

Education Challenges After Treatment: Middle School through College

Alma Morgan, MEd
February 27, 2007 • 12:00pm ET

OPERATOR: Hello, everyone, and welcome to *Education Challenges After Treatment: Middle School Through College*, a free telephone education program. It is my pleasure to introduce your moderator, Carson Pattillo.

CARSON PATTILLO: Thank you and hello, everyone. My name is Carson Pattillo. I am the Vice President of National Education 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 we welcome all of you.

The Leukemia & Lymphoma Society appreciates your participation in today's program, *Education Challenges After Treatment: Middle School through College*. And today's program is a part of the Society's *Focus on Childhood Cancers* educational series. And this program today 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 serving families touched by childhood cancers. And I will have the pleasure of introducing her in a couple of moments.

You all should have received a packet of information that includes brochures about some of the Society's services, a flyer on some of the publications that you can order from the Information Resource Center, and Alma Morgan's biography. And we encourage you to look through the materials at your leisure.

You'll also find in your packet an order form for The Leukemia & Lymphoma Society's materials and an evaluation form for you to fill out for today's program. And for nurses and social workers, you can receive continuing education credit for today's program. And we have included an evaluation form marked specifically for you in the packet. And if you can please return that form in the envelope provided to claim your one hour of credit. And all other program participants may use the envelope to return their program evaluation.

After our keynote presentation by Alma we will open up the program to questions from all of you, our telephone audience. And today we have just about 1,300 individuals participating today via telephone from all over the country, in addition to several international participants, so we welcome all of you.

If we are not able to get to your questions today you can call the Society's Information Resource Center, which we frequently refer to as the IRC. And the toll-free number is 1-800-955-4572, and be assured that that number is on the materials, on many of the materials that are in your packet. Dialing that number

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CARSON PATTILLO: will connect you with an information specialist, who can answer your questions or help you obtain more information. And we also encourage you to call the IRC to order materials specific to your needs. And the regular hours for the IRC are between 9a.m. and 6p.m. East Coast Standard Time, Monday through Friday.

We are also audio taping and transcribing today's live program for future posting on the Society's Web site. And the program archive will be available for you to access in a few weeks on The Leukemia & Lymphoma Society's Web site, <http://www.lls.org/survivorship>.

Now The Leukemia & Lymphoma Society provides critical information and support to all patients, families and caregivers touched by blood cancer. And the Society has 64 chapters nationwide and two in Canada, and we offer a comprehensive array of free services to patients and families touched by leukemia, lymphoma and myeloma. And the Society's mission is to cure these cancers and provide support for patients and their families. And 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 of introducing Alma Morgan. And she is back by popular demand. Alma Morgan is an educational consultant in the hospital education program at Virginia Commonwealth University Medical Center for the pediatric hematology/oncology program. And she visits approximately more than 90 schools a year, developing educational plans for children initially diagnosed and transitioning back to school following treatment. And she also conducts in-services for classmates regarding childhood cancers, sickle cell disease and hemophilia. And while the classroom presentation provides 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 the compassionate adult that they are. And prior to her 19 years at VCU Medical Center, she worked as a teacher in the private and public school sectors as well as correctional and adult education. Alma believes strongly in the partnership between the medical team and the school team and operates under the philosophy that all children can learn and be successful in the educational environment, with the proper resources, accommodations, creativity and confidence boosters. You can read Alma's biography at length in the packet.

And Alma has a little bit of a cold and some bronchitis going on, but her dedication, she is here and eager to talk to all of you. And Alma, I welcome you and I'll turn the program over to you.

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Thank you, Carson. And I guess I should say it's a blessing I'm not singing on "American Idol" tonight. I think they would probably kick me off with this voice today. But I'm going to try the best I can. And I hope if anybody has any questions, they can call me later and I'll be glad to clarify if they're having difficulty understanding me today.

I want to also to begin to thank The Leukemia & Lymphoma Society for all it is doing to address the educational issues for children and teens with cancer, and how we as professionals can meet their needs and make the transition back to school following treatment, and later on in life, as easy as possible. I think the Society is building the foundation on what needs to happen educationally for these children. Not only is the Society offering these teleconferences, but local chapters are providing conferences and workshops for school personnel and parents, as well as providing the *Trish Greene Back to School Program* and valuable other materials and resources. So I really encourage everyone to contact their local chapters to get these tools and resources. They're invaluable.

As the saying goes, it doesn't take just one person, but a village, to raise a child. In this case it definitely takes a village to see that the educational needs of children and cancer survivors are met. Trust me, it is not easy. We are making great strides, but the challenges are still there.

