

**Pediatric Cancer:**  
*Insights, Challenges, Strategies and Resources*

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**Daniel Armstrong, PhD**  
**David Gordon, MS**  
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**Operator:** Good afternoon and welcome to "Pediatric Cancer: Insights, Challenges, Strategies, and Resources," a free telephone web education program. It is my pleasure to introduce your moderator, Ms. Lauren Berger.

**Lauren Berger:** Thank you, and hello, everyone. On behalf of The Leukemia & Lymphoma Society, a warm welcome to all of you, and a special thank you to Dr. Daniel Armstrong and to Mr. David Gordon for sharing their time and expertise with us today. We have almost 800 people participating from across the United States and international participants from Canada, China, Korea, Mexico, Switzerland, and Venezuela. This program is sponsored by The Leukemia & Lymphoma Society. I would like to introduce The Leukemia & Lymphoma Society's President and CEO, Mr. John Walter, who will share a few words. Thank you, John.

**John Walter:** Thank you, Lauren. I would like to add my welcome to the parents, patients, caregivers, and healthcare professionals on our program today. We are fortunate to have as our presenters, two individuals who have dedicated their careers to improving the lives of childhood cancer survivors and their families. Dr. Daniel Armstrong and Mr. David Gordon are both experts in childhood cancer survivorship, and we appreciate their dedication to supporting the mission of the Leukemia & Lymphoma Society through their research and their work every day with children and their families. I wish to thank them for taking the time out of their busy schedules to help further your understanding of insights and challenges of childhood cancer survivors as well as the strategies and resources available to help.

The Leukemia & Lymphoma Society is committed to bringing you the most up-to-date information about blood cancer. We know it is important for you to stay current so that you can work with your healthcare team to determine the best options for the best outcomes. Our vision is that one day the great majority of people who have been diagnosed with a blood cancer will be cured or they will manage their illness with good quality of life. Since 1954, LLS has awarded more than \$750 million to fund research specifically targeting blood cancer. We will continue to invest in research for cures, programs and services that improve the quality of life for patients and families. We hope this program will be helpful to you and your family's journey forward.

Thank you and I'll turn the program back over to Lauren.

**Lauren Berger:** Thanks. You should have received an agenda and a biography for each speaker. Dr. Daniel Armstrong is Professor and Associate Chair, Department of Pediatrics and Director, Mailman Center for Child Development at the University of Miami Miller School of Medicine, and he is the Associate Chief of Staff at Holtz Children's Hospital at the UM/Jackson Memorial Medical Center. Mr. David Gordon is the Executive Director of the Living Through Learning Foundation and Assistant Professor, Department of Education, at Wagner College in New York.

The first half of our program will be presented in an interview format. If you are participating on a computer you'll see slides displaying the questions that I will ask our speakers.

**Lauren Berger:** Additional supporting information and resource documents are available by clicking on the drop-down menu on the left side of your screen. These materials are also available on The Leukemia & Lymphoma Society website, and you can access them at [www.LLS.org/programs](http://www.LLS.org/programs). If you don't have Internet access, you can contact an LLS Information Specialist after our program and they'll mail you a copy. And I'll give you the telephone number at the end of our program.

Following the interview portion, we'll take live questions from the telephone and the web audiences. We are also audiotaping and transcribing this program for posting on the LLS website. This will provide you with an opportunity to read or listen again to today's program. You should have also received an evaluation form for this program. Please complete it online at [LLS.org/teleconeval](http://LLS.org/teleconeval), or use the envelope in your packet to send us your feedback. Nurses and social workers, you can earn CE credit.

Dr. Armstrong and Mr. Gordon, we are so privileged to have both of you with us today. So let's begin our program. Please describe some of the significant physical and cognitive effects from treatment for childhood cancer, both long-term and late effects. And also, do some of the treatments have the potential to cause different effects than others? And what is the timeframe for these long-term and late effects?

