteria, science class or in art class. Different foods as well as chemicals, paint, etc., may make the child feel ill.

One of the most important is the physical changes in appearance. They are often difficult for children returning to elementary school. This difficulty is not just

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hard for the child returning, but also for the classmates. The child may be returning without his or her hair. Almost all schools have a no-hat policy, so even when the child returns with a hat or scarf on his head, the other children question why he is allowed to wear a hat and they are not.

For the girls that wear wigs, many of the wigs are not natural looking and this raises attention to the child. Fortunately, class in-services, that I will address later, make the child feel more comfortable as well as fellow students.

In addition to the hair loss, the child may be returning with an altered appearance due to drastic weight loss or weight gain. For the child that has suffered with mouth sores as a side effect of the chemotherapy, he may have lost a substantial amount of weight due to the pain associated with the mouth sores and the burning of the esophagus. However, on the other hand, the child who has been on large doses of steroids, may have experienced a significant weight gain in which he presents with bloating, stretch marks and puffiness in the face that alters his appearance.

In addition to the ones I've just mentioned, these children are immunosuppressed. Their blood counts are low, which make them more prone to infection. If the counts drop too low they will be encouraged to stay home and not attend school until the counts rise. However, being immunocompromised does make them susceptible to catching colds and other transferable diseases. That's why it's always important to educate the classmates and make sure that you practice good personal hygiene in the class – washing hands, using the tissues that the teachers provide and just be careful of your neighbor, not sneezing and coughing on them.

Still another challenge may be mood swings. When a child is on steroids he may be extremely angry and irritable or he may be extremely tearful and sad. We always call that the Dr. Jekyll-Mr. Hyde. Whatever, the teacher needs to be notified when the change in medicine might alter the mood and the behavior of the child, so that the teacher understands and the child can be comfortable in the setting at school when he's having these outbursts.

In regard to cognitive challenges, these children often demonstrate challenges upon return to school at the time that they first return and then something that we call cognitive late effects.

Short-term memory loss, that is one of the main ones that I get calls about. The student will study his spelling words the night before and know all 20 words,

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goes to school and takes the test, and only knows how to spell eight words on the test. The same thing happens to the third grader who is learning his multiplication table. He practices his drills at home and knows them, but he cannot remember the tables at school.

Next we have difficulty with word retrieval. The student starts talking and suddenly forgets the word he needs to tell his story. He knows the word, but he cannot retrieve it. He becomes very frustrated.

Another big cognitive effect that I get a lot of calls about is slower processing. The student has studied for his test and knows the information, but he is only halfway through the test at the end of the period. When granted additional time he scores in the 90th percentile, but when he is timed he scores in the 40th percentile.

Likewise it may take the student four hours to complete his homework, sometimes six, when it only takes his peers two hours.

And of course, let's talk about poor comprehension. The student is a fluent reader, but it takes so much for him to decode the words that he has lost the comprehension by the time he gets to the end of the passage.

Another big issue in regard to cognitive effects is poor organization. If you look in these backpacks and in their desks, papers are everywhere, they're a mess, they're unorganized. The student writes down his assignments in his agenda book, but then he forgets to take the book home to complete the work. And if he does do the homework, then he might forget to put it in his backpack and take it back to school. Or it might be in the wrong folder.

And of course, let's talk also about multi-tasking. His mother tells him to get dressed, put on his shoes and pack his backpack. He gets dressed, goes to the stairs, gets ready to go out the door, has his backpack on his back, he looks down and he doesn't have his shoes on.

So there's lots of issues here in regard to the cognitive effects that we do need to address in order to make that return to school successful for the child and we have to first know that these cognitive effects do exist. And sometimes when a child returns and they have their hair and they look okay and they've been out of school for a good while, it's hard for the teacher to remember where they've been and what they've been through and they don't have any idea of the late cognitive effects that exist.

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When faced with these physical and cognitive challenges, who guides these children back to normalcy? I always say it's a partnership, a partnership between the medical team, the school team, the parent and the child. A strong partnership is crucial in orchestrating a successful return to school program. If each player is actively involved in this partnership, then the following will be accomplished. The education needs of the child can be identified, the characteristics or factors that impact the child's academic success can be addressed, the accommodations that are needed to assure success can be determined, an educational plan can be written to address the needs and accommodations, and the parties in the partnership can communicate frequently to review the educational plan, address new issues and concerns, and work together to assure success.

I cannot stress enough the importance of all parties being involved and communicating on a regular basis rather than only when a problem or concern arises. Each person in this partnership is an equal team player.

Besides the partnership, what other support services and resources are available to assist these children when returning to elementary school after childhood cancer? It is at this time that I want to address two federal acts and statutes that provide educational services to children with childhood cancer.