Teens who are getting chemotherapy and going to school every day, but throwing up in the trash can because they don't want to fall behind, are receiving Fs on their report card because the work is a day or so late. Parents are being informed that their child is in danger of being retained due to missing too many days and falling behind, without exploring other options and ways to make up the missed work. Then, of course, we have the school divisions that say children with cancer should be placed on homebound instruction and not attend school because it is too stressful on the child. When in reality, the child wants to attend school and feels stressed about being excluded from the class or social life that school brings. Therefore I have to ask, is it stressful for the child or for the teacher who will be asked to make modifications and accommodations for the child?

These are just a few of the scenarios that I am confronted with on a daily basis. I know that many of you are faced with the same challenges because of the calls and the emails I get from you. Yes, there are educational challenges after treatment, but because of you, those of you that have called in today, we can join forces to see that our children can meet their educational goals and have access to resources and tools that will support them in all their endeavors, through middle school, high school, college and work.

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The greatest challenge has already been met. These children and teens are living and have already survived one of the biggest battles they will ever have to fight, childhood cancer in general.

Therefore, what are the challenges for childhood cancer survivors for middle school through college? For the teleconference in November I discussed the challenges for the children in elementary school. In many cases, the challenges are the same for children in middle school and high school, but to a far greater degree.

While in elementary school the child has only one or two teachers that he must interact with on a daily basis. The child knows the expectations of the teacher and the structure of the classroom. In turn, the teacher is with this child approximately seven hours a day and knows the child's strengths as well as the child's limitations.

Unfortunately, when the child transitions to middle school, he now has seven or eight teachers a day, each with different expectations and routines. As the student transitions to middle school, he is given a sense of independence. He now has a locker, he must make class changes and has more books, notebooks and supplies than ever before. These are small challenges within themselves.

Now let's take the child who is a cancer survivor, who is returning to school following treatment. He still has many of the physical challenges such as fatigue and overall low stamina. Walking from one end of that big school building to the other can be very tiring and he doesn't want to get a tardy slip, which will result in detention. He is still drinking his fluids and he needs to go to the restroom often, but time does not always allow for that. The teacher gets upset when he asks to be excused because then everyone in the class wants to be excused.

And let's talk about PE when he must dress and he is still self-conscious of the stretch marks due to the drastic weight loss or weight gain.

He is still a little embarrassed about how his thin hair has not grown back in some spots.

All of these are physical challenges. They can last several years following treatment.

Now let's discuss the cognitive challenges or should I say the late effects of treatment? Many times these late effects do not show up until two to five years after treatment. By this time the child looks physically well. He is a cancer survivor. And unless the parent or child lets the teachers know, the teachers have no idea that he is a cancer survivor.

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However, what is the child faced with at school in regard to his academic work? He may realize that the ability to focus and concentrate for long periods of time is difficult. He is frustrated that it is taking him four to six hours a night to get his homework completed. When he talks with his peers, he realizes they are spending only two to three hours a night to make the same grades.

When writing or note-taking for any length of time, his hands start to hurt with the neuropathy.

Often he studies for hours to prepare for a test and feels he knows the information, but has forgotten everything by the next day at school. When he takes a test, it always takes him additional time to finish, which in turn either makes him late for his next class or he must turn in the test incomplete.

The teachers are reporting that he is not turning in homework and his parents are upset over the zeroes on homework. However, he forgets to write his assignments in his agenda book and often does not hear the oral directions of the teacher. He heard her say to read chapter 5, section 2, but he did not hear that he was supposed to complete the section review at the end of the chapter.

When orally called upon to discuss a topic or answer a specific question, he knows what he wants to say, but the words will not come. What is happening?

When sitting with numerous teens and families for their neuro-psych feedback sessions, it is quite apparent that many of these cancer survivors face the same or similar cognitive deficits. Short term memory loss, difficulty with word retrieval, slower processing skills, poor organization and the inability to multi-task are all common late effects. Many times these children or teens parallel a student with ADD, attention deficit disorder, because the poor organization, inability to concentrate and inability to multi-task are major problems within the school and the home setting.

Again, many times the child or teen realizes that his work habits, study skills or overall academic skills are different than before. But the young person in middle school or high school does not want to raise attention to these problems. The middle schooler or high schooler just wants to get on with life and resume some normalcy.

Working with this age can be difficult because they so much do not want to appear different. Being in middle school is challenging enough without interspersing physical and cognitive challenges from having cancer.

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Besides not wanting to appear different, the young teen does not want to worry Mom and Dad. Many times the child remembers the worry of his parents when going through treatment. The child remembers seeing Mom or Dad cry and he is trying to protect them from any further worry.

Now let's discuss the social challenges that middle school brings. The young person in middle school, they are straddling the line between childhood and adolescence. There's quite a variation in the maturity level of the young people in middle school. Consequently, the student who has battled childhood cancer often is more mature than his or her years. These young people have experienced surgeries, radiation, chemotherapy, blood transfusions, bone marrow transplants and other medical procedures that their peers have no knowledge of. In addition, the cancer survivor has spent a lot of time with adults in a grownup world. Often during treatment these young people were isolated from peers due to risk of infection. Their immunity system was suppressed and the child was not allowed to go to birthday parties, sleepovers, swimming at the pool, to the beach, and thus did not have the opportunity to play and interact with other peers.