**Dr. Armstrong:** Thank you, Lauren. I'll take a crack at this one. Of course, that's about a four-hour lecture in a university setting to answer, but I'll try to do it in three to four minutes. When I began working with childhood leukemia in 1978, the five-year survival was about 28-29 percent. Today, that survival is approaching 90 percent.

One of the consequences of that--and we're all celebrating that tremendous growth in survivorship--is that we now have young people who survived this disease but experience the consequences of the treatment necessary to get that survival. And those consequences are what we call late effects. Late effects can occur in many systems of the body. The more common areas that we see in children would include delayed growth, difficulties with endocrine function for children who get radiation to the head, loss of thyroid function, cardiac difficulties down the road with problems with heart muscle.

The potential for a second malignancy exists in a small percentage, sometimes not the same cancer coming back, but a different type of cancer, and often in the field of radiation therapy. We can have reproductive consequences. There can be psychosocial difficulties. And one of the focus' of our talk today is cognitive function. It's important to recognize that when we talk about late effects, we're talking about things that happen after treatment has started, sometimes years after it's finished. And it's often tied to the fact that children are growing and developing. In many cases, in the brain in particular, what we find is that the abilities that a child has, and the parts of the brain that have developed prior to the treatment, tend to remain relatively intact, and those skills go forward in a positive direction. It's the things that grow and develop after the treatment that are at most risk for difficulties. And so, the age of the child at the time of treatment is important. And we clearly know that things like dose intensity and the specific type of treatment that's given, combined with the

**Dr. Armstrong:** age of the child, helps to make decisions--or helps us to predict children who are at greater or less risk for these long-term effects.

In the cognitive area, we've really done a lot of research that helped us to understand what kinds of things to expect. Late effects don't occur in every child in the same way. They really are specifically related to different components of treatment or different combinations of different types of treatment, along with age and things like gender. And prior histories and genetics all play into that. But we have been able to say, in the leukemias and lymphomas, in terms of cognitive functioning, that there are some specific treatments that we're really concerned about. Acutely during treatment, children who are getting vincristine are likely to have some fine motor difficulties, because it affects the peripheral nervous system. Just as we know that you can get jaw pain and foot drop and difficulties with constipation, we also can wind up having slowed motor speed, which can interfere with handwriting, drawing, fine motor coordination kinds of tasks, while the children are receiving the vincristine. Fortunately, most of those difficulties tend to disappear once the vincristine is eliminated and treatment is finished.

Other things that we're concerned about is that children who get cranial radiation (radiation to the head) are at significant risk for some long-term learning problem, as are, as we looked at recently, children who have received higher doses of methotrexate during the consolidation phase, and children who get intrathecal chemotherapy, or the chemotherapy that's given into the spine. Not all children who get these treatments will have these late effects. It's somewhere in the neighborhood of 30 to 50 percent that we'll wind up seeing the problems with, with another 70 to 50 percent who may not have any problems whatsoever and do fine. And unfortunately at this time, we don't have the way to be able to predict. But we do know that these treatments lead to changes on neuroimaging, and potentially some changes in the biochemistry in the brain. Those, in fact, then affect things like processing speed, the ability to sustain attention to plan and organize.

And those skills and functions translate into real world difficulties, perhaps in the areas of being able to do math calculation, to read quickly, to perform well on school-based tasks, and, in fact, in some daily living functions related to social function and the ability to keep up with peers in social situations. And so, I'll stop there with the overview, Lauren.

**Lauren Berger:** Okay. Sure. Thanks. Okay. So, that's really very comprehensive, and lots more questions to ask. So, what cognitive testing should be done as a baseline for a child in treatment for cancer? And then, when should additional testing be done and by whom? And where can you get these services? Also, just one more. How can they be accessed if the treatment center does not offer them? And will they be covered by insurance?

