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Advocating For Your Child's Learning Needs: Through Treatment and Beyond Wednesday, February 13, 2008

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To access an audio re-play and transcript of our entire *Focus on Childhood Cancers* series, please visit www.LLS.org/survivorship.

Advocating for Your Child's Learning Needs: Through Treatment and Beyond

Dr. Daniel Armstrong
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OPERATOR: Hello, everyone, and welcome to *Advocating for Your Child's Learning Needs: Through Treatment and Beyond*, 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'm the Vice President of National Education Programs for The Leukemia & Lymphoma Society. On behalf of The Leukemia & Lymphoma Society, we thank you for choosing to spend your time with us today. We welcome all of you.

The Leukemia & Lymphoma Society thanks you for taking the time to participate in today's program, *Advocating for Your Child's Learning Needs: Through Treatment and Beyond*, featuring Dr. Daniel Armstrong.

Today's program is a part of the LLS *Focus on Childhood Cancers* education series. We thank Dr. Armstrong for sharing his time and expertise with us today. I would like to inform all of you that Dr. Armstrong graciously has extended the time that he's going to be with us today, so the call will go from 12:00 to 1:30 Eastern Standard Time. He will be with us an additional half hour to answer your questions. We're so grateful to him.

I'm also proud to say that today's program is solely funded by The Leukemia & Lymphoma Society.

You should all have received a packet of information that includes a welcome letter, an agenda, a biography of Dr. Armstrong and some brochures about LLS services. Please make note of the *Co-Pay Assistance Program* brochure/flyer and the *Learning and Living* brochure/flyer. These are two important pieces of information I'd like you to read through at your leisure.

You will 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. For nurses and social workers, you can receive continuing education credit for today's program. We have included an evaluation form marked specifically for you in the packet. Today you can receive up to 1.5 credit hours for participating in the hour-and-a-half program.

After our keynote presentation by Dr. Armstrong, we will open up the program to all of you for questions from our telephone audience. We have 1,400 individuals registered for today's program via telephone from all over the country, in addition to several international participants, and those patients and caregivers from Venezuela, India, Iraq and Pakistan. A special welcome to all of you.

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CARSON PATTILLO: If we're not able to get to your questions today, you all can always reach out to the LLS Information Resource Center toll-free. We refer to the Information Resource Center as the IRC. That toll-free number is 1-800-955-4572. Dialing that number will connect you with an information specialist. The Information Resource Center's hours are between 9 AM and 6 PM Eastern Standard Time, Monday through Friday.

We're also audiotaping and transcribing today's presentation for posting on the LLS Web site. The program archive will be available for you to access in several weeks on the LLS Web site at www.LLS.org/survivorship.

For those of you who are new to us, The Leukemia & Lymphoma Society provides critical information and support to all patients and families and caregivers touched by blood cancers. LLS has 68 chapters nationwide and in Canada, and we offer a comprehensive array of free services to patients and families touched by leukemia, lymphoma and myeloma.

The LLS mission is to cure these cancers and provide support for patients and their families. We hope that today's program is a step forward in providing all of you up-to-date information about addressing the issues of childhood blood cancers and advocating for your child's learning needs through and beyond treatment.

I now have the distinct pleasure to introduce our guest speaker, Dr. Daniel Armstrong, who is a friend of LLS and is back by popular demand. Dr. Armstrong is Professor of Pediatrics and Psychology at the University of Miami Miller School of Medicine, where he is an Associate Chair of the Department of Pediatrics, the Director of the Mailman Center for Child Development and Director of the University of Miami Sickle Cell Center. He is also an Associate Chief of Staff for the Holtz Children's Hospital at the University of Miami, Jackson Memorial Medical Center. Dr. Armstrong has been an active researcher in neurodevelopment in children with cancer, sickle cell disease and HIV/AIDS. He has served as the Chair of the Psychology Committee of the National Cancer Institutes' Children's Psychology Group and is currently Chair of the congressionally mandated Sickle Cell Disease Advisory Committee of the National Heart, Lung, and Blood Institute. In 2005, Dr. Armstrong was selected as the second recipient of the Micah Batchelor Award for Excellence in Children's Health Research. This award allows him to conduct innovative research on the prevention of cognitive late effects in children treated for cancer and sickle cell disease.

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CARSON PATTILLO: Dr. Armstrong, we are so pleased and thrilled once again that you've joined us today. I'd now like to turn the program over to you.

DR. ARMSTRONG: Thank you, Carson. And thanks, all of you, for joining us today, and a special thank you to The Leukemia & Lymphoma Society. We have had an awful lot of opportunities over the last few years to collaborate on a message about these late effect issues, so that physicians, healthcare providers who are critical to the care of children with cancer, parents and teachers and grandparents and everyone else down the road can become informed and become educated. And by that education, become empowered to be advocates for the children, so that the outcomes of successful cancer treatment are good ones.

It is a real pleasure to be able to join you today and thanks to so many of you for calling in.

One of the things I've learned over the last two decades, working in this field, is that I'm probably the last person who you want to talk to. In fact, when I was working actively in the clinics in the acute care area, I worked closely with a very good social worker colleague, and when we would walk into the door, they called us Doom and Gloom. Usually meant not good news. Not all the time.

After cancer treatment is completed, we all want to think that we're done, that this was a bad chapter in our lives, that our child has been successfully cured and we don't have to worry about that any more. Unfortunately, what I'm going to talk about today is the one thing that says that that isn't done. As we have been able to move forward in successful development of treatments for leukemias, for lymphomas, for children with brain tumors and the like, we have been very successful in improving the survival rate that 25 years ago was probably in the low 20% to 30% of children who were diagnosed "would-be" survivors. We're now approaching 88%, 90% long-term survival in the leukemias.

Because of that, we have children who are surviving long enough to tell us what is the result of the treatment that they have been given. And that really is what we're going to be talking today, are those consequences of treatment.

There are issues related to how children do during the acute phase of treatment, while they're getting chemotherapy. There are issues related to how children do in the period of time after treatment is finished and while they're still in the school system, up through graduation from high school. And we're now learning more about what happens when they get to be college age and go to college, and what happens when they finish college and enter the work world, the time

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to get married, to have children, develop families. And one of the reasons that so much of what we're doing is just now coming to the point where we can talk about it in a teleconference like this is that we are just now getting a large enough group of children who are surviving to that point so that we can learn from them. That is a celebration I think for all of us and for everyone who has a child today, a sense of relief and hope for the future, that we were not able to offer necessarily in previous generations. So we are very excited about that.

The success has been so good that we now anticipate that by the next few years, about 1 in 900 adults in the United States will be a childhood cancer survivor. About 1 in 450 to 500 adults between the ages of 25 and 40 will be a childhood cancer survivor. That means, if it's not your child, if you walk around and just bump into adults on the street, you've got a pretty good chance on a crowded day at a football game to encounter a number of folks who are childhood cancer survivors, and that is a real celebration. As we have worked with these children and now adolescents and young adults, moving through their lives, we really are learning a great deal about the late effects of the treatment that we've given.

I'd like to start by indicating that there's been a process here that is important. The first step was being able to say, hey, we're seeing these effects. The second was being able to do research to better describe these effects and identify the things that they were related to. The third step was trying to see what kinds of things we can do about them. And at that level we really actually have two or three different approaches.