The first is Section 504 of the Rehabilitation Act of 1973. Section 504 is a bill of rights statute that prohibits discrimination based upon disability. Now you might say at this time that a child with cancer does not have a disability, however, what constitutes a disability as explained using the criteria. A person who has a mental or physical impairment which substantially limits one or more major life activity, has a record of such an impairment or is regarded as having such an impairment.

Children who have been diagnosed with childhood cancer definitely have an impairment, for impairment is defined as any disability, long-term illness or disorder that substantially reduces or lessens the student's ability to access learning in the educational setting because of learning problem, behavioral issue or health-related condition.

Childhood cancer is definitely a long-term illness that lessens a student's ability to access learning in the educational setting. School attendance alone is an issue, for the child with cancer misses school for hospitalizations, clinic visits and just not feeling well.

The side effects or cognitive late effects of treatment hinders major life activity such as the ability to sustain attention, focus and concentrate for long periods. Due to neuropathy, children often have difficulty walking and even writing or

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taking notes can be painful. For children with brain tumors, walking, seeing, hearing and speaking are life functions that become impaired due to the seriousness of the disease and side effects of surgery.

The major life activities that the criteria addresses include the following: self-care, manual tests, walking, seeing, hearing, speaking, sitting, thinking, learning, breathing, concentrating, interacting and working.

Therefore, after hearing what constitutes a disability, the definition of an impairment and a listing of major life activities, one can understand that a child returning to school after a diagnosis of childhood cancer definitely meets the criteria.

For one, children with cancer have physical impairments that limit one or more major life activities. Secondly, the impairment is recorded on the clinic or hospital dictation. And third, the clinic or hospital dictation is a legal document of the impairment.

Now that I have addressed the educational plan known as the 504 plan, I would now like to discuss IDA 2004 or should I say IDEIA, which stands for the Individuals with Disabilities Education Improvement Act. This act or should I say federal law provides funding for special education. It provides a free public education to all students who fall within the special education category. IDEIA was formerly known as Public Law 94-142. We first instituted this law in the 70s, however, it was reauthorized in 1997 and has recently been revised again.

The purpose of IDEIA 2004 today is to ensure that all children with disabilities have a free public education that emphasizes special education and related services designed to meet their unique needs and to prepare them for further education, employment and independent living, and to ensure that the rights of children with disabilities and parents of such children are protected.

A child who would qualify for special education services under IDEIA would have to meet the following criteria: have a disabling condition, which limits his or her progress in the regular classroom, or any child who needs special education or related services to make progress or appropriate strides in their education.

Many times when discussing IDEIA parents may say, "My child does not need services in special education, they do not have a disabling condition." I would like to now share what constitutes a disabling condition. They are autism, deafness, blindness, developmentally delayed, emotional disturbances, hearing impairment, learning disabilities, mental retardation, multiple disabilities, orthopedic impairment,



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other health impairment, specific learning disabilities, severe disabilities, speech-language impairment, traumatic brain injury and visual impairment.

Children with childhood cancer often qualify for services under the disabling condition of other health impairment. Their medical or healthcare condition has impacted their educational performance. I have children in gifted programs and at The Governor's School for the Gifted with an IEP, Individualized Educational Program.

Now the question comes as to whether the child would be best served under a 504 plan or an IEP, Individualized Educational Program, under the handicapping condition of OHI, Other Health Impaired. My personal opinion is that the child returning to elementary school after the diagnosis of childhood cancer needs an educational plan, either a 504 plan or an IEP. Yes, they do need a healthcare plan that's written with the school nurse. However, a 504 plan and an IEP are federally mandated plans. They are plans that are shared with each teacher so that each teacher knows the educational needs and the accommodations of your child.

If the child is being academically successful in the classroom and just needs accommodations in regard to his medical condition, then I find that he can be served adequately with a 504 plan. However, if the child is struggling academically due to missing a lot of time from school, falling behind in his schoolwork and becoming skill-deficient, or showing signs of cognitive late effects that call for specialized instruction and teaching strategies, then I recommend an IEP under special education or IDEIA.

I want to mention again the late cognitive effects that I keep talking about. I know that last year Daniel Armstrong out of the University of Miami, Dr. Daniel Armstrong, did a wonderful program on the cognitive and late effects related to childhood cancer. And if you were not able to hear that teleconference, you might want to contact The Leukemia & Lymphoma Society and get a hand-out of that presentation, because it really did go into extensive detail about the cognitive and late effects.

As a parent you may wonder how to go about getting services for your child. This is where I'm going to teach you how to do my job.

First, if your medical institution has an educational consultant or hospital liaison that works with the schools, contact this person to be your advocate. I would do this prior to the return to school.

Next, either you the parent, the medical team member or a teacher needs to request a child study team meeting to determine what accommodations or

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MS. MORGAN: modifications are needed and how these accommodations can best be provided.