**Mr. Gordon:** Okay. This is David Gordon. I'm going to take a shot at that one to start. Similar to the first question, this is also probably a lengthy lecture at a college as well. I think what the person's really trying to get at is understanding all of the parts involved in getting cognitive testing, and then how those parts make connections for the child as they move through their academic career. I'll take a quick step back. For a student with a learning disability, typically

**Mr. Gordon:** what they receive from a testing standpoint are usually an intelligence test, and some academic tests. And that's usually the extent of what's necessary to see if a student has a learning disability. But, for our population, and Danny just alluded to this and spoke to it a little bit in the question before, is, survivors of a childhood cancer that receive cognitively threatening treatment also really need to have memory testing and/or what we would call executive functioning testing. And that's the part where Danny was saying how the treatments can affect planning, organization, or how they follow multistep directions. And then, that has direct impacts on subjects like math, and can affect attention in other areas as well. So, really, for baseline testing, a child with leukemia should receive intelligence testing, academic testing, and memory/executive functioning testing.

As far as when additional testing should be done, it depends oftentimes on the individual situation. One of the great parts about baseline testing is, if you think of a child learning almost as a puzzle, it gives you that frame or that border of the puzzle that we can then start to fill in. And so, when you have baseline testing, if a child starts to struggle, a year or two years or five years after therapy, potentially due to their treatment, you have something to compare the new testing to.

So, what I would really recommend, without knowing specifics of the case, is you want to have teachers and parents and the learner themselves be aware of when a child's struggling, so that you can access the system and request some additional testing. As far as who does it, whenever possible, it's really helpful to have a neuropsychologist do the testing. And oftentimes that's available within the treating center. So, there are oftentimes many neuropsychologists on the pediatric hem/onc team at a number of centers. And so, you can just talk to your center, and, if they have a neuropsychologist, they can do the testing.

There are also private neuropsychologists that can be hired to do the testing. And you're going to get a much more comprehensive result than if you maybe just work through the school system, again depending on the resources the school system has. That being said, I know for some of you out there, you're like, "Well, what if we're at a center that doesn't have a neuropsychologist on staff? What are our options?" One option, and I know of a number of hospital-based school programs with limited resources that will do this, is they will actually have the treating physician send a letter to the school district saying, "So-and-so has been diagnosed with leukemia. And we know that you know that there are treatments that they're going to receive that can cause neurocognitive late effects that can affect learning. Could you please do an evaluation, kind of almost on a voluntary basis, that will include intelligence, academic, and some memory testing?"

And it's not ideal, but it can be a very effective way. And one of the nice parts about it is it allows you to start early on to build a collaborative relationship with the school district, which can be very, very helpful for your child down the road. As far as insurance coverage goes, and I'm sure Danny will pipe in on this in particular, as well as some of the other areas that I just discussed. Oftentimes, our survivors of childhood cancers are able to get a neuropsychologist covered under insurance due to the fact that there is such a rich history,

**Mr. Gordon:** and such rich research that shows that this population of learners does tend to have issues, not only while they are receiving therapy, but even more so from a cognitive standpoint two to five or seven years after treatment's over.

**Dr. Armstrong:** David, I would add in on the insurance piece. I rarely get turned down for insurance, but it does take a little bit of work to explain to the insurance company what the condition is. It's relatively important to make sure that the insurer realizes that this should be covered under the health benefit rather than the mental health carve-out. The late effects are a consequence of cancer and cancer treatment, and most insurance companies will make that link. And when they do, then they wind up covering the service. If it's couched as a problem with school or educational issues, then it becomes a non-covered benefit and will often not get covered by insurance.

**Lauren Berger:** Thank you. Now, what questions should be asked of the oncology healthcare team about the effects, and what information should also be provided to the family practice physician or the pediatrician? And in terms of the family, what medical records should the family keep that may be needed at a later date?

**Dr. Armstrong:** Well, let me answer the third question first. Families should keep everything. And the reason for that is that you're going to need to, as parents, educate future health professionals about what your child's treatment entailed. Your child, when they become an adult, will need to be a self-advocate for their care. And, in many cases, in fact in most cases, the amount of time that records are required to be kept ranges from seven years to 21 years, if at birth. And then, after that, hospitals and other organizations have the right to be able to destroy the records.