Therefore, socialization is an issue when reaching middle school, for the students who have experienced cancer often lacked the skills to socialize with age-level peers. By the time students reach middle school, social cliques or groups have been formed. The cancer survivor feels as though he does not belong. Intervention needs to take place in order to help the middle school survivor find an interest group or club in which to belong.

In addition to these physical, cognitive and social challenges are the obstacles that the survivor in middle school faces in regard to scheduling and curriculum. It is in middle school that students begin taking classes for high school credit, particularly in regard to math and foreign language requirements. Special guidance should be given to these cancer survivors, so that good choices can be made. Choices that will build self-confidence rather than create larger barriers.

As I have focused the past few minutes on the challenges of the middle school survivors, the same challenges are faced by the high school survivors. Thus the survivor in high school is more determined than ever to forget he ever had cancer and to find normalcy at whatever the cost. Unfortunately, the high school survivor is making choices that will impact his future. If he wishes to go to college following graduation, he must be concerned with the type of diploma he is working toward. If he's striving for an international baccalaureate diploma, an advanced diploma, a standard diploma, a modified diploma or an IEP diploma,

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depending on the diploma he is pursuing depends on the classes he is taking and the course credit he is earning.

In addition, the student has to be concerned with standards of learning and state testing assessments. Each state will have different requirements for graduation, but it is important that the teen survivor and his parents are aware of the choices available and the requirements, so that the student is working toward his future aspirations. Waiting until the junior or senior year to be concerned with post-secondary vocational goals is a little late.

Unfortunately, I have had many middle school and high school students return to school and struggle for years before they are ready to admit that something is different and they need help. Some may say it is denial and others may say that they just did not want to admit that they were still struggling with the aftermath of having childhood cancer.

One young man who had always dreamed of going to a specific four-year university was devastated spring of his senior year when he received his rejection letter regarding admission. Not only was he not accepted at his dream school, but was rejected at all his top choice schools.

When I was called to meet with him, his parents and his guidance counselor, he cried and said, "I'm being punished again for having cancer." We all knew that this young man was struggling academically in high school, but he would not talk about his weaknesses and/or his late effects. We tried to talk with him, he always claimed everything was fine, and when questioned about his average to below average grades, he lightly made excuses and said he was going to buckle down.

A 504 plan was in place for this young man with lots of accommodations to support him. However, he stated he did not need the accommodations. The teachers were not concerned because they saw a very social, positive young man. It was his cover.

Therefore, how can we assist the middle school and high school survivor who is facing cognitive, physical, social and academic challenges?

First, a rapport and a strong partnership has to exist among all the key players. The key players, meaning the medical team, the school team, the survivor and his parents or guardians. This partnership has to exist not just during treatment, but for many, many years following treatment. These challenges do not arise overnight or just at the time of treatment. They show up for years following treatment.

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We as medical professionals see these patients routinely. We see them for years, weekly, biweekly, monthly, bimonthly, every three months, every six months and then going yearly. During this time relationships are established and the patient learns he has an extended family. The physicians, the primary nurse, the social workers, the educational consultant, the child-life therapist, the psychologist, the chaplain and all the other therapists at the hospital. All of these people are working with the child for many, many years.

Then the child goes to school and relationships are developed between him and his teachers, counselors, coaches, case managers, etc. Hopefully, a strong rapport is developed between the school team.

In an ideal situation or maybe I should say a rose-colored world, these two teams work closely and consistently with the teen and family. In the best cases the survivor is seen by the medical team when he comes in for his routine follow-up appointment. If I, the educational consultant, or any of the other medical team members talk with the patient and identify an educational issue or concern, then I contact the school and a meeting is held.

Vice versa, if the school identifies that the survivor is having an academic problem and they think that it may be due to his past medical condition, then they call me and we have a meeting.

The medical team and the school team work closely with the teen and family when the need arises.

Secondly what needs to happen, an educational plan, either a 504 plan or an IEP needs to be written when the child is transitioned back to school following diagnosis. These plans should not be terminated as soon as the student finishes treatment, for as I have addressed numerous times, the physical and cognitive challenges do not always go away as soon as treatment ends. And in many cases do not surface until several years following treatment.

Nine times out of ten these students are going to need accommodations to help them be successful. I discussed at length during the teleconference in November the educational plans and the accommodations that are needed for all cancer survivors. You can request a transcript of the November teleconference from The Leukemia & Lymphoma Society. However, today I will address some accommodations that are needed for the middle and high school student. I know in November I stressed mostly the accommodations for elementary age students. So today I'd like to stress the following ones for middle and high school students.