One is, for those children who have difficulties, and I'm going to talk about that a great deal today, we need to find interventions that work to help them with the difficulties that they are experiencing today as a consequence of the treatment that they've had. But at the same time, we have a feedback loop to the investigators who are developing the new treatment protocols for childhood leukemia and lymphoma. Those investigators are using this information about survivors to think carefully about what drugs are being used, what treatment approaches are being used and can those be altered in a way that still yields the very high success of curing these different types of cancer, yet reduces the toxicity, reduces the chance that we'll have long-term effects coming through. And hopefully, this conversation won't have to happen 50 years from now.

And so that's really where we are.

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DR. ARMSTRONG: The final point in that sequence becomes one, and it is a take-home that I hope that each of you will have as we finish this conversation today, that we are now doing a lot of work in empowering parents to become advocates, who can then move public policy and social change, so that access to the kinds of evaluations and treatment options for cognitive late effects are available more broadly throughout the United States. That's one of our next major changes as we move forward.

When we think about the effects of childhood cancer therapy, it almost requires an advanced course in neuroscience for most of us. We've thought about learning problems in our typical population over the years and we've seen folks who have severe cognitive impairment, who get very intense special education supports, often in isolated special education programs that are withdrawn from the mainstream, with highly specialized teachers. We've seen children who have specific learning disabilities who became part of our vernacular. We talk almost as easily now about attention deficit hyperactivity disorder, or ADHD, as we do about the common cold. We have really educated our population about the possibility of learning problems and differences in learning styles.

When we look at most of those types of learning problems, there's an assumption that the cause is either inadequate instruction, so the children aren't learning because we aren't teaching them correctly, or that there is some kind of potentially genetic contribution that results in this type of learning style.

When we talk about learning difficulties in children with cancer, we actually have a number of mechanisms that we now have to consider. One is that the child with cancer may wind up having learning problems that aren't related to the cancer or the treatment, but to the presence of a genetic condition. We now know that there are specific genes that are related to a child's inability to read, that there is a high contribution of genetic factors to attention deficit hyperactivity problems in children. And having cancer doesn't mean that you can't also have that other problem. And so as we tease this through, we have to think about the contributors of family genetic factors.

We have to think about the fact that the cancer and its treatment, depending on what it is, can actually damage the structure of the brain. That's particularly true in tumors of the central nervous system, what we call brain tumors, that damage the brain tissue, but it can happen with lymphomas. And we can have more subtle kinds of effects to the structures of the brain from some leukemias in very rare cases. These effects can damage a part of the brain that's already been built

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DR. ARMSTRONG: and when that happens, then some of the abilities that are related to those structures can be impaired as well. So structural damage is really the one thing that we've known more about for a longer period of time and we understand better.

But we also are learning that there are other mechanisms, other things that happen in the brain – the brain is a very dynamic organ. These things happen in the brain that can lead to learning problems and we are learning how treatment causes that to happen.

One of the big things that we know about is injury to the blood vessels in the brain. We all know about what happens when there's injury to a large blood vessel; that's called a stroke, and we've seen that in our 85-year-old grandmothers. We see that in children, but fairly rarely. Cancer treatment can cause damage, not often to large blood vessels in the brain, but the brain has an awful lot of very tiny blood vessels that supply nutrition and oxygen to the brain, which allow it to do its work; this is called the *microvascular network*.

Chemotherapy and radiation, used in the treatment of childhood cancers, can damage those blood vessels and cause them to not be able to carry blood, and because of that, the nutrients and the oxygen don't get to where they're supposed to be, the brain doesn't work and may actually die off, parts of it may die off because it's not getting adequate nutrition and oxygen. So that's one of the mechanisms that we're now understanding and looking at much more closely.

We can get disruptions in the chemicals in the brain. We always hear that somebody is having a behavioral problem, that they're having a chemical abnormality, and we do know that there are a whole variety of chemicals in the brain called neurotransmitters, which allow messages to move from one nerve to another nerve in an efficient manner. The treatments that we give can sometimes change those chemicals. They can either cause too many of them to be available in the brain, or too few of them to be available in the brain. Or they can cause damage to the places on the nerves where the chemicals move from one nerve to the next. The chemical may be there, but it can't get through. Almost like a blockade in a harbor with ships. So we know that that can happen.

We know that we can get metabolic abnormalities where the activity of the brain doesn't work. That's often related to the fact that we aren't getting enough oxygen or enough nutrition, which can be related to the blood vessel problems I mentioned a few minutes ago. We can get changes in the hormones in the brain

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DR. ARMSTRONG: that can cause changes in the personality of the child, behavioral complications, but can interfere with learning as well.

The two main things that we see in the treatment of children for leukemia and lymphoma are the—and they really are kind of very common for us—one of them is the damage to the small blood vessels causing something called calcification, where the blood vessels become hardened and the blood can't get through. I mentioned that a few minutes ago.

But one of the other things we're seeing more and more as we do the research are things that are related to the development of myelin. Myelin is a special insulating sheath; it's a protein that builds up around a nerve and as it grows it allows the electrical messages in the brain to be transmitted much more quickly. So the thicker the myelin gets, the faster everything works. It's like buying an upgrade on the processor in a computer.

One of the things that we have seen is that a number of our treatments for childhood cancer interfere with the growth and development of the myelin. So it's not that we necessarily destroy myelin, but we interfere with its ability to grow as the child grows. So the child may not have learning problems at the time that we're giving the treatment, but their learning problems may become evident 2 or 3 years later when their myelin has not grown as quickly as the myelin of their friends and their peers the same age. So everyone else is learning—our children who've been treated for cancer are learning, but not at the same rate. And appear to be falling behind and losing ability. So that happens.

The other thing that happens is that as the brain develops, there is an interesting process. The brain grows from the bottom to the top and the back to the front. And as that happens, structures that are lower down start off being very important, but as new structures grow higher up, that are able to do things better and faster, the older structures are trimmed off.

One of the things that we see happening to some degree in cancer treatment is that some of those structures aren't trimmed off and some of those higher connections don't happen. So everything slows down.

And those really are the three major things that we see as contributing to learning problems in children treated for cancer.

Now there are others, and I would call these the environmental and learning factors. Just because a child has acute lymphoblastic leukemia doesn't mean that he and his friends don't decide to play Superman off the back of the pickup truck

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and have a head injury. The head injury has nothing to do with having leukemia, but it can cause some learning problems if it's a concussion that's bad enough.

Children who are being treated for cancer have in many cases a real barrier because what we do with many of our kids is put them into hospital and homebound school programs, sometimes because we really don't have a choice and sometimes because we're afraid that they might get an infection if they go to school or think they might get teased. Well, the difficulty with that is, as well intentioned as most of our hospital and homebound programs are and as good as the teachers are who do that work, they are spread very thin, and most of our children only get a few hours of instructions a few days a week. Maybe an hour or two a day, three days a week in many cases. It's really hard to stack that level of exposure to the learning process up against being in class with a group of peers and a teacher 6 or 7 hours a day. So the opportunities for learning are sometimes a problem for us.

Those are problems, but much of our research has now shown that the long-term cognitive difficulties that many of the children have are really not related to that lack of opportunity to learning. It can only make things worse.

And when we think about specific things related to cognitive late effects, there are a whole host of things that we've learned. One is, for children who have brain tumors, how big the tumor is, where it's located and what type of surgery is done and what consequences happen with surgery; those can be very big factors in whether a child is going to have difficulty or not.