And so, it's really important to keep the records of everything you have for the future, because also, some of the things that we know about late effects today, we didn't know 10 years ago. And the reason we didn't is we didn't have children who survived that long for us to be able to know what will happen. So, we are just now beginning to learn what are the late effects that occur in 30 and 35 year olds, who were treated when they were two to four years of age. And we will be 20 years down the road before we find out what is going to be happening in the 50 and 55 year olds. So it's a very important point to make sure you keep everything.

There is a tremendous resource that is available. There are 20-25 of us who have been meeting for several years in the Children's Oncology Group to help develop a comprehensive database for all the different types of late effects that are associated with all the different types of treatment for all kinds of cancers in children. You can access that at a website called [survivorshipguidelines.org](http://survivorshipguidelines.org). Survivorship guidelines is all one word. You can go there and actually be able to pick out the things that your child received and be able to see what does the literature, the current literature, say about what the late effects are, what kind of surveillance needs to be done, are there any kinds of interventions that can be done, any kinds of prevention.

**Dr. Armstrong:** There are some health links that are attached to those different components in the survivorship guidelines. And that is one way of being informed about what you need to know. And then you could take that to your oncologist and be able to sit down and say, "Well, what do you know about the things that my child got?" There are some programs that are being developed. In fact, the Children's Oncology Group is now piloting a program that includes an individualized passport where a child or a parent can go in and put in all the components of treatment that their child got, and the computer will link to the survivorship guidelines database, and be able to print out for you a one-to-two-to-three page document that says, "These are the things you need to be concerned about. This is what you can do about them. This is how often you have to be checking them."

It's very important to have that conversation with your oncologist and be prepared later to have it with your pediatrician, and very prepared to have it later on with the adult internal medicine or family practice person, the cardiologist, the adult neuropsychologist, because unfortunately, those folks didn't train on this kind of information when they went through school. So there is a constant educational process.

**Lauren Berger:** Can you also just define late effects in terms of timeframe?

**Dr. Armstrong:** Sure. Well, it's not so easy. Late effects are different from acute effects, meaning these are the things that we see not at the time the treatment is being given, but often in the years following the time the treatment has ended. And so, many times we'll come through and say, "Oh, boy. My child just sailed through this." And then, two or three years later, we begin to notice some problems in school, or there are some problems--the pediatrician is a little concerned about growth.

And so, these are the kinds of things that we see in the years that follow successful treatment. Those things can show up within six months of finishing treatment, and some of them may not be seen until four to five years. The reason for that is often we don't know that there is a problem until the child reaches an age when, developmentally, other children acquire a skill or have a particular growth spurt, and the child that's been treated for cancer doesn't. And so, that's one of the reasons it's called a late effect.

**Ms. Berger:** Thank you. What information should be given to the school and the teacher prior to and upon return to school?

**Mr. Gordon:** Okay. I'm going to hop in here again for this question. It's a great question and it's--I'll preface it with, it depends on the family and how private they are, and what type of information they're comfortable sharing, and to what depth. So, that's one thing that for the practitioners that are out there, just to always keep in mind. For sure you want to talk with the family and have a really open discussion about that. And as practitioners, you have a sense of the families you work with and your own comfort level with that.

That being said, I think there's a number of things that are really helpful to share with the school that are going to ease both the experience for when the learner is out of the

**Mr. Gordon:** classroom and receiving treatment in the hospital, as well as, for when they gear-up to return to school on either a part-time or a full-time basis.

From a medical standpoint, you want to make sure that the teacher has the correct information as far as diagnosis and treatment goes. And then you really, much more so, want them to be aware of any physical changes that the child's experienced, whether those are short-term or long-term, the fatigue issue that the child may be experiencing, again both short-term or long-term. Infection and infection concerns oftentimes will come up, and you want to handle in a very direct way, not just with the teacher but obviously with the school nurse and with the administration as well.