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Permission to wear a hat or scarf if the student still has thinning spots where the hair did not grow back. Two sets of books, one for home and one for school, due to the fatigue issues and the heavy backpacks that weigh 40 to 50 pounds. Modified workload with emphasis on quality versus quantity when the student is spending four to five hours on homework nightly. Particularly in regards to algebra and other higher math courses, if the student can show he can master the concept with 10 problems as opposed to 20, this really would cut down on the amount of homework he would have each evening and the hours spent on homework. Extended time to take tests and quizzes. This must be documented on an educational plan as a need in the school environment before the student is going to be able to ask for extended time on SAT testing. A parking space close to the main entrance of the school. For students in PE, they can ask for a private dressing stall and permission to wear sweats as opposed to the regular gym suit. And then we have permission to leave class five minutes early to get to his next class. Students often need additional time to get to the locker, water fountain and to the restroom.

I had one young lady that was diagnosed with Wilms' tumor and had lost a kidney at 2 years of age. She had just entered the ninth grade in high school and was having difficulty getting to the restroom between classes. This had never been a problem in elementary and middle school, but the time constraints were different in high school and she did not have time. This had to be written into her educational plan.

Extended school year to make up any work for credit that may have been delayed due to medical condition, so that the student does not have to repeat the credit-earning classes. I know it's so frustrating for these young people who are working for their graduation credits and they get halfway through the year and then they might be hospitalized for several days or another medical condition in which they're going to be out of school for an extended time. And when they go back they feel so far behind and they feel like the year is lost and they have to start over.

Well, that doesn't have to happen. You can ask for an extended school year and over the summer that work can be made up then.

And then other factors that often help the high school student who is earning credit for graduation and may need a lighter case load is to take a class in summer school, take a class online, take alternative PE in the summer, or you might want to take driver's education privately.

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I want to stress at this time that survivors of childhood cancer may have many of the physical or cognitive challenges that I have discussed, but the majority of the young people I know work very hard and will go the extra mile to be successful. School, grades, a social life, career aspirations, etc. are very important to them. Yes, they become frustrated over having to work so hard, but they still have high ambition. If these young people want to take IB, honors and advanced placement classes and they have been in accelerated programs in the past and done well, why should we now take this away from them?

Yes, they may have to work a little harder and they may need extended time or a modified workload or another modification. But please, shouldn't we let them try?

As professionals it is our job to try and help these young people achieve their goals. Yes, and sometimes we must be very creative, but where there is a will there is always a way.

Okay, back to what we can do to help with the challenges. One, we can work as a partnership and build a strong and lasting rapport. Two, we can write strong educational plans that will stay in place for as long as the student needs the accommodation. And three, we will address transition issues and write transition plans, particularly for the students in high school.

I have many friends who are high school guidance counselors. Unfortunately, because of high case loads and the many, many job requirements that they have, little time is available to counsel students on career options and goals. Therefore, this is a job that rests with all the other significant people in the life of the student – the medical team, the school team, parents and friends.

This transition component is very important. Our medical team at Virginia Commonwealth University is often called upon by the survivors for appointments or consults during a transition period. I describe transition as the movement of a student from one critical period in life to the next, depending on the circumstances. Transition can occur when a child is diagnosed and then transitions back to school, when he transitions from elementary school to middle school, middle school to high school, high school to post-secondary education or post-secondary education to work.

Today, since I am addressing the high school and college age survivor, I would like to address what is included in the post-secondary education or education following high school. I find in general that students with chronic illness often do

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very well when followed by the pediatric team and they're able to attend school regularly. However, when the student graduates from high school, he or she often feels lost and without direction. Therefore, what is available?

Well, we have community college, four year college or university, internships, apprenticeships, vocational and technical training, independent living, employment and work.

What homework needs to happen to explore these post-secondary education options with our survivors? The student needs to explore career goals, interests, hopes and dreams. They need to design a plan and determine what is needed to reach the goal. Meet with individuals who work in the field of interest and who can offer guidance and support. Determine what accommodations and supports are needed.

If the student's high school has a career counselor, ask to meet with this individual on an individual basis. Check out directories and pamphlets to read and research various careers.

If the school has a counselor from a department of vocational rehabilitative services for the state assigned, go meet with this individual and see what services are available at the state level. If the school does not have someone assigned from the state, find out where the state agency office is located and contact them for an appointment with a vocational and rehab counselor.

I often fill out referrals and take patients to meet with these counselors. They are very, very helpful in arranging for career assessment, job training and employment.

Somewhere in exploring career options and goals and writing a transition plan, the student needs to address several critical questions. How does my medical condition impact career goals and plans? Do I have any weaknesses or limitations that I need to address? And do I have a disability?