The child's study team has ten working days to meet and take action. The child's study team will determine what evaluations are needed in order to make a decision about placement. The following are evaluations that may be requested: medical, psychological, educational, social history, speech, language evaluation, occupational therapy evaluation and physical therapy evaluation.

The team will determine what evaluations are needed and the school then has 65 days to complete the evaluation. At the end of 65 working days the team reconvenes for an eligibility meeting to determine if the child is eligible for services. The process, as I just outlined, is specific for special education. I have found that students can qualify much earlier for services under a 504 plan, for usually the medical documentation from the hospital and educational from the classroom teacher can qualify the student for services.

After finding the child eligible for services, the school then has 30 days to write the educational plan.

At this time I must elaborate that if your child seems to have cognitive late effects, you can request a neuro-psych evaluation through your medical institution. This can sometimes be quite costly. Therefore you might want to go to your school division and request the child study team meeting and ask for testing that way. That is of no cost to the parents.

Possible accommodations to include on the 504 plan or the IEP are the following. And the list is lengthy, but I think it's important that I go over each one because these are the accommodations that I usually find that I write in most plans here in Virginia.

- Student will be given two sets of books, one for home, one for school. Those backpacks weigh, for fourth and fifth graders sometimes with all their books, they can weigh 30 pounds. They're way too heavy for the child to carry.
- Student will be granted permission to carry a water bottle or juice box to drink throughout the school day. We don't want the child being dehydrated.
- Student will be granted bathroom, guidance and office passes when needed. Many schools might laminate a pass and give it to the child and that way they just have to get the teacher's attention when they need to be excused for bathroom, guidance or clinic passes.

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- Student will be allowed to wear a hat or scarf.
- Student will be exempt from physical education activities involving contact sports, strenuous exercises and long distance running. Many of these children return to school with portacaths and we definitely don't want them participating in contact sports. And sometimes due to the fatigue issues, I think they need to save that energy rather than running the track.
- Students will be exempt from the Presidential Physical Fitness Testing that is completed in the fall and again in the spring.
- Student will be granted a short school day or a rest period during the day, if needed. Sometimes students, if they have difficulty getting up early in the morning, they might go in late. Or they might have a morning rest period or maybe an afternoon rest period. If the rest period will help them get through the school day and be productive, then I say give them a rest period. Let them rest for 45 minutes.
- Student will be granted a midmorning or afternoon snack if needed. This is for the children that are on steroids. I had a little girl a few years ago and the teacher's apple kept disappearing off her desk. And then her pretzels would disappear. And she found them in the little girl's desk, she was in kindergarten, and she was hungry, she was on her steroids.
- Student will be assigned a moderate workload with limited assignments requiring quality versus quantity. And I usually pick on the math teacher for this one. If the child can do 10 problems a night in math as opposed to 20 problems, and show that he can master the concept, then why not accept 10 problems? His schedule is already very full. Coming to the hospital, going to clinic visits, taking medication, getting the rest that he needs.
- Student will be granted extended time to complete classwork, quizzes and tests. This is for the child that has the slower processing. He needs that extended time in order to do satisfactory on his tests and quizzes.
- Student will be granted an intermittent home-bound teacher to assess with assignments with days missed for hospitalizations, clinic visits and feeling poorly. When children return to school four to six weeks after diagnosis, of course they're still going to have interruptions in their daily schedule at school. They might miss one or two days a week. However, on those days an intermittent home-bound teacher that's assigned by the school division

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can come in and work with the child an hour or two every now and then to keep them caught up on those days that they do miss.

- Extended school year will be provided during winter break, spring break and summer as needed. If a child has lengthy hospitalizations and they get quite far behind, rather than saying that they're going to have to repeat the year, ask for an extended school year. That way they can do a lot of catching up in the summertime, so they'll be with their classmates in the fall.
- Student will be assigned preferential seating in the classroom. Now this is not to punish the student and say that you have to sit in the front, it's the preferential seating that's suitable for learning. And it's usually not beside the air conditioner or the heating unit because it buzzes and makes a lot of noise and blows air on them all day.
- Student will be given word banks and formula banks when needed. This is particularly for the child who's having trouble with short-term memory.
- Student will be given tests in shorter segments and in a small group as needed. Sometimes it's difficult for these students to focus for long periods of time. That way if the test is given in shorter segments, they can focus on that particular item and then move on to the essays or the multiple choice questions the next day.
- Student will be given assignments and directions both orally and written. That's to compensate for the visual and the auditory learners.
- Student will be given an extra set of notes when lectures are given. Yes, fourth and fifth graders, they are becoming the art of note-takers. And I tell you, sometimes that's difficult because if you're missing a lot or if you're having neuropathy in your hands, and it's difficult to write for extended periods of time, they might need a set of notes from their teacher.
- Student will be assigned a case manager or peer buddy to keep informed of class activities. And that's very important. We want them to be able to be in the school yearbook and to have their pictures taken and we want them to make sure that they don't miss their field trip or the party they're having in class.