For children with leukemia and lymphoma, we really narrow that down to a couple of other things that are very significant. In the past, most children treated for leukemia or non-Hodgkin's lymphomas were treated with radiation therapy to the head and to the spine, called cranial-spinal radiation. What we've seen over the years is that that treatment, combined with intrathecal chemotherapy—chemotherapy that was injected into the spinal column—was very related to long-term cognitive effects. Most children who got radiation therapy to the head had some type of long-term learning problem.

In the late 1980s in leukemia, we began looking at the issue of whether there were other culprits. In one of the treatment groups, the protocols began coming out that did not use radiation therapy and instead just used intrathecal chemotherapy in the spinal tap, and higher doses of chemotherapy given through the vein. One of the drugs that were increased in the dose was methotrexate.

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DR. ARMSTRONG: We were going to look at that in 1988, and the funding agency told us it was a really important study. It was a well designed study, let's put it that way. They thought that we did good science. But it wasn't important because we weren't radiating anymore. Well, the outcome of that was that about 5 years after that protocol started, we began seeing that there were a lot of children who were having seizures and tremors and significant learning problems, and the National Cancer Institute came back and told us not to develop any more leukemia studies until we'd taken a look at that. We've now looked at that in a variety of different areas and have a very, very large study funded by the National Cancer Institute, to look at the role that methotrexate plays in long-term learning effects. Whether we can do something different, in a very few years we'll find out more and hopefully be able to alter our therapy in a very meaningful way.

But the chemotherapy we now know, one of the things we learned in brain tumors, was that these treatments actually could prevent using radiation therapy and lessen the effect, but they didn't completely eliminate the long-term learning problems.

Now the difficulty, and you would almost logically say, well, then why use chemotherapy in radiation if we're going to cause these problems? That's one of the reasons we have an 80% to 90% cure rate in most of these diseases. So we really are faced with dealing with the long-term cognitive effects until we find a better way to treat. And having a child who is alive and able to go on with a life that can be in most cases very high quality.

When we look at other culprits that come along, I mentioned surgery. We can have, in children with brain tumor surgery, unintended damage and bleeding, that can produce children who might have had to be wheelchair-bound and having other complications. But most of what we are talking about now is this combination of radiation and chemotherapy.

We've also looked at the fact that this is not an "if you do this, this happens" and we can say this for every child with certainty. It's a complicated process that we've uncovered.

One of the things that we've learned is that because the child's brain is developing and growing and it grows until we're in our mid-20s, the age that a child is treated makes a big difference because the effects of radiation or chemotherapy tend not to be on the parts of the brain that have developed up to the time treatment is given. So everything that happened in the past seems to be relatively protected. But the effects are on the things that will happen in the

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DR. ARMSTRONG: future, as the brain grows and develops. So how old a child is when they're treated makes an awful lot of difference, with younger children having a greater risk for having problems and having more problems in more different areas of function than children who are older when they're treated, because less has developed up to that point.

We've found that in the leukemias and lymphomas, for reasons that we don't fully understand right now, the child's gender makes a difference, with girls having a greater risk for long-term learning problems than boys.

As I mentioned before, radiation is almost a certainty for causing learning problems, and we really are concerned about children who get radiation therapy.

Chemotherapy is this great term that we use for all drugs used to treat cancer. We are learning more and more that it's not all drugs that we use, but some of the specific drugs that can cause these long-term problems. There is a great deal of research now that's starting to look at specific ones. I mentioned methotrexate a few minutes ago. That's probably the one that we're looking at most closely. We're also looking at the corticosteroids, prednisone or dexamethasone, as potential high risk drugs.

There may be other drugs. There certainly are questions about many of the other chemotherapies and whether they will also cause some problems with cognitive late effects. We don't know yet because most of those drugs have not been studied very well in this area. But the studies are being designed and folks are starting to look at that.

There are certainly surgical factors, and if a child has had to have a shunt or has had a seizure, their risk for long-term cognitive problems is greater. If they've had an infection inside their brain, that goes up as well.

That's the bad news.

Now how do we look at this from a developmental perspective? The first place to start is to think about how children grow and develop in a typical sense, without having had cancer, its treatment. What we see is that the brain really organizes itself in some really systematic ways that are predictable. When we look at the newborn, we have a pretty good idea of what is going to be happening with that newborn over the next 2 to 2½ years. We know that because they're the things we're concerned about. We're concerned about gross motor development. So the questions are always, when did the child pull to a sit, and when did they pull to a

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stand, and when did they cruise along the couch, holding onto the edge of the couch, when was the first step, was I there for it, when did my child run, when will my child ever stop running? We kind of go through this process.

It's a similar one for language, with cooing, and then cooing becomes meaningful sound, and then babbling, and babbling becomes words, and did they say "Mama" or "Dada"? Probably said "ball," much to all of our dismay. But we go through this process and then we see language really begin to explode. A whole series of single-word vocabulary, then starting to use two- and three-word sentences, and then being able to use language to communicate. That pattern is really there.

Fortunately for most children treated for leukemia and lymphoma, the most common age at diagnosis is a little over 2 years of age. So most of that gross motor and language development is in place and tends to be an area of strength in the long term.

But then when we begin treating children between 2½ to 5, what we do is we potentially interfere with typically developing areas and fine motor coordination. We really don't expect the 3 year old to be able to tie their shoes; that's something they learn to do when they're 5 or 6 years of age and that's really why we invented Velcro®. We don't expect the 2½-year-old to be able to sit for a prolonged period of time and sustain attention to a book. A few pages and we're okay. But we do expect a 5 or 6 year old to be able to go through a story without being distracted and running all around. We expect children who are older to be able to do more and do more quickly, so processing speed is important. Memory comes along during this period of time. Unfortunately, if the child is treated earlier, at 2½ or 3, we may see disruptions in those abilities, when they are supposed to be showing up in the typically developing child, and they don't, and the child has been treated for cancer.

Long term, one of the things that come up is that as the brain continues to develop, it takes on higher and higher levels of skills. So we get complex reasoning, the ability to think about and figure things out, to be creative, to plan and to organize, to regulate emotions. These are things that come on at 9, 10, 12, 13, 15 years of age. So we can see disruptions in those behaviors later on in life, way after the treatment has been given in the young child. Sometimes it is a real surprise. But it shouldn't be a surprise if we think about it as a developmental course, because we don't expect children to necessarily be able to do those things until they get to those later ages, under the best of circumstances.

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DR. ARMSTRONG: Treatment seems to have its greatest impact on the part of the brain that develops after treatment is given. That's an important take-home for everyone. The parts of the brain that have developed before treatment seem to be relatively safe. Not completely safe, we do see some isolated problems that show up, but in most of the cases those things that are in place before treatment tend to remain in place and become strengths for the future.

Now what are the things that, in terms of what a child can do, that we are most concerned about? Well, the biggest one is slowed processing speed. If the myelin isn't developing, if the connections aren't developing, if the blood supply isn't there, the brain slows down. It still works and children are still able to do things, but it takes them much longer to do it, it takes them longer to get a joke, it takes them longer to complete a homework assignment. The slow processing speed is the biggest problem that we see.

We also see a specific type of attention problem that shows up, and some parents have described it as a "spaciness" or an "episodic spaciness." Every now and then there's a brief period of not being able to sustain attention, so they have little gaps in their attention and when they have gaps in their attention, they miss the information that is occurring during that sequencing. It's really frustrating for the child and for everyone around them because they think, why don't you—"Well, I was paying attention." But maybe not for that little 10-second period.