If the student has a 504 plan or an IEP in high school and is going to pursue a degree or certificate at a college, university or post-secondary institution, then he or she may wish to meet with the office of students with disabilities at the post-secondary education institution. When going to the meeting he should bring documentation of the disability and how it affects a major life activity. Major life activity that involves thinking, concentrating, walking, speaking. It's a long list and I did cover that on the last teleconference that we did. Documentation of the disability and how it impacts academic progress. Most recent evaluations completed. His last IEP or 504 plan that was written. And a list of accommodations that were needed then.

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Here are the challenges that I find as an educational consultant when assisting my young people with this transition from high school to college. One, the student is usually 18 and the specialist in the office of students with disabilities at the college or university relies on the student or survivor to tell them what accommodation he or she needs. The problem with this is that the college road is new and different and the survivor has never walked the path before. Therefore, how does he know what accommodation he needs or even the accommodations that are available?

It is at this time that the parents, the case manager, counselor, consultant or someone that knows the child or young survivor well, needs to accompany the survivor to the meeting and advise him on course selection and accommodations that might be beneficial. This can be a sticky time for while the student is of age and striving for independence, he still may need some guidance.

Sometimes the student does not want parental support or any support, for that matter. The college is saying we no longer hold their hand, they are in college. I am saying that we all need to hold their hand a little longer, for them to find their way and to be successful.

By holding their hand, what can we teach them? We can teach them to self-advocate for themselves.

Then that brings up another great question. How do we teach young people to self-advocate? I think this is something that has to be started very early. For the elementary student, I often do age-appropriate in-services for classmates to educate them on the diagnosis of childhood cancer, treatment, side effects and the way they can be supportive to their classmate. The students are usually very receptive and I often hear from the patient or family that it really makes a difference in the socialization and the ways the peers interact with the student who's going through treatment.

I usually get the patient himself to assist me with the presentation and in many cases this serves as therapy for the child. When I suggest this to middle school students they are sometimes skeptical about it, making a difference and the sincerity of the peers. However, I'm always amazed at the outpouring of compassion and support that these middle schoolers offer. They can come up with some of the most creative ways to reach out to their classmate such as decorating the locker when they are out for hospitalizations, sending posters or gift baskets, buying funny hats or socks, or just visiting and being a faithful friend.

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I find that when I can assist with these in-services it opens the door for the student to talk friendly about his diagnosis and how it has impacted him. These same students are then the ones that volunteer for support organizations, with The Leukemia & Lymphoma Society, Relay for Life® or the Association for the Support of Children with Cancer. When these young people then enter high school and are earning community service hours for the National Honor Society, Beta Club, Key Club or others, they are telling their stories and organizing projects, programs and events that will benefit others with cancer.

Teaching advocacy skills at a young age creates our leaders of tomorrow and encourages our young people and survivors to use the resources and tools that are available, so that they can reach their goals and be successful.

The bottom line is empowering our young survivors to be successful. Can they be successful? Absolutely.

Now bragging on my place of employment – or should I say my home away from home, VCU Medical Center – we are doing many, many things to encourage our young adults or survivors to be successful. One, we offer a summer enrichment program to reinforce academic skills, promote advocacy development and provide community awareness. Two, we offer a graduation celebration and luncheon for all our pediatric hematology and oncology patients who are graduating from high school. We invite school superintendents, principals, counselors, teachers, family and friends. Each graduate shares educational accomplishments as well as their challenges. Three, a survivors' clinic meets every Wednesday. Team members are available to meet individually with the survivor regarding specific issues and concerns. Four, a young adult survivors' retreat, ages 20 to 30, is sponsored as a weekend getaway, where survivors can socialize as well as share concerns and seek advice from other survivors. And five, we offer conferences and workshops for school personnel and parents, so that they can address educational issues for these children. The more we can do as professionals to educate others on the needs of our survivors, the more we can do to empower our young people and promote good quality of life.

In conclusion, I would like to share some advice or helpful suggestions you may wish to pass on to your children or the survivors with whom you work.

One, when taking SATs and applying to college, don't get bummed out by your scores. Take the SAT several times and with accommodations such as extended time. If the SAT scores are still low, take a prep course or take the ACTs.

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Two, don't be afraid or too proud to ask for accommodations. And if you need them, use them.

Three, visit schools in search to find a good fit. Sometimes smaller schools have smaller classes and offer more individual attention and guidance.

Four, if you have some late effects such as short term memory loss or slow processing, you may want to carry a low case load with only 12 credit hours per semester. No one says you have to finish college in four years.

And five, stay connected to the people who have supported you through your journey and those in which you have built a strong rapport, for they will continue to offer support and guidance throughout your life. Let them hold your hand a little longer while you are seeking your independence.

This concludes my presentation; however, before I close and take questions, I would like to encourage all of you, if you have further questions, please feel free to call or email me. The Leukemia & Lymphoma Society, they have my office number and my email address, and they would be more than happy to share that with you.

Thank you.