So these are just a few of the accommodations and modifications that I find are beneficial and needed when the child returns to school following diagnosis. The list is more comprehensive for the young people in middle school and high school,

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for they are dealing with six or seven teachers as opposed to one or two in the elementary school. Also the work can be more challenging in the upper grades when taking advanced, honors or IB courses. Also in the upper grades you have to be concerned with the graduation requirements, SAT testing and post-secondary planning.

While I believe that educating teachers and school personnel is of utmost importance prior to the child returning to school, I also believe strongly that class in-services are needed to educate classmates. I believe that all children want to be compassionate, caring, supportive friends. However, when we do not educate them on the illness of their friend or classmate, they feel awkward and will often say things that are rumors or things that are not true in order to get answers.

Therefore I suggest that a consultant or member of the medical team visit the school prior to the child returning and talk with them on their level. I usually begin my presentation talking about cancer cells and how they grow and multiply, taking over the good cells. I then talk about the specific names and diagnoses such as acute lymphoblastic leukemia or Ewing's sarcoma, the side effects of treatment and suggest hints on how they as classmates can be encouraging and supportive friends. I find that the in-services allow the classmates time to answer questions, makes them feel less afraid, makes the child returning to school feel more comfortable, and allows for the students to put the illness behind them and go forward.

In many cases the child returning to school wants to be present and they assist me when I do the presentation. I take in my puppets, I take in portacaths, I take in the butterfly needle, and we do the presentation. It is almost like therapy for the child returning to school for he or she may show the portacath and my puppets, demonstrate how medicine is given through the central line, removes the hair from the puppet and returns the hair to the puppet, showing that the hair does grow back. We talk about cancer not being contagious. And then we usually close with a story. For the children with leukemia we might read Sam Fights Back, about a dinosaur with leukemia. For children in the upper grades, fourth or fifth grade, we might read about How the Jester Lost His Jingle, that talks about even during difficult times that we have to have humor in life and find something sometimes to laugh about and that laughter spreads.

In conclusion, I would like to summarize that when an elementary age child is first diagnosed, contact the school and let the teacher and staff know of the diagnosis and the need for home-bound instruction until he or she is ready to

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return. Parents must sign a release of information so that the medical team and the school team can share information and still meet the educational needs of the child while he is out of school. Prior to return, contact the school for a child study team meeting and meet with the team to discuss an educational plan and accommodations that the child will need upon returning. Bring the team handouts and information about the disease. I often take each team member a packet put together by the Virginia Chapter of The Leukemia & Lymphoma Society. In the packets I have lots of handouts. I love the one, Learning and Living with Cancer, Advocating for the Child's Educational Needs. I also love the one called Can Survive, by Keene.

The Leukemia & Lymphoma Society does a wonderful packet and I can't stress enough, go to your chapter and request these packets.

Next, schedule an in-service to educate classmates and to ask for their encouragement and support. Lastly, allow the child to resume normalcy and feel good about himself. Work to build his confidence and self-esteem by praising him on his academic work completed, showcase his artwork, assign him a part in the school play, or allow him to be an assistant to the PE teacher when he cannot participate fully in class.

It is important that the child returns and feels a part of the class. He has already faced many challenges, obstacles, and it is now time for him to do what he knows how to do, attend school and be a part of his peer group.

As we all know, our children are our most precious gifts. Helping these children in elementary school return to school and experience academic success is not the job of one person, but the job of each and every person involved in the life of that child.

The survival rate for childhood cancer is 85% or better and we have to prepare these young people for a quality of life that will assure success. They have already at a young age fought the battle and it is time to allow them to live life to the fullest.

This concludes my program. I hope that I have answered questions you had prior to the teleconference and that you are now empowered to advocate for your child or any child you know that's returning to school following the diagnosis of childhood cancer.

So at this time I'm going to turn the program over to Peyton and we're going to have questions and answers.

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PEYTON MASON: Thank you, Alma. And thank you for presenting this important information in a very clear and understandable way and walking us through these laws and resources that help childhood cancer survivors in their return to school.

As Alma mentioned, it is now time for the interactive part of our program, the question and answer session. And before the operator gives instructions for the audience to enter the Q&A, I'd like to remind all of you that we do have hundreds of participants on the line and for everyone to benefit, please try to keep your questions general in nature so that Ms. Morgan can provide an answer general in nature. And your phone line will be muted after you ask your question, so that the presenter can respond.

Operator, will you please give instructions to our teleconference participants so they can queue themselves to ask a question?