And again, one of the things that's really important is, especially as we talk about school issues and cognitive issues, is making sure teachers have an idea of what things become or can become issues for students over time from a cognitive standpoint. You know, they're with the child seven and a half hours a day, working on learning and working on different aspects that are engaging the brain. So, they're probably some of the people that are most likely to notice changes in a child's learning, oftentimes them and the parent. So, you want to make sure that they're aware of those types of issues as well.

Then, another thing that I think is really important, is many times teachers and schools become very concerned, and rightfully so, when a child is diagnosed with cancer. But they also aren't really sure how to act or how to interact with the child and the family. They don't want to "push the child too much," is often something that we'll hear. So, you really want to be able to, if possible, meet with the key players from the school and explain how and what you would like for your child, so that, when they do reintegrate back into the classroom, it can be a really smooth transition.

A number of treating institutions have specific programs, whether they're called school reentry programs or school intervention programs, where staff members from the hospital will go out and talk to the classroom teacher and talk to the students in the classroom. So you can really demystify the experience, which I think is the important piece. You want to make sure that ultimately the teachers have correct and accurate information, that there's not any misinformation going around, and just demystify the experience in general.

And finally, I think just making sure that the teachers and the school are really aware of any of the academic, social, or emotional issues that may be going on with the child, so, again, if something does start to show itself as an issue, it can be addressed quickly before it becomes a more significant issue down the road.

**Ms. Berger:** Thank you. Does research show that, later in life, childhood cancer survivors can regain some of the lost cognitive skills?

**Dr. Armstrong:** Well, this is the question that I get asked probably more than anything else, Lauren. And what we see is that we can perhaps lessen the impact that these long-term, cognitive difficulties can have. But we don't have data yet that can suggest that we can completely reverse them and get a child back onto a normal course for a whole lot of different reasons.

There are some emerging, promising treatments, however. One of the things that really catches a lot of people's eyes is the whole idea of cognitive remediation. This is the idea of being able to put the brain through a series of exercises using mass practice, using computers and the like, and try to exercise the brain to regain cognitive strength. And it's a promising approach that's been shown to be effective following acute stroke and traumatic brain injury. And it has shown some promise in children treated for cancer, although one of the difficulties is that, as we talked about with the long-term effects, that these things are developing over time; there are some real concerns that, by the time a child shows the difficulty, so much brain change has taken place that the effects of the cognitive remediation may be limited.

So there are some folks who are really starting to look at doing the cognitive remediation before problems are detected in the hopes of preventing them down the road. And that's a promising avenue to be thinking about. There clearly are some things that we can do in terms of educational support and early intervention. Informed early intervention in the classroom can be very helpful. What we have to recognize is that we are seeing damage to the brain in those children who experience late effects, and so they will learn differently. And they may not learn the same way that other children with specific learning disabilities or intellectual disabilities will learn. And there are ways that they can learn, but there are also places where they may hit a wall and not be able to learn. So accommodations for learning will be necessary.

There is some promising work that's being done really looking at keeping children on a typical learning path until the point where they hit a wall, and then making a shift from a primary reading/writing approach, to learning to increasing their dependence on listening, oral devices, spoken language, and being able to boost comprehension and expression in a pathway that doesn't seem to be as affected by the treatment.

There's also some work that's being done in the use of different medications. There was a large study sponsored by the National Cancer Institute using methylphenidate, which is commonly used in the treatment of a lot of different types of attention deficit hyperactivity disorder that showed for some children there was a significant improvement with the medication. That comes with a caution, particularly for children treated with anthracyclines or any of the drugs that might damage the heart, because methylphenidate has actually been associated with risk of sudden cardiac arrest in the general population. And for children treated for cancer who have taken a drug that can damage the heart, that needs to be thought about carefully and monitored carefully with a pediatric cardiologist. But all of these kinds of issues, cognitive remediation, compensatory intervention, educational support, and potentially drug therapies, are all the things that are really emerging. None of these are fully fleshed out. While there's promising research, there's still a lot to be done.