CARSON PATTILLO:

Thank you so much, Alma, for such an informative presentation. And it's so heartwarming to know we have such an advocate out there to help us, to help patients, to help survivors, their families in the schools. So thank you so much.

And yes, all of you, if you would like to contact Alma you can certainly get that number by calling the Society's Information Resource Center and we can provide that number for you.

Alma, please relax your voice and soothe it with some water and we'll get to the questions and answers in just a moment.

And before we start the interactive part of our program, I just wanted to mention to all of you, to talk to you about a new program that The Leukemia & Lymphoma Society offers. It's called the *Prescription Drug Copay Assistance Program*. And the *Prescription Drug Copay Assistance Program* offers assistance to patients towards prescription drug private insurance premiums, prescription drug private insurance copay obligations and Medicare Part B, Medicare Plan D and Medicare supplementary health insurance and Medicare advantage prescription drug premiums or prescription drug copay obligations.

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CARSON PATTILLO: The Society's *Prescription Drug Copay Assistance Program* funds are currently available for the following diagnoses: myeloma, Hodgkin's lymphoma, non-Hodgkin's lymphoma and acute myelogenous leukemia. And patients whose income is at or within 300% above the United States federal poverty guidelines are eligible for assistance including a couple other parameters. But if you are interested or would like more information, you can contact the Information Resource Center or you could go on the Society's Web site to obtain more information.

And let me give you a direct number for the copay program. It's 877-557-2672. We're very proud to offer this new program and hope it can be a benefit to you or ones that you know.

So the interactive part of our program, the question and answer session. I'd like to have the operator please give instructions for the audience to queue themselves up for questions. And I'd like to remind all of you that because we do have over 1,000 people participating today on the line, for everyone to benefit, if you can please try to keep your questions general in nature and Ms. Morgan will provide an answer general in nature. And your phone line will be muted after you ask your question, so Alma can respond. Operator, if you can please give instructions to our telephone 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.

Your first question comes from Kathleen in Ohio.

KATHLEEN: Hi. I was reading on Alma's bio here about a new publication, *Learning and Living with Cancer, Advocating for Your Child's Educational Needs*. It's a pilot program that is being transitioned into an educational program that will be conducted in all 66 chapters for the Society. I'm very interested in hearing a little about that and when will that be available?

MS. MORGAN: It is available right now through The Leukemia & Lymphoma Society.

KATHLEEN: Through all 66 chapters?

CARSON PATTILLO: All 66 chapters throughout the Society are offering this locally through the chapters to their local constituency.

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- KATHLEEN:** And is this a special program or is this just a publication? I guess I'm a little unfamiliar with what it is.
- CARSON PATTILLO:** It's a program that's offered to the community at a local venue, but there are collateral materials. There are also materials that are handed out that provide summary information that was also talked about during the program.
- KATHLEEN:** Thank you very much for that. And I appreciate so much this program. My son is a survivor and he is a freshman in high school this year and all of these things are just really coming to a head for him. I appreciate the fact that there are areas in the country that have facilities like you have in Virginia that address these. We don't really seem to have these facilities and people knowledgeable about testing for children that have survived cancer and different things like that. And I've just been trying to do so much research on this. And it is very difficult. And he is struggling and I hate to see him struggle. And I appreciate all these pieces of information that you've given us over the phone.
- MS. MORGAN:** I'd like to share real quick one thing. And this is for everyone listening who has a survivor. Each year when you're meeting at the beginning of the year with his teachers, take in this information from The Leukemia & Lymphoma Society, take in these handouts. Meet with his teachers. Let the teachers know he is a cancer survivor. These are some late effects that you might be seeing in the classroom. And tell them up front, "Call me immediately if you see that he is struggling or having a problem, so that we can address it and get some accommodations and some help for him."
- CARSON PATTILLO:** Also, Kathleen, you had mentioned the Learning and Living with Cancer booklet. That is a booklet that we promoted inside your packet, there was a flyer, and it is something you can order free of charge through the Society's Information Resource Center. And it talks about advocating for your child's educational needs and recaps some of what Alma talked about. But it absolutely is a free publication that you can take with you. And Alma mentioned, it's a great takeaway to bring into the school system or whoever you're having a conversation with regarding your son.
- MS. MORGAN:** I give every teacher one at the meetings I go to. I take one for every teacher.
- CARSON PATTILLO:** Great. Kathleen, you can order one if you'd like one, or order a couple if you'd like to hand them out and bring them to the school. But this definitely is a takeaway, a collateral material that has information for you. So thank you for bringing that up and good luck with you and your son. We'll take the question, please.