OPERATOR: To participate in the call by asking a question, please dial star-1 on your keypad. We will take questions in the order they are asked. Be aware that due to time constraints, we can only take one question per person. Once your initial question has been voiced, the operator will transfer you back into the audience line. Again, to participate in the call by asking a question, please dial star-1 on your keypad.

PEYTON MASON: Thank you. We'll take our first question, please.

OPERATOR: The first question comes from Cecile in California.

CECILE: Hi, my question is how do you feel about the paraprofessional? I requested one for my son and that seems to be working great for him. I made sure that she was college educated, she has a bachelor's. What are your thoughts on that?

MS. MORGAN: I think using paraprofessionals is a wonderful resource, I do. I know that a lot of school divisions are hesitant and they want to use the least restrictive environment and they want to try other strategies first, but if a school is willing to provide a paraprofessional, I think it's a wonderful idea. And I really do think it makes a difference.

PEYTON MASON: Thank you, Cecile, for your question. We'll take the next question, please.

OPERATOR: The next question comes from Julie in Illinois.

JULIE: Hi, my question is about accessing resources available through public schools. My son goes to a private school. How would you recommend I access those resources?

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- MS. MORGAN: Here in Virginia if a child attends a private school, you can have resources through the public school. You have got to enroll them in the public school in their zoning area. And then they are enrolled in the public school in that area, then the school division has to provide the home-bound teacher or the supportive staff if you need OT-PT or speech.
- PEYTON MASON: Thank you, Alma. And just a reminder for additional information, please do call our Information Resource Center about your local area and what resources are available. We'll take our next question, please.
- OPERATOR: Your next question comes from the location of Lauren in Vermont.
- LAUREN: Hi, do you have any advice or suggestions for home-schooling parents, problems we can look for or things that we should be doing to make sure we're not missing an opportunity to help our children with cancer?
- MS. MORGAN: Absolutely, I would still use the resources that they have available at the Department of Education in your state. I would contact schoolteachers in your local school zoning area and ask them for their expertise, particularly in the area of special education. And I would certainly use resources by The Leukemia & Lymphoma Society and the American Cancer Society.
- PEYTON MASON: Thank you, Alma, and thank you, Lauren, for your question. We'll take our next question, please.
- OPERATOR: The next question comes from the location of Amanda in California.
- AMANDA: Hi, I was wondering if you would apply the accommodations to a child that has finished treatment. My son's going to enter kindergarten next year and he'll be six months off of treatment and so I was wondering what you recommend.
- MS. MORGAN: Absolutely, I always apply the accommodation list to children that are only six months after treatment. In fact, once these plans are put in place, I usually ask the parent to leave them in place for two to three years following treatment. Of course, you can cut the resources, you might not need all of them that you had when they first returned to school, but once you have a plan it's better to keep it in place than let it expire and then have to go back to the drawing board, request another child study team and start the process over.
- PEYTON MASON: Thank you, Alma. And just a reminder to those of you on the phone that we do have these materials available for you, these booklets, the Learning and Living booklet you can order through our Information Resource Center. And as Alma



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- PEYTON MASON: mentioned, Dr. Armstrong's program, he had actually Part 1 and Part 2 that he presented last year on "Cognitive and Late Effects in Returning to School," it's available as a booklet. So please call that number, 800-955-4572, and we'll be able to provide you with that information. We'll take our next question, please.
- OPERATOR: The next question comes from the location of Kiki in North Carolina.
- KIKI: My son, he's 15, and he already does have LDD anyway to begin with. His teachers – he's home-bound some because of the chemotherapy with CML, but my question is a lot of the teachers are letting a lot of work just slide. Is that healthy? Just because he's so fatigued.
- MS. MORGAN: I sometimes, if the child is really suffering from fatigue, I ask for modifications in workload. And I think that teachers have a good – they are good judges on what the child needs to know in order to advance to the next level. And if they will concentrate on the curriculum and on the objectives that are needed to pass the current grade that he is in or the classes that he is currently enrolled in and go to the next class, then I think there can be modifications and it's okay.
- PEYTON MASON: Thank you and thank you, Kiki. We'll take our next question, please.
- OPERATOR: The next question comes from Cheryl in Missouri.
- CHERYL: My grandson is 11 years old and he has developed personality disorders due to some of the chemo and depression. He's on Celexa®, Risperdal® and Zofran® for this IBS. Can we look forward to these conditions continuing when he goes back to school?
- MS. MORGAN: I'm going to answer that saying that I'm not the medical expert on that. I have worked with children in which the depression and some of the behavioral disorders have continued and they can be covered also in the 504 plan and the IEP that I have addressed. In fact, I would really, really encourage you to address having an IEP if he does not already have one, to address these behavioral issues. Because that can be a protection to you and to the child.
- PEYTON MASON: Thank you, Alma, and thank you, Cheryl. And Cheryl, just a reminder we do have a booklet available for you on the emotional aspects of childhood cancer. And also the Society is there for you at the local level. We do have family support groups for the childhood cancer survivor as well as for the family to seek support. So just a reminder to reach out to our local chapter and you can be connected with them through our Web site or through the Information Resource Center.