The children are not hyperactive, they're not bouncing out of their seats, their behavior doesn't draw the attention of the teacher, but they may appear to be daydreaming in class. That was one of the early presenting symptoms before we began to understand what was happening with most of the children.

Memory difficulties that can come in, typically and most commonly, the memory problems are related to things that children see. It's processing visual information that is the most difficult. Processing auditory information, the things that they hear, actually tends to be often an area of strength. That's because of the timing sequence. The auditory memory develops earlier in the sequence than the visual memory. But that can have an effect on their ability to do a lot of things in school.

Fine motor coordination and speed is another component. This really translates mostly to handwriting. The ability to copy, to draw, to write cursive, to line up columns in a math problem. Those kinds of things come through. What we frequently see are children whose handwriting is either neat, but very, very slow, or is quick and illegible, even to them. So handwriting can be a big problem. But

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DR. ARMSTRONG: that's a problem not only for the reports that they have to write, but for their ability to take notes and be able to read them later.

We see problems with planning and organization. This usually has its onset around 10 to 13 years of age, where children just have real difficulty being able to keep track of things, to organize things. We call this an executive function difficulty.

Most of you who have children, who are typically developing, in that age range, will tell me that that's what your typically developing child does. And that is true. But one of the things that we see is that many of our children treated for cancer have that same problem, but the typically developing child by high school often has learned how to organize. Many of our children who've been treated for cancer don't get that, even as they get older and more mature. So we have to think about how to help them with that.

We see problems in math. Most frequently that is related to their ability to do calculations and that is most frequently related to their ability to memorize multiplication tables and to reverse multiplication to do division. That is related to visual memory. It's the ability to look at numbers, which don't have any inherent meaning themselves, and organize and remember relationships that don't have an inherent meaning. We wind up seeing children who have difficulty for many, many years, even after much drilling, remembering what 9×6 is.

Well, that translates often into failure in math, even on applied math, the ability to use math. What we've learned by looking very carefully at how they work, is that most of the children understand how math works, they get the wrong answer because they can't remember what 9×6 is in the equation of setting up the problem. So we have to think very much about the fact that this may be a primary memory deficit, and by working around this, using things like calculators, for instance, we can often see children be able to do grade level and age level math applications, if we can just help them with the calculation component.

Similarly, reading difficulties come in. What we've found is that most children are able to figure out how to learn to read in terms of decoding words and letters, but this is a very labor-intensive visual task, it's slow, it can be very tedious. When they read there is often a problem with the visual information of the reading being stored inadequately in their brain, in their memory. They can find it, but it's like putting it in the front of the garage where all the stuff is. It takes a good deal of looking. That process often interferes with their ability to comprehend what they've read. So they may be able to very specifically read the words, but they

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DR. ARMSTRONG: may have great difficulty being able to understand. Unfortunately, that's not just a reading problem. It is a Spanish, it is a Social Studies, it is a World Literature, it is an English Literature, it is a Science problem. Because everything that we learn from content, as we move through the school grades, involves reading. So it's an area that we have to really be able to concentrate on.

So with that summary, who's really at risk? Well, we pretty much say all children who have had a malignant brain tumor are at risk. We used to say that with the brain tumor area, we were concerned about the children who had radiation or chemotherapy and those who only had surgery, that was not terribly invasive, were okay, but we've just recently published a paper in the *Journal of Clinical Oncology* and have another one about ready to go, that is showing that children with low-grade tumors that don't require chemotherapy and radiation still wind up having some long-term consequences from the tumor and the surgery. So we really put all children with malignant brain tumors into the category of those who are at significant risk.

We are concerned about children with acute lymphoblastic leukemia: those who are treated with intrathecal chemotherapy, whether they get radiation or not, and those who get higher doses of methotrexate during the consolidation period. Now it is important to recognize that we know a couple of things about this. One, there is clearly a significant risk for these children to have long-term learning problems, but not all children have the problems. We're seeing somewhere between 40% and 50%, in the studies that are coming out, will have learning problems associated with this kind of treatment, but 50% to 60% won't. We at this point don't know why some do and some don't and we don't have the way to be able to identify which ones will or won't. That's one of the reasons that we're doing the big study that is going on right now, that's funded by the National Cancer Institute, with the hope that we will understand the biochemistry, the genetics, the structural development that goes along with this treatment, and then to do two things. One, be able to identify which children are at risk and ultimately be able to change the treatment, so that they aren't at risk or that their risk is significantly lowered.

Any children who are treated with bone marrow or hematopoietic stem cell transplant using total body radiation after being treated for leukemia, it's sort of, well, we got all the leukemia treatment and now we get radiation and we get immune suppression. So we need to look closely at that group of children and make sure that everything is going okay.

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DR. ARMSTRONG:

There's a group of children who don't have leukemias, lymphomas, don't have brain tumors, but who have tumors in the head or face and the treatment involves radiation to that tumor. Tumors of the orbit, tumors of the skull. That radiation hits the tumor where it is on the head or face, but some of it inevitably penetrates into the brain. So we can have alterations in the growth and development of specific areas of the brain that can be very confusing, so we need to watch carefully for that group of children.

A group of children that we are going to be looking at carefully, because we're starting to get reports of children with stage 4 neuroblastoma. One of the reasons we've not studied these children is that this was a disease that for many years we just didn't have very much success, so we didn't have survivors. Over the last 6 to 10 years we've had some dramatic changes in the treatment and we do have children who are becoming long-term survivors of neuroblastoma, so we're starting to mount some studies there.

Similarly, some of the children who have retinoblastoma, tumor of the eye, some of them in the past have gotten radiation therapy to the eye and others have gotten enucleation and high-dose chemotherapy regimens, so we're starting to look at that population as well.

That's enough of the bad stuff. What are we doing about it?

Well, as I mentioned first, we have a phenomenal system in the United States and across the world of collaborative research networks. The Children's Oncology Group in the United States is the organization that works together with about 250 hospitals in the United States, Canada, Switzerland and Australia, to be able to develop treatment protocols that are effective. One of the first steps that we have is using this information with the folks who are designing the new drugs and designing the protocols, to make changes in those protocols, so that the next generation doesn't have to deal with the late effects. I can assure you that those discussions happen all the time. Everyone is now thinking very carefully about that. We haven't all found the right answers, but the discussions take place as we continue to look.

What about the children who do have long-term problems? That's really where I think I'm most concerned and many of you are concerned.

Part of this is education, being able to make sure the children get back to school as quickly as they can. We actually have some very interesting data on children 10 years away from their treatment, who are still in school. Now these would be high school students. We found that even matching on disease and the type of

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DR. ARMSTRONG: treatment, children who went to school during treatment, compared with children who are in hospital, homebound and did not attend school, the children who did not attend school were more likely to have lower scores on self-reported quality of life and more likely to be in special education programs than children who attended school during their treatment. So we really can use those data as a very strong encouragement to everyone, to make sure we get children back into school, back into the classroom as quickly as we possibly can, and to explore other opportunities to have a child be in the classroom, even if they can't. The development of technology is being explored with the possibility of children being able to be in class by computer and a video camera. So those kinds of issues are coming up, to get back into the classroom.