**Lauren Berger:** Thank you. So, we'll keep a watch on that, and hopefully good things will be heard.

**Dr. Armstrong:** We can hope.

**Lauren Berger:** Yes. What information is needed to access services at the school?

**Mr. Gordon:** Okay. I'll do my best, because this is another rather large, encompassing question, and it also depends on what the child needs. I think, if I'm understanding it correctly, the person's really just trying to understand the mechanism of accessing special education to receive services. So, without getting into too much depth, people should just be aware that there are three main pieces of education law that can apply for our children with cancer and blood disorders.

So, one is what's called, the Individuals with Disabilities Education Act (IDEA). And that's really where special education resides. Another one of the laws is something called the 504 Plan, which we can talk about more down the road, hopefully, if there are some questions on that. And the third is something called the Americans with Disabilities Act, which really applies for our learners and young adults in either college or work settings.

But to actually access services in schools, the student needs to be able to demonstrate need. So to really do that, a student either has to be struggling academically, or oftentimes, what many treating institutions will do and what we'll often experience is, our population of students will be covered underneath special education through another mechanism called "other health impairments."

So that's primarily what people need to do. There needs to be a need for those services. And just to be clear, at this time, special education and IDEA and accessing, a lot of times you'll hear the language "having an individualized education plan." That all refers to the Individuals with Disabilities Education Act. And with that, to be classified underneath special education, you need not only accommodations, but also specific services from either a special education teacher or an occupational therapist or a speech therapist or a physical therapist.

And once the need is put into place, or requested, the student then has to be tested and evidence has to be produced. And that's why, again, that baseline testing is so helpful, so that if a student really is struggling with math or with reading, we have some neuropsychological testing that can demonstrate the need at that point in time for the student, and then they can access services through a special education teacher, to receive extra help for reading or writing.

Accommodations can be done through special education, through the Individuals with Disabilities Education Act and an individualized educational plan, but they can also be done, and oftentimes are done, through something called the Section 504 Plan, which refers to a different law which we can get into down the road. But, long story short, many of our children that either have leukemia or are leukemia survivors don't need direct special

**Mr. Gordon:** education instruction. They really just need accommodations, meaning, due to some of the processing issues, they might just need some extra time on tests. If there's attentional issues, they might need a distraction-free environment.

If they're having issues, or if it's difficult for them in a classroom lecture to listen, take in the information, process it, and write it down all at the same time, which can be really quite challenging, maybe they might need an accommodation of getting a note taker, so that they have full and complete notes, so that when they're in a lecture style class they can just kind of listen to the content. With this it depends on the need of the child. And then, depending on the need, depends on which of the laws is really going to come into play. And if we have a chance, and some time later on, if there's some questions on this we can talk about this a little bit more specifically as well.

**Lauren Berger:** Very good. Thank you. What are the common psychosocial issues for patients and family members, and what kinds of services are available or appropriate for these cases?

**Dr. Armstrong:** Well, you know--this is Danny. I think one of the things that comes through, we need to look at this in, once again, acute versus long-term. For families up front, a cancer diagnosis is like taking you into a science fiction world. You don't know any of the rules. You've never thought about this before. You have no guidance in how to deal with it.

So one of the first tasks that comes up is, "What do I do in terms of discipline? You know, am I too easy? Am I too hard? What should my expectations be? How do I deal with the effects of the drugs and my child's behavior?" And that really is an acute issue that overwhelms a lot of families during the first time or first months and years of treatment, as does the whole issue of how do I manage the distress associated with needles, ports being accessed, needing to get sedated for a spinal tap, going into the MRI machine; all of those kinds of things that come along.

So there's an acute distress that is there, and it's there for both parents and for the children. Fortunately, most kids do fairly well through treatment and after treatment. In fact, most of the long-term studies from the Childhood Cancer Survivorship Study suggest that, when children with cancer grow up, they're really not any more likely to have anxiety, depression, or significant psychological problems than their peers.

There are some exceptions, however, and those are children who have central nervous system related complications and who have learning problems. Almost all children with brain tumors and the subset of children with leukemia and lymphoma who have learning problems, are more likely to have some of the anxiety/depression that comes along down the road.