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- PEYTON MASON: We'll take our next question, please.
- OPERATOR: The next question comes from the location of John in Oregon.
- JOHN: My daughter has cancer and she's in remission, but we're having lots of problems with the school, not even reading background information. She's a survivor of cancer long-term and she has lots of late effects.
- MS. MORGAN: Have you met with the school to talk about her diagnosis and what the late effects are that she is experiencing?
- JOHN: Absolutely.
- MS. MORGAN: Absolutely, and they are still resistant to give you services?
- JOHN: Yes.
- MS. MORGAN: I would request a copy of the presentation that we did today. I think that if you will follow those guidelines under what constitutes a disability and an impairment, that you will find that she will qualify under a 504 plan or an IEP. And if she is really struggling in school, has these late effects, I would not accept no for an answer.
- PEYTON MASON: Thank you, Alma, and thank you for your question. And just a reminder we will have the transcript of this program posted on [www.lls.org/survivorship](http://www.lls.org/survivorship). You can also contact the Information Resource Center to have that emailed to you. Within a couple of weeks we should have the transcript online. We'll take our next question, please.
- OPERATOR: The next question comes from the location of Carol in Indiana.
- CAROL: Thank you, I think you've answered my question.
- PEYTON MASON: Thank you, Carol. We'll take our next question, please.
- OPERATOR: The next question comes from Susan in New Jersey.
- SUSAN: I know this forum is specific to school age children, but my son was diagnosed just when he turned 2 and he's not in kindergarten yet, but we've had early intervention over and he is delayed. Are there any benefits or acts that assist children that are not yet of school age?
- MS. MORGAN: Have you contacted the preschool handicapped program in your local school division?

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- SUSAN: No.
- MS. MORGAN: He would most likely – I would advise you to contact the preschool handicapped program of your school division. They will come and do an evaluation and then determine if he qualifies for services.
- SUSAN: What services would be then under the 504 ...
- MS. MORGAN: It would be under special education. And he could receive, if he qualifies, OT, PT, speech and educational services.
- PEYTON MASON: Thank you, Alma, and thank you, Susan, for your question. We'll take our next question, please.
- OPERATOR: The next question comes from the location of Gabriella in Florida.
- GABRIELLA: My son has just turned 4 and he seems to be doing very well. He has ALL. And I'm wondering if it would be worth it to put him in preschool and expose him to all the germs and everything, since he's really not school age and it's not necessary.
- MS. MORGAN: Has he finished treatment?
- GABRIELLA: No. He's one year into it.
- MS. MORGAN: He's one year into treatment. I would talk with the medical personnel, his doctors and nurses, and I would base that on how his counts are. If he does not seem to be immunosuppressed and his counts seem to be average or better, then I might consider a preschool placement. I find that even a preschool placement one or two days a week sometimes really makes a difference for these young people.
- GABRIELLA: You think it's worth it for him to be exposed to that many kids? I would only take him during counts.
- MS. MORGAN: I know that we have started in our clinic, we have started a preschool program one day a week this year, so that the children can get together one day a week and participate in some preschool activities, just for social and peer interaction.
- PEYTON MASON: Thank you for your question. And thank you, Alma. As Alma had mentioned, how important it is to really talk with your healthcare team and really be a partner with the healthcare team as well as with the local school personnel. We'll take our next question, please.

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- OPERATOR: The next question comes from the location of Anne in Virginia.
- ANNE: Hi, thanks for taking my call. My son is in third grade and he's about a year and a half into treatment. The school's been great, the teacher is very supportive. He got As and Bs this last time around, but it's below grade level. And before treatment he was always at the high end. My husband seems to think we need to let him press on and do the regular thing. I wonder how early I need to get some of these accommodations. We already have a plan in place, so they're available. Especially as he's starting multiplication tables, should we even put him through that or we just see if he can use a multiplication bank?
- MS. MORGAN: Anne, what plan does he have in place?
- ANNE: And all of that's in place, has been great, and they said it's there if we need it. But right now ...
- MS. MORGAN: Does he have a 504 plan or an IEP?
- ANNE: I think it's an IEP.
- MS. MORGAN: And why did you say if he's making As and Bs that he's below grade level?
- ANNE: Because he's making As and Bs, but the work he's been given is below grade level. The teacher seems thrilled with his work and I said is there danger from being held back and she said oh, no.
- MS. MORGAN: He's just returned to school?
- ANNE: No, no, he's been back, he went most of last year.
- MS. MORGAN: If you've talked to his teacher and she feels comfortable that he is keeping up and that he's staying with the rest of the class, I would not worry at this point. But I would keep that IEP in place.
- ANNE: Thank you.
- PEYTON MASON: Thank you, Anne, for your question. We'll take another question, please.
- OPERATOR: The next question comes from the location of Joy in Georgia.
- JOY: I'm a school counselor and I have a kindergarten student who is toward the end of his treatment, so obviously he had already been diagnosed and treated before he began kindergarten as a new student here in our school. The question that I have is the teacher and I have been trying to determine if it would be best to talk