Then there are a whole host of other things that I'd like to talk about. One of the things we've looked at is whether we can do an intervention with different types of medications. The National Cancer Institute sponsored a large trial at St. Jude Children's Research Hospital, Duke University and the Medical University of South Carolina, looking at a stimulant drug used to treat ADHD, called methylphenidate. The results were that there were a number of children, a fairly high percentage, who had a positive response to the methylphenidate. They did find that the children tended to respond to the drug in a different way, that they often needed lower doses, and some of them had reactions to the drug that we didn't typically encounter in the general population of children with ADHD. It raised some other questions. We don't have very much research on using what are called psychotropic drugs with children. So there are questions about whether there's anything about the drug that might interfere with active chemotherapy treatment, or if these things might actually make some of the side effects more intense and worse down the road. These are questions that are going to be looked at very carefully, but ones that, if a physician has recommended that your child get on one of the stimulant medications, you should discuss.

There have recently been some warnings by the Food and Drug Administration about the use of some of the psychotropic medications with children who've been treated for cancer. There's a class of antidepressants called the SSRIs [selective serotonin reuptake inhibitors] that received black box warnings because of increased risk of thinking about suicide and depression, in adolescents in particular. There have been some warnings about methylphenidate and some of the other medications because of increased risk for depression and anxiety, and one of the combinations of methylphenidate and the dexamphetamines, because of potential heart risk.

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DR. ARMSTRONG: I point these out because there's a risk–benefit decision that you have to discuss with your physician as you consider these medications.

If your child has had treatment that can affect their heart, then you should have a very serious conversation about whether to use a drug that can cause heart problems. If your child has received a treatment that might affect the chemicals in the brain, the neurotransmitters that I mentioned earlier, and there's an increased risk of depression or thinking about suicide with one of the drugs, you need to be able to have a very careful monitoring plan. The issue is, is the risk greater from giving the drug or is there a greater risk because of your child's behavior, their inability to learn, from not having the drug? That conversation is something that needs to go on with each of our cancer patients as they move forward.

The next component we have is cognitive rehabilitation. My good friends, Bob Butler and Donna Copeland, have developed a very nice cognitive remediation strategy that is based on the idea that if we exercise the brain using very specific kinds of tasks, that we may be able to develop something called *plasticity*, the ability of the brain to recover and develop alternative learning pathways. They've been doing a study funded by the National Cancer Institute and have found some improvements in attention and some modest improvements in some of the academic areas. It wasn't the home run that they hoped to have, but it's promising research to move forward on.

It also raised an issue, looking at a developmental model, as to whether the treatment, using this cognitive rehabilitation and restructuring approach, was something that needed to be started much, much earlier: before the development of the brain had been interfered with; perhaps during active treatment. That's difficult because most families are a little overwhelmed with all the things that are going on and don't necessarily want to think about this issue. One of the things that we may need each of you to do is to help educate the parents of your friends who are being treated for cancer, the other children that you know, about the issue, about the possibility of needing to get started earlier. I think we'll see some clinical trials that are going to be moving in that direction.

Another component that we've used that is really for children who have significant late effects has been compensatory intervention. This is finding ways to work around the problem. Children with cancer have access to special education services under either IDEA [Individuals with Disabilities Education Act], where you can get an individual education plan, or the section 504 regulations of the Rehabilitation Act, or 504 plan you hear about.

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DR. ARMSTRONG: Basically this is an educational legal document that describes how the school can respond to your child's specific learning needs. It usually involves having an evaluation of the child, reviewing that evaluation with the child study team, and then finding that the child meets the qualifications for one of these services under eligibility guidelines that states and the federal government have established. And then providing the components in their education process that helps to address the areas of difficulties.

When we look at children with cancer, we realize that this is not a one-time thing. We have to anticipate new areas of difficulty over time. So our compensatory intervention plan has developed some fairly simple approaches. One, since processing speed is the area of function that's most frequently a problem, we extend the time to complete assignments. We try to reduce homework demands, so that reinforcement of learning can occur at home, but the amount of time that that takes doesn't deter learning and cause other problems with motivation and "I'm just working too hard" kinds of difficulties. And we're trying to help children learn to use organizational strategies. Instead of having a book bag, develop a series of small Trapper Keeper®-type things that can be zipped up for each class, so that the only papers that you need are in that one pouch and if they get mixed up, it's just the math papers that get mixed up with one another, it's just the English papers that get mixed up with one another. In the days of electronics, being able to use PDAs [personal digital assistants] and the like, especially with older children, to be able to give them alarm reminders of things that they need to do and organizing skills.

The biggest part of our intervention has been to shift from reading and writing, which is the visual and motor process, to listening and speaking, where the auditory strengths are in place. So we've used books on tape and disks for all the reading. We sometimes have children visually read along while they listen. Sometimes that doesn't work, sometimes they just listen. But what we find is that comprehension is very high when they listen.

Using software that allows children to wear a microphone and as they speak, the computer recognizes their voice and translates it into a word processor, so that they can dictate reports and essays, then edit on screen, sometimes be able to play it back in their own voice, so they can hear what it was that they wrote, and then be able to go to a printer and turn in their work. It saves a lot of time and it captures the quality of what they're thinking about.

To be able to use calculators.

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DR. ARMSTRONG: Testing at school, as many times as possible, as oral instead of written. We see children have real difficulty with standardized tests, where they have to "bubble" answers on an answering sheet. We've looked at it carefully and what we've found frequently is the child may know the answer to the question, they read a question, they say the answer is C. They go over to the bubble sheet and they bubble in C. Then the next one the answer is B and they go in and they bubble on B. But they got mixed up, so the C went to question number 1, but the B went to number 3 on the line. So then the next one is A, so they put it in. What they wind up doing is getting the correct answer bubbled in the wrong place and their scores go way down, and so we have problems on things like SATs and standardized testing; that is a visual spatial difficulty, not a knowledge or content information. So working around the actual process of testing is important.

We need to be able to anticipate that because this is a developmental problem, new problems will show up when other children can do something and the child with cancer can't. So evaluations need to be repeated.

And then we need to be able to move this to college. Because many of our children are certainly bright enough and capable enough to be successful, but need support in school. Our issues begin with the process of educating admissions counselors, because sometimes our kids have really good grades, but very poor SAT scores and don't get past the admission process. Once they're there and into school, working with disabilities services offices, to make sure that they get the supports that are necessary. Finally, to be able to find very strong senior advocates. There is an old story about a rabbit working on his masters thesis in the woods and different predators came through. He would take them into a cave, he would walk out and the predator would not come back out. Finally a bird, who had been observing this, flew down and said, "What's going on here?" The rabbit took the bird into the cave and sitting in the cave was a giant lion. The rabbit turned to the bird and said, "It's not the topic of the thesis that matters, it's the advisor." Very important point for many of our children. Getting the chairman of the psychology or education department to be the advisor in college can be very helpful at negotiating some of the conflicts that will inevitably emerge with the professors in a variety of different classes: getting an advocate.

When we look at all of this and we look at what's happened with the compensatory intervention model over the last 20 years, we've worked with a group of children diagnosed with a specific type of brain tumor, under 6 years of age in special education programs, we've developed with them this compensatory intervention model. Of those children, all but ten went from being in special

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DR. ARMSTRONG: education programs to graduating from high schools, all but one with regular diplomas. Five of those children went on to become Florida college scholarship recipients with an overall B minus average. All have had different accommodations in place in college. Two have gone on to graduate school.

So as we move forward into the future, we've got to make sure we've got good education. This program sponsored by The Leukemia & Lymphoma Society is one of the fabulous opportunities for all of you who have called in today, to be educated about this and to improve your advocacy on behalf of your child and all children treated for cancer.