What we do know, is, that while children in general do fairly well, their parents don't. And there have been a couple of studies that have looked at parents 10 years after treatment, and those parents are still having difficulty. A little bit anxious, there may even be some symptoms of posttraumatic stress. Not the disorder, but some flashback times and thinking

**Dr. Armstrong:** or hearing things, and some will develop nauseous reactions to even seeing the treatment team. The children can do that as well. So those are the kinds of things that can happen, short-term and long-term.

The question that really comes up is what do we do about that? And in most cases, a multidisciplinary team, using the resources of a social worker, a psychologist, if available, sometimes the oncologist, the nurse practitioners and nurses in the clinic, clergy, school counselors, many times just providing some support for being able to cope with the difficulty of treatment, will suffice. For some children, folks begin to think about, "Well, should we use some of the psychostimulants, the antidepressants and the like?" And it's not really clear, whether these things are good or bad.

The Food and Drug Administration has come out with some black box warnings for those kinds of drugs in the general population. I mentioned a few minutes ago that, for the stimulants like methylphenidate and others, the concerns there are the potential for heart reactions, and even in a few cases, the potential for sudden death because of a cardiac arrest. And so, we have to be really careful about making sure that the treatment that the child received doesn't increase the likelihood that that kind of event could occur. And that requires a careful discussion with the oncologist and the cardiologist, and it needs to be balanced out against how big the problem is.

Similarly, the antidepressants, the selective serotonin reuptake inhibitors, or the SSRIs, have been under a black box warning because, in children and particularly in teenage girls, there is an increased risk of depression, anxiety, and even suicide for some of the ones who have started on that. And there have been some black box warnings all around. This doesn't mean the drugs aren't effective. Some of them aren't. That's one of the reasons for the warning. They're not effective with children. But in some cases, they may be essential to use. But it's really a conversation that you need to have with your doctor about those treatments.

**Lauren Berger:** Thank you for sharing all this very important information with us. It is now time for the live question and answer portion of our program. We're so pleased that so many of you are on the program today. And so, for everyone's benefit, please keep your questions general without too many personal details, and our speakers will try to provide an answer that is general in nature. Operator, please give instructions to participants to ask a question.

**Operator:** To participate in the call by asking a question, please press star, then the number one on our keypad. If you would like to withdraw your question, press the star, then the number two on your keypad. If you are joining us by web, simply click on "ask a question," type your question, and then hit "submit." We will take your questions in the order that 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-one on your keypad, or click on the "ask a question" button, type in your question, and then click "submit."

**Lauren Berger:** Thank you. We'll take the first question from the web. The question is, "My 17-year-old child was just diagnosed with lymphoma. What fertility issues do we need to consider?"

**Dr. Armstrong:** Well, first let me give you a disclaimer that I'm by training a psychologist and not a reproductive specialist. But, when we get into this, the overlap between reproductive science and the psychology is really important. First, the risk for reproductive issues is often very drug-specific, very treatment protocol specific, and very treatment intensity specific. And so, there really is not a way to answer the question in a broad way that would be completely accurate. There are some drugs that can cause risk. But in a 17-year-old female, the risk is less than it would be in a 17-year-old male, where many of these drugs actually cause a significant drop in the ability to produce sperm, or even a complete inability to produce sperm.

However, the issues that come in are the whole question about, "Will I be able to have children if I get this treatment? Are these risks associated with treatment on my future children?" Once again, these are all questions that need to be addressed specifically with the oncologist. Parents, however, come back to see me sometimes when their child is 25, 26 years old, preparing to get married, and is angry with them for subjecting them to a treatment that has left them infertile. And it's a little difficult to realize that you wouldn't be having this problem if you hadn't gotten the treatment, because the treatment was the thing that allowed your child to live to this point.

And so, there has to be some discussion about making the decisions that have to be made, and then the options that come into play. Many times these young people are happy to be alive. They're happy to be able to contribute. And a discussion with their partner about alternatives often yields some really good outcomes where these young people wind up being great parents, sometimes to adopted children