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- JOY: to the class about his being absent every week. We weren't sure with really young students. He's not showing any physical effect, no hair loss at this point or anything like that. So just wanted some advice on if it's always the best thing to do, to talk to the class or in some situations like this one, if they're not asking questions, not to.
- MS. MORGAN: If the class is not asking questions, if the child looks perfectly normal and seems to have great peer interactions at school and doing fine, then I would not raise attention and do a class in-service.
- PEYTON MASON: Thank you, Alma, and Joy, thank you for your question. That's a really good question and we appreciate school personnel like yourself being on this call and obtaining this information for your students. We'll take another question, please.
- OPERATOR: The next question comes from the location of Gail in New Jersey.
- GAIL: My question was already answered.
- PEYTON MASON: Thank you, Gail. We'll take our next question, please.
- OPERATOR: The next question comes from the location of Sharon in Canada.
- SHARON: Hi, my son was diagnosed with ALL in December of 2004 and he's currently 9 years old. His new teacher this year – and she stated to me that she has 29 children in her classroom and she will not treat our son any differently from any other children. And her line of communication with me is pretty much nil. I was wondering how I should address this way of thinking.
- MS. MORGAN: Does he have any educational plan in place?
- SHARON: The American system? And there's no such system I'm aware of in Canada. So I'm sort of dealing with this new teacher this year. He had a teacher the previous two years who was amazing and wonderful and very supportive and communicated. So I don't know if she's just taken a stance ...
- MS. MORGAN: I would get as much information that I could possibly obtain on the cognitive and physical effects of childhood cancer, current and late effects. I would request this packet that we have from The Leukemia & Lymphoma Society and get them to mail this to you. And I would take it and I would ask for a school meeting with the child study team, which would involve the administrator and the teacher, the school nurse, and I would sit down with them and I would go over this packet again.

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- SHARON: Okay, because I have provided them stuff from our medical team and our local oncology center.
- MS. MORGAN: Sometimes you have to do it in a formal setting and you have to request a formal meeting with the school personnel.
- SHARON: And that makes the difference.
- MS. MORGAN: And it makes a difference. Particularly sometimes if the administrator hears your concerns.
- SHARON: Because she is aware of my concerns, but I don't know how I can get around this teacher not wanting to basically deal with it at all.
- MS. MORGAN: I'd just say education is the key factor. And I hate to say this, but sometimes, sometimes we cannot make every person compassionate and caring. And trust me, that's my pet peeve, I wish we could. And I feel for you. And I would talk with the administrator and next year I would see if I could not hand-pick a teacher for my child that's going to be supportive and compassionate and encouraging.
- PEYTON MASON: Thank you, Alma. And Sharon, thank you so much for being on the call today and for your question. And we do have two chapters in Canada, in Toronto and Vancouver, so we'd be pleased to connect you with the local patient services manager at the chapter closest to you that could assist you with obtaining this information and working under the Canada laws. We'll take one more question, please.
- OPERATOR: The next question comes from the location of Howard in California.
- HOWARD: What would you suggest if the medical testing such as a neuro-psych exam is not honored by the school system? They usually use their own testing. And it almost shows the opposite results a lot of times of what the medical testing is.
- MS. MORGAN: I would take the neuro-psych evaluation in to the school. I would share it. If it shows the opposite, then I would say that I wanted another evaluation completed. Because who's to say which one should be honored. The school will say theirs should be honored, you'll say that the one from the medical facility. So I would ask the school to provide another evaluation.
- PEYTON MASON: Thank you, Alma. And thank you, Howard, for your question.