We have to be able to deal with public policy systems. I can guarantee that one of the questions that I'm going to be asked in just a minute is, "How can I get a neuropsychological evaluation done: the school says they don't do it, my insurance won't cover it, how do I get this paid for?" It's a huge problem. We've got to be able to do public policy advocacy. Some states have already passed laws requiring that insurers cover this as a health benefit. Another state I understand just introduced the legislation yesterday, to have that happen. But that happens because parents work with professionals and work with legislators to be able to inform and develop good policies. So advocacy is going to be very important.

Then we need to really work on these intervention models and find out what works. Is it medication, what's the risk? Is it cognitive restructuring and rehabilitation, and when do we do it? If it's compensatory interventions, what are the typical patterns and how do we get access to the resources necessary to carry those out?

There is an incredible emphasis being placed on the whole idea of late effects in all areas. I've talked today an awful lot and almost exclusively about cognitive and learning effects, but we know that many other areas of the child's body and life and quality of life can be affected by treatment.

The Late Effects Committee of the Children's Oncology Group has been working for a number of years and has developed a set of late effects guidelines. Those are available to you at www.survivorshipguidelines.org. There's a group that meets about once a month to review all the new evidence for: is there a problem, how do you screen for it, how do you evaluate it and how do you treat it. That will ultimately transfer into the ability for every child who is a childhood cancer survivor to be able to have their own special passport that will tell them, based on what you've got, these are the things that you need to look for. I would

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DR. ARMSTRONG: encourage you to be aware of that resource as it grows and it is a live and growing resource. Once again, that's www.survivorshipguidelines.org.

We need to be able to think about these issues because paying attention to children's learning and their school is a crucial component of success. We've done very well by carefully working with a nation of collaborators. Every parent for the last 30 years who has sat down with a doctor and has signed a consent form to say yes, I'm willing to have my child participate in this clinical trial, has been a significant contributor to the lives of every other child who is today a survivor of cancer. Had we not had the collaboration between the physicians and the healthcare teams and the investigators and the parents in that process, we would not have survivors to be concerned about today. So we thank you and we thank all of those who came before you in making that happen.

Our focus now is on how do we save the lives of these children the second time, by helping them to have full and productive lives: to be successful in school and in college, to develop relationships, to raise families and to make contributions back to the world.

In Florida we have a college scholarship program through our local ACS [American Cancer Society] that funds about 170 children a year for college scholarships. Many of them have graduated. And we've recently found something very exciting to know. About 20% of young people who graduate from college go on to graduate school. In our cancer survivorship population, that number is about 50%, much higher than in the rest of the nation. Most of those children go into careers and fields that involve helping other people. They're in medicine and psychology and education and nursing and law advocacy. We are producing not only survivors, but major contributors to the well-being of our world. To each of you who have raised a child, there is that hope to look forward and we thank you for all the effort that you've done.

Carson, I'll wrap it up with that, and we can perhaps open things up to some questions.

CARSON PATTILLO: Thank you so much, Dr. Armstrong, for such an informative, hopeful presentation. You gave us a lot of information and nuggets to think about and move forward.

As you mentioned, it's the time for the question-and-answer session, the interactive part of our program. So for all of you, before the operator gives instructions for you to enter the queue for the question-and-answer session, I'd like to remind you because we have hundreds of people on the line, for everyone to benefit, if you could please try to keep your questions general in

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- CARSON PATTILLO: nature for Dr. Armstrong and he will provide an answer general in nature. Your phone line will be muted after you ask your question, so Dr. Armstrong can respond.
- So if we can, please, Operator, give instructions to our telephone participants so they queue themselves for the questions.
- 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 received. 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.
- Our first caller is Katherine from Massachusetts.
- KATHERINE: Thank you very much for that informative presentation. My question is being posed as a social worker, working in pediatric hematology/oncology. The question is regarding proton beam radiation. I'm wondering if there's currently any clinical trials or anything going on that is evaluating the late effects of that type of treatment versus conventional radiation.
- DR. ARMSTRONG: There are some investigations that are looking at, first, the efficacy of proton beam radiation. Proton beam RT [radiation therapy] is actually only available I think at five sites in the United States at this point. So there's limited access in a general sense. It does seem to be promising in that it has a very similar effectiveness in treating the tumors, and there is at least the hope at this point that it'll have lower overall toxicity. It's been an intervention that has been in place not for long enough to really be able to do the kind of outcome studies. Those typically take anywhere from 5 to 10 years after a protocol has started, and so we're not at the point of being able to say yes or no. There are some studies that are looking at that and I'm aware of investigators who are working on the effects of proton beam, but it will unfortunately be a few years before we know the degree of benefit, if there is one.
- CARSON PATTILLO: Katherine, thank you for the question. Let's take our next question, please.
- OPERATOR: The next question comes from Stuart in Florida.
- STUART: My son was diagnosed at 14 years of age. He has ALL [acute lymphocytic leukemia]. What should I expect to be different from him than someone who was, say, diagnosed at 6 years old?

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- DR. ARMSTRONG:** That's a really good question. We are looking at whether there are any other specific things related to adolescents. But in a general sense, the older child, the effects tend to be on the structures that develop between 14 and the early 30s. Those tend to be similar to the things that I talked about. There's still a slight drop in processing speed for adolescents who are treated as compared to the younger children. There can be some difficulties, although very mild, in the area of handwriting and some of the visual-motor integration. There can be some difficulties in some of the visual memory area. But what we typically see is really more of a processing speed and maybe a little bit of attention, as the primary things that might happen in the adolescent. Unless there's something very significant going on that causes changes in brain structure. We do know that there are acute processes called encephalopathies or leukoencephalopathies that are active processes that can actually reverse some of the prior development. But those are very rare. I'd be remiss if I didn't mention that this is one of the possible things that we do see sometimes. But for the older child, it really tends to be some of the same things that I mentioned, but at a less severe level. Now that's not true of kids treated for brain tumors, but for leukemias and lymphomas, that tends to be the model that we see most frequently.
- CARSON PATTILLO:** Stuart, thank you for the question. Let's take another question, please.
- OPERATOR:** The next question comes from Yolanda in Florida.
- YOLANDA:** Hello, doctor, thank you for that wonderful information. I have a quick question. Number one, are there any vitamins or supplements that we can give to kids for late effects to help it? As far as cognitive rehabilitation, can video games help? My son was playing video games throughout—he has AML [acute myelogenous leukemia]—and he missed a year of school and has fallen right back in, never had algebra before and is doing well. Somehow maybe the visual with the video games helped him. Is that even a possibility?
- DR. ARMSTRONG:** That's actually a really good question. First, the risk factor for a child with AML for cognitive late effects is fortunately, or at least at this point, appears to be less than it does for a child with acute lymphoblastic leukemia. So that is a helpful factor. But we do have some indications, and this is actually in the general population as well, that playing video games helps to sharpen at least some of the visual-motor processing speed. Because if you're not seeing things and responding quickly with that little joystick, you don't do very well in the game. So there is some indication that that can help. But it tends to also be a very circumscribed skill area, meaning that that particular visual-motor task and speed of processing there can be supported by the video games, but it doesn't

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DR. ARMSTRONG: necessarily generalize to other areas of processing speed, not necessarily to handwriting and not necessarily to being able to do math. But it's one component that may, and I'll underline may, prove to be an important part of an arsenal to help with the long-term cognitive effects. So the kids when they come to see me, I always tell them that it really is okay to be able to play video games some of the time. And that they can tell their mom and dad that Dr. Danny said that they could play video games some of the time because it might help. The parents love that, too, by the way.