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- OPERATOR:** The next question comes from John in North Carolina.
- JOHN:** Yes, I'm interested in knowing if there is a computer program to help students who have difficulty with the bubble cards on the SAT program.
- MS. MORGAN:** I'll have to say I know there's lots and lots of technology out there, John. I am not technology savvy. I would contact the Department of Ed in your state and ask for the technology coordinator and see what's available. Each state, the Department of Ed in each state has testing and assessment coordinators and they would know what technology would be available to assess and to assist with testing.
- CARSON PATTILLO:** Thank you, John, for the question. We'll take our next question, please.
- OPERATOR:** The next question comes from Manish in India.
- MANISH:** I'm calling from India and my daughter was treated for AML, acute myelogenous leukemia, one year back. Now she wants to join the medical profession. So can I allow her to join that?
- MS. MORGAN:** Well, you know what I say? It goes back to me saying wherever there's a will, there's a way. I think that she, of course, needs to finish – is she in high school now?
- MANISH:** Yeah. [Inaudible]
- MS. MORGAN:** Has she finished high school?
- MANISH:** She has already finished high school.
- MS. MORGAN:** Already finished high school. I can only address here in Virginia that students have to take the MCAT in order to get into medical school. So I would suggest that she take the prep courses in order to train to take the medical test, and then take the medical test and see if she would be accepted into a medical school.
- CARSON PATTILLO:** We had a little bit of difficulty because of the translation, but I hope that was an answer for you and thank you so much for being on. We'll take our next question, please.
- OPERATOR:** The next question comes from Kim in Minnesota.
- KIM:** Hi. Thank you so much, Alma, and Leukemia and Lymphoma Society for this wonderful program. My daughter is a leukemia survivor. She's on a 504 plan. She was also diagnosed about a year ago with cognitive learning issues, mainly the working memory and the processing speed. And she's a senior in high school right

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- KIM :** now. And so we are wondering is this always going to be the case? Her diagnosis. Or does it get better or worse at times? We have heard that it can get better and it can get worse, but it will never go back to the way it used to be before treatment. And the second part of the question is should she be retested on occasion?
- MS. MORGAN:** Absolutely. Every 18 months to two years she should be retested. And I find in answer to your question, I find the late effects a lot of times do not go away, but I find that young people learn to compensate for them. And I think that when they have good neuro-psych evaluations, they offer good strategies. And that she is going to have to try these strategies and learn what works for her. And she is one that I would absolutely take her evaluation and I would see wherever she's going to college, take that to the office of students with disabilities and meet with them and get her a good plan, educational plan, at the school, and working with the professors. And I would strongly encourage taking a low case load. And possibly looking at the smaller schools where she can get a lot of individual help.
- CARSON PATTILLO:** Thank you very much, Kim, for being on. We'll take our next question, please.
- OPERATOR:** The next question comes from Hilary in Florida.
- HILARY:** My son is like your first caller, he's actually going into high school next year and he's in a private school. And I guess my question is how often does a child not exhibit late effects? When you were talking initially, I thinking she's talking about ADD because we've had that in the past. I've not had him tested, although because he is a more mature child, especially after what he's been through, his grades are still pretty good. He's having more difficulty actually socially. He's convinced everybody still thinks he's sick, even though he looks great, he's in school all the time now. But I'm wondering when do I intervene or have to get him help because of low self-esteem or feeling like he doesn't have friends.
- MS. MORGAN:** He's in middle school going to high school?
- HILARY:** Next year he'll be in high school. And like I said, am I naive thinking that he's not having or going to have late effects? Because he is an A-B student and he's always been an A-B student.
- MS. MORGAN:** I think that's wonderful. And not all young people have the late effects. They might have some weaknesses. But like I said, a lot of them learn to compensate. They work very hard for their grades. I have young people who are going to law school and medical school. And one young lady that I know well has her PhD in physical therapy. So they're in careers in which they are very, very successful.

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- MS. MORGAN:** Also in regard to the socialization and your son, I have this saying and I've heard it from mainly my young people. "Ms. Morgan, if you can survive middle school, you can survive anything." And I believe that. I find that when they get to high school they are with more mature students. A lot of the pettiness and the socialization and the silly things that happen in middle school, they go away in high school. It's a lot more groups, groups for the students that are more mature, and then groups for the ones that are very creative. So I think it's so many interest groups in high school and clubs, that he can choose his own. I think you're going to find that he's probably going to be much happier in high school.
- CARSON PATTILLO:** Thank you, Hilary, for the question. We will take our next question, please.
- OPERATOR:** The next question comes from Steven in New Jersey.
- STEVEN:** Are there colleges that have a preference or are more preferential to students who have the late effects from treatment?
- MS. MORGAN:** I'm going to be honest with you there. I've been asked to do some work and I've gone to several meetings, meeting with the network of coordinators of disabilities for some of the colleges here in Virginia. And you know what they tell me? "We never knew that these late effects existed for not only the young people that are coming to us in college, but for the older people that are coming that might be cancer survivors." And so I think that sometimes we have to educate the office of disabilities at the colleges on these late effects also. And as much research that we can share with them, neuro-psych evaluations, any other evaluations, reports. Medical, anything medically that you can share with them when you're trying to get your child in college and they've made a decision and you know you're going to go there, meet with these office of students with disabilities. I find that every college has an office of students with disabilities, or I don't know of any here in Virginia that do not. Meet with them and you might have to do some education there, but I think if you can get them enough documentation and enough education on the diagnosis and the late effects, that they're willing to work with you.
- CARSON PATTILLO:** Thank you, Steven, for the question. Let's take our next question, please.
- OPERATOR:** The next question comes from Gary in New York.
- GARY:** Hi, Alma, thank you very much for presenting. Twofold. One, do you think that the pre-IQ of treatment is indicative of the latent effects after treatment? And the other question I have was regarding radiation.