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- PEYTON MASON: We actually have a little bit of extra time and I know there are a couple of more questions in queue, so Operator, we'll take another question, please.
- OPERATOR: The next question comes from Robin in Virginia.
- ROBIN: Thank you, Alma, for presenting the challenges of these children. What we were wondering is do you have any suggestions for children that are going to college or young adults, how to prepare them for college?
- MS. MORGAN: I do have some suggestions and I think that The Leukemia & Lymphoma Society is going to address this later on in the year. If not this year, the first part of next year, for college age students. But I definitely think that you have to start preparing children early in regard to graduation requirements, are they going to get a standard diploma, advanced diploma, modified. What course range are they taking, advanced, honors, IB. What kind of degree do they want to pursue. We have to educate them on taking the SAT testing, are they going to need a prep course for the SAT test. And let's go and see schools. Take field trips, go and visit schools, go and visit vocational programs. I always say that once you set your foot on campus you know whether or not your child belongs there and the child can feel whether or not he belongs at that school or if he should keep looking and find another one. I hope that answered your question, Robin.
- PEYTON MASON: Thank you, Robin, and thank you, Alma. Operator, do we have another question in queue to bring in?
- OPERATOR: The next question comes from Crystal in Iowa.
- CRYSTAL: We have a kindergarten student who was recently diagnosed with neuroblastoma and he's undergoing treatment, but the prognosis is not good and it looks like it will be terminal. He is returning to our school and we are preparing – we are going to have people come in to speak with our class from the hospital. But we want to know is there anything that we need to do for the mere fact that it's terminal and to prepare the class if there is something we can do to work in that direction, I guess.
- MS. MORGAN: I think it's wonderful that you're preparing the class now and that you're doing the in-services. And I would do the in-service and educate the classmates, on their level of course, about childhood cancer and the treatment and the side effects. I find that sometimes you do not have to tell the children how serious it is because they already know that. Children know at a young age, they know so much more than we ever realized that they know. I give them an opportunity to ask questions and I always answer their questions truthfully. And every now and

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MS. MORGAN: then – I always praise the child that asks this – “Is my friend going to die?” And the way to answer that is that we never know when any of us are going to die, but that he does have a serious condition.

And I would just make it so that the child can attend school. I’ve had numerous cases like this before. I’ve had classrooms where they would bring a couch in to the school and the child could sleep during the day, if he wanted to sleep all day, then he would sleep all day and wake up every now and then and just talk to people. That’s where he wanted to spend his last days. If a couch is not feasible, then I’ve had them where they bring bean bags in and the child has his own personal blanket and pillow and he can curl up the bean bag and take rest and participate to what he feels like doing. It’s basically how the child feels and he kind of has the limit there.

I hope that answered your question.

PEYTON MASON: Thank you, Crystal, for your question, and thank you, Alma. Operator, we’ll take our last question, please.

OPERATOR: The next question comes from Patricia in California.

PATRICIA: I was wondering if you could explain the difference between the neuro-psych testing that you have alluded to and the testing that we do within the school system for preparing a child to enter into special education.

MS. MORGAN: I find that the neuro-psych evaluation goes much deeper into the cognitive development of the child. It really looks at the short-term memory, the auditory processing, visual discrimination, processing speed. Whereas I find that the psychological, that the school systems are doing, many times just basically, they look at the IQ scores, verbal performance, and is there a discrepancy and do they qualify. And I like to use, when I’m having children, referring them for neuro-psych evaluations, I like to refer them to a neuropsychologist that has experience in working with children and cancer and has experience in regard to the late effects of treatment. So that they know what they’re looking for when they’re working with these children.

PEYTON MASON: Thank you, Alma, and thank you, Patricia, for your question.

Our one hour program has now come to a close. Please help me thank again Alma Morgan. We are very grateful that she has donated her time to us today. And we thank Alma for all that you do every day in supporting children and their families.



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MS. MORGAN: Peyton, can I add one thing today?

PEYTON MASON: Sure.

MS. MORGAN: I want to offer, if anybody has questions and we did not get to them, I'm free or I will call you back as quick as I can, based on my schedule. But I would love to talk to you and answer your questions if you have concerns or issues. My number here is 804-828-0426 and my email is amorgan@mcvh-vcu.edu.

PEYTON MASON: Thank you, Alma. And Alma's contact information will also be available to you by calling the Information Resource Center if you didn't have a chance to write that down.

We would also like to thank all of the participants on the line today. We hope that many of your questions were answered and that the information provided will assist you in your next steps.

A reminder to all of you to fill out your program evaluations. If you're a nurse or social worker, to fill out your continuing education credit form. If you can please, mail that evaluation back in the envelope provided in your packet. Feedback is extremely important to us and has helped us to plan the most meaningful programs for you, so your comments and suggestions are very appreciated.

And as a reminder again to all of you that our Information Resource Center is open to receive your calls. Do not hesitate to contact us if you have any further questions. Our master's level information specialists are available to provide you with more information, can link you with your local chapter and again can connect with Alma Morgan, who has graciously provided her contact information for you to contact her directly. And again, that number is 800-955-4572. It's included on the materials in your packet. And please watch your mail. Alma had mentioned that we do have upcoming programs. We have two other programs coming up in the winter and spring in our childhood cancer series, so please watch your mail and our Web site to register for those programs.

On behalf of The Leukemia & Lymphoma Society, I'd like to thank all of you again for sharing this hour with us. Good-bye and we wish you well.

OPERATOR: Thank you. That does conclude today's conference call. You may now disconnect.

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