The first question is the vitamins and supplements. We really are not at that point. I think that the issue that we have with vitamins and supplements is that we have a very clear realization that there are two things about vitamins and supplements at this point. One, vitamins and supplements are drugs. They may not be marketed by the large pharmaceuticals, but they are drugs, they have chemical effects. And unfortunately, in many cases, they are unstudied drugs. So there is an issue that you need to have with any vitamin and supplement, that if you're considering that, you need to sit down with your child's physician and say I've read about this or I've heard about this and I'm thinking about adding this, is there anything that we know that would make that unsafe? That discussion needs to happen with anything that we add to a standard protocol. Most oncologists will look at this and sit down and have an honest discussion with you. There have been, some of the herbal supplements and some of the vitamins that have actually been studied now by the National Institutes of Health, and being able to go back to their data, can be very, very helpful. We're not at the point of being able to have that information for late effects at this point. I wish that we could, but we're not there. But you do need to have that conversation with your doctor and make sure you look at it very carefully and have an open discussion about whether it is safe and appropriate.

CARSON PATTILLO: Yolanda, thank you for the question. Let's take another question, please.

OPERATOR: The next question comes from Kathleen in Iowa.

KATHLEEN: Hi, Dr. Armstrong.

DR. ARMSTRONG: Is this a caucus? [Laughs]

KATHLEEN: Must be. I just want to thank you so much because you've been my best source of information. My son is an ALL survivor. He was diagnosed when he was 5 years old and he's now 15, so we consider ourselves very lucky. He has most definitely moved into this area of late effects. He was lucky enough to be tested

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KATHLEEN:

through a program, a neuropsychologist who is studying ALL children. So he went through all the testing, he did show to have definite problems and we had been seeing it in school, specifically with math and reading. My problem is that the school system, even with the doctors' recommendations for a 504 plan, have really not been terribly cooperative with this. I've gone through meeting after meeting after meeting and I finally did get them to agree to a 504 plan, but they don't really want to put anything on it unless I can prove that these things specifically involve his learning. Well, it puts the onus on the parent to come up with all this information, which I'm finding extremely difficult. I asked them to put on about the bubble testing because I've read through you that this could be a problem. And those specific different things that you have mentioned, they want me to prove that it is his problem and not through the doctor's testing results, but to show that his grade is significantly hampered by such and such a problem. How do I get around this? He's now a sophomore and this is the second year I've been working through this and his grades are dropping rapidly.

DR. ARMSTRONG:

There are a couple of things that can be helpful. There are, in addition to the learning pamphlet that The Leukemia & Lymphoma Society has put out, there are two other resources that I highly recommend to you. One of them is a report from the National Cancer Advisory Board of the National Academies of Sciences that was done in 2003. You can get access to this if you just put in a childhood cancer survivorship search at the Web site www.nap.edu. This book was a report from the National Academies of Sciences on childhood cancer survivorship issues. There's a number of sections there that summarize all the research that had been done up through 2003, which was fairly substantive. This is a report by the organization in medicine and health, created to report to the President and to Congress on issues related to the health of the American people and scientific applications. You can either download the book or there's a way to be able to purchase that one online. The second one is an outstanding book that was done by Nancy Keene and the Candlelighters Childhood Cancer Foundation on educating the child with cancer. That's available for free for any parent, any physician of a child with cancer and any teacher of a child with cancer at the Candlelighters' Web site: www.candlelighters.org, and that's a free resource. That really does summarize an awful lot of the issues that come along. And the other thing is that we've had phenomenal support from the National Children's Cancer Society for the development of what we're calling a Just in Time educational resource for parents. It's a video, streamed video, educational session, similar to what I've done on this teleconference, for teachers about specific diseases. With that we are creating downloadable PDFs that provide the summaries of the

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- DR. ARMSTRONG: evidence, list the references and the like. So that any parent, when they need it, or any teacher, when they need it, will have access to that resource on the Web. We're still a few months from getting that completed and up. Some unexpected delays over the last few months in the production, but that should be available within the next few months. Those are some of the ways that you can help to address that. But the publication from the National Academies of Sciences, the report to the executive and legislative branches, carries a little bit of weight.
- CARSON PATTILLO: Kathleen, thank you so much for participating and for the question. Let's take another question, please.
- OPERATOR: The next question comes from Allison in North Carolina.
- ALLISON: Hi. I am really thankful for your time that you've spent today. You just mentioned it very briefly, which is really on the height of my curiosity, is the leukoencephalopathy. I have just began reading extensively about that and one of the things that I read, there's ongoing studies I've read, but kids that were high-risk ALL, who received high dose, more than six treatments of intrathecal methotrexate, have a 40% chance of having symptoms like leukoencephalopathy, which I just heard about for the first time 3 weeks ago. I was researching this more because my daughter is 2 years post-treatment for ALL and she's had increased cranial pressure, marked cognitive effects through the psychological testing that we did as a baseline in the beginning and have done every year since, and has had increased balance or ataxia issues. It doesn't appear—and we're in the state of North Carolina and we have great physicians here—but it doesn't appear like there's a lot of knowledge on this leukoencephalopathy, but it appears to me that it could be a widespread problem. Can you talk more about that, or where I could find more research, or who I could talk to?
- DR. ARMSTRONG: You actually raise an interesting question because the leukoencephalopathy is a term that can actually be a very large catch-all for a whole variety of symptoms that get presented. The ones that we're most concerned about is when there is a deterioration of the brain, that frequently presents with an acute event like a seizure or a loss of consciousness or the like. Then there's a whole variety of other more subtle kinds of things that get tossed into the leukoencephalopathy category, all of which can be concerning. The big difficulty is that there are some strategies for being able to treat leukoencephalopathy when it occurs, but it's also one of those areas where the treatment protocols haven't really been standardized and it's an awful lot of—frequently what happens when you have a case of an acute leukoencephalopathy, is one doctor will call several of the other

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- DR. ARMSTRONG: doctors around the country and say what are you doing for this, what have you found that is most effective? It isn't an area that has been subjected to the kind of clinical trials for treatment that would be really informative. It is still sort of an emerging area. The thing that you really need to do with that is to sit down with your physicians and ask them who are the folks who might be doing this, do you know anybody else from your meetings that could help to inform in this area. I've worked with some children over the years and there are some significant and disturbing presentations that can occur in some of these children, sometimes years after treatment is finished and they seem to be doing just fine. But as you are indicating, a relative—compared to everything else that we're doing, a relative lack of the kind of standardized descriptive and clinical trial studies, that help us to fully understand that. So the best thing right now, and unfortunately the only real support, is a really good conversation with the oncologists that you trust and if they're uncomfortable, the discussion with them about who else can we ask the question.
- CARSON PATTILLO: Allison, thank you for the question. Let's take another question, please.
- OPERATOR: The next question comes from Terry in Utah.
- TERRY: Hi, Dr. Armstrong. Thank you so much for this. This is, oh, this is so wonderful to have this information. Two quick things. I just need to recap the answer you gave the other lady about a research report from 2003. I didn't get the whole address. NAP.edu, was that it?
- DR. ARMSTRONG: NAP.edu, right. National Academies Press.
- TERRY: The name of that research was what?
- DR. ARMSTRONG: *Childhood Cancer Survivorship*. It's a summary report on all the research on childhood cancer survivorship.
- TERRY: And then the name of the book at Candlelighters.
- DR. ARMSTRONG: *Educating the Child with Cancer*.
- TERRY: Okay, then my real question was how could we—you talked about legislation that was happening to require states for the neuro-testing, to require insurances to pay for the neuro-testing. I have found after we get the neuro-testing, the same as this other parent that called in, I can't get the schools to believe, even with my neuro-test in hand, it's just too unfamiliar to them. The public school system seems to be a club of hard and fast rules for what they know and letting