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- MS. MORGAN:** First question, yes. Yes, I think you do have to look at the IQ. I think you have to look at sometimes – you know, sometimes I have young people that I’m working with and they come to me and before they even are diagnosed they have an IEP. They have a learning disability.
- GARY:** I’m actually talking about the opposite. I’m a social worker. My son has ALL for the last ten months, he’s in remission. He’s a pretty intelligent fellow. He did very well on his IQ. And I’m wondering if maybe if he wasn’t handicapped from the start, that that may help him and assist him later on in dealing with the challenges.
- MS. MORGAN:** I agree with that, too.
- GARY:** The other question I had real quick was about radiation. He’s about to embark on his 12 treatments of radiation. I’m wondering if you can talk a little bit about what you have seen with the side effects post-radiation.
- MS. MORGAN:** I find that they’re very, very tired following radiation. And concentration is difficult. And that’s where I say modify that workload at school. Take a smaller class load if you can. Go easy on yourself during that time. And then work back to get your physical stamina back.
- CARSON PATTILLO:** Gary, thank you for the question. We will take our next question, please.
- OPERATOR:** The next question comes from Diane in New York.
- DIANE:** Hello. My son is in eighth grade, he’s going to be going to high school. He’s been doing great in school and I haven’t really seen any of those cognitive late effects. However, he is kind of laid back about school because he gets by, he does well. Bs, As sometimes. My question is, I believe it’s going to be three years post-chemotherapy and radiation, that how do I know if it’s just him being laid back or do I still go for the neuro-psych testing? He’s had three, I believe, since he started. He was 8 when he started. He just turned 14. So there’s that fine line between him putting effort into his work or just something else going on. And I just never ever know what to do. Do I push him? Is it him, is it late effects? I just never know what to do.
- MS. MORGAN:** I find that middle school is not as demanding as high school. When they hit high school – and I think a lot will depend on the courses that he will be taking – is he going to take the more advanced classes that are going to challenge him, is he going to take standard courses? And then is he laid back and making good grades because he’s not being challenged enough? So I don’t know if I’ve really answered your

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- MS. MORGAN:** question or not. I don't think I would get a neuro-psych right now. I think I would send him to high school, see how he does that first semester, and then go in and meet with the teachers at the conference and ask what they're seeing. We've given numerous talks – I know Daniel Armstrong, Dr. Armstrong out of Miami, and myself, on late effects. And I'm sure you know what they are. And after talking with the teachers, see if they parallel each other. I hope I answered your question.
- CARSON PATTILLO:** Thank you, Diane, for the question. And the archives programs that Alma just mentioned can be accessed on The Leukemia & Lymphoma Society's Web site. And you can download transcripts and have the written word in front of you and also listen to the talk, if that is any interest to you, Diane, or anybody else, on the program today.
- So our one hour program has come to a close. If you can all please help me thank again Alma Morgan. We are very grateful that she has donated her time to us today and we thank her for all of the work that she does every day in supporting families touched by cancer.
- And we would also like to thank all of the participants on the line. We hope that many of your questions were answered and that the information provided will assist you in your next steps.
- And a reminder to all of you to fill out your program evaluations and if you are a nurse or social worker, to fill out your continuing education credit form. And if you can please return the evaluations in the envelope provided. Feedback is extremely important to us and it helps us to plan the most meaningful programs for you, so your comments and suggestions are certainly appreciated. And this program we had today and the one we had several months ago with Alma on transitioning back into school, elementary and high school and college, came from all of you in your feedback from the evaluations, so please keep them coming.
- And our Information Resource Center is open. Do not hesitate to contact them if you have further questions, if you'd like Alma's number, if you'd like to order free materials. Our master's level information specialists are available to provide you with more information and can link you with your local chapter. The 1-800 number is on the materials in your packet.
- So on behalf of The Leukemia & Lymphoma Society, I'd like to thank you all for sharing this hour with us. Good-bye, we wish you well, and we look forward to the next opportunity to talk to you.
- OPERATOR:** Thank you. That does conclude today's conference call. You may now disconnect.
- END