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TERRY:

something new in is just too frightening for them and they don't know what to do with us, so they keep avoiding us, they keep throwing us out. Is there any way to fast-track the schools and in a legal way? You know, like some kind of legislation or something, is anybody working on it, who would we talk to? So that we can get this in place, so that every parent who has a late effects child—I mean, testing is only the half the battle. Then you have to get these schools to believe it and even if they believe it, my next problem was where do we put this child? And they wanted, like the other lady said, to give him a 504 and then not put anything on—I mean, they finally agreed to the 504, then they won't put anything on it and they certainly won't—and a 504 just wasn't enough. He needed to be in special ed.—I remember the day they put him in special ed., they very, very, very angrily put him in there and they said we're only doing this because we can't get rid of you any other way and you need to know that you are taking services away from kids who really need it.

DR. ARMSTRONG:

We've certainly all heard that before. I wish I had the quick answer to this. This is a building advocacy issue. As some of these other states pass the law requiring this coverage, then getting that information into the schools will be really critical. I think getting the resources that I mentioned a minute ago is also another major step forward. You are correct, although I've not encountered a school that had malicious intent, meaning that they wanted to harm the children, they just didn't understand it. It's not within their scope of knowledge. And with education and the implementation of some of the interventions that we've put into place and being able to show the benefits that they have for the child, that often is what triggers not only for your child, but for any other child coming through, the kind of resources and supports that really are needed. But it is a—we have to look at this in a step by step fashion. Most of our school districts in America are under-funded, special education is under-funded and they're stretching their resources as far as they can. This is an area they don't know anything about, so our educational outreach has not been all that great. We're starting to get neuro-psychologists around the country aware of this issue, how to do the testing and how to write reports that are influential in being able to get access, but even then we've really not made it. And often the psychology community that we have that does the testing for the schools, it has not had access to this information at all. And so it really is foreign to them. Those school psychologists could be incredible advocates if they were fully informed. And so one of the things that we are doing with our Web-based program is recognizing that we need to have easy access to that. You can't wait until a teleconference in the middle of February to be able to pull it off. They need to have it when they need it. It needs to be specific to the

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- DR. ARMSTRONG: kinds of problems that that particular child has as a function of their illness. If they sit down and they hear that this is not just you complaining about your child, but every other child with ALL in the country is likely to have a similar pattern, then we begin a process of getting them to be advocates. My experience a few years ago was a great one. I went into a high school and encountered exactly what you've said. We had a staffing specialist from the region with us in the meeting and I presented the plan that this child needed and the assistant principal sat there shaking his head the whole time. And then when he finished he said, "We can't do that here, we don't do that here," and he turned to the staffing specialist and said, "Tell him what we can do." Fortunately this staffing specialist had worked with me on 15 or 20 other cases and had seen the benefits and she looked at him and said, "We're going to do whatever he says." But that is a process that takes a little bit of time to build up. And unfortunately, that's really where we are. This is new ground. You are the pioneers. And we are seeing a ground swell of parent advocacy groups and professional advocacy groups beginning to take this to the legislatures, to make the kind of statutory and regulatory changes at state levels, and potentially somewhere down the road we've got some real advocates in Congress for this as well at the federal level, to be able to move the bar more quickly. But that becomes, if we do it one at a time, we'll get one at a time. Being able to have a conference like this and have however many we have, 1,400, 1,500 parents become educated and advocate, is really the way we move to that policy. So I encourage you not to stop trying.
- CARSON PATTILLO: Terry, thank you so much for the question. I also encourage you to contact your local chapter, if you're not already connected with them, and speak with a Patient Services Manager and possibly coordinate a program that LLS can bring into the school system to educate the school personnel, school nurses and the like. We have a program in place and you certainly can talk to your local chapter about that.
- DR. ARMSTRONG: Carson, to give you credit, and I really neglected this. One state that has passed legislation requiring the evaluation component came out of a chapter of The Leukemia & Lymphoma Society.
- CARSON PATTILLO: Yes, it was. Actually from Connecticut, yes.
- DR. ARMSTRONG: So you get credit there for that advocacy and this teleconference is another great example of that. Thank you.

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CARSON PATTILLO: Right, thank you. Terry, Allison, Kathleen, you continue your passion and your mission for your children. And we're right there with you.

I am sad to say that our program has come to a close. Please help me thank Dr. Armstrong. We are so grateful that you have donated your time to us today.

We at LLS hope that many of your questions were answered and that the information provided will assist you all in your next steps for yourself, for your children, for your family.

Also a reminder that our Information Resource Center is open now, and do not hesitate to contact us at any time if you have further questions. Our masters level information specialists are available to provide you with more information and can link you with your local chapter. The number is 1-800-955-4572.

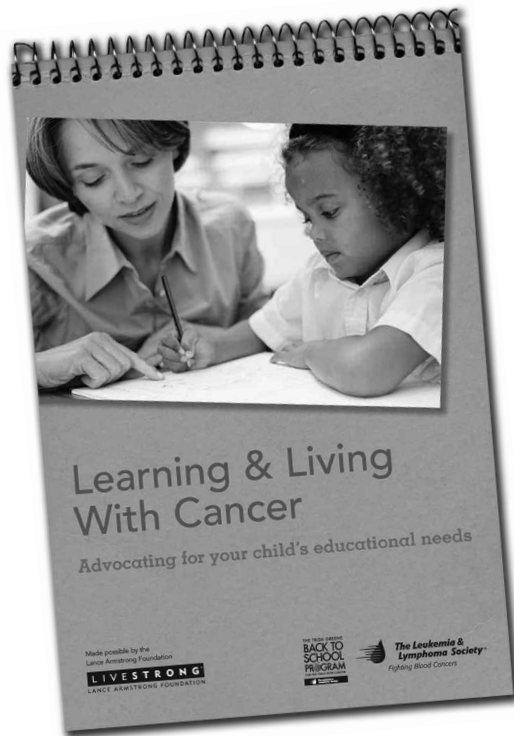
Also if you can please watch your mail for our upcoming programs, which are a part of the *Focus on Childhood Cancers* education series.

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

DR. ARMSTRONG: Thank you.

OPERATOR: This concludes today's conference call. You may now disconnect.

END



The Leukemia & Lymphoma Society is committed to serving families whose lives have been touched by childhood cancer. The *Learning & Living With Cancer* informational brochure highlights:

- Insights about the challenges children with cancer may face and what can be done
- Information about the laws that protect the child's educational needs
- Specific ways that schools can help meet the child's educational needs

If you would like to order this free booklet, please call The Leukemia & Lymphoma Society's Information Resource Center (IRC) at (800) 955-4572, e-mail infocenter@lls.org, or view it at www.LLS.org.

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Our Mission: Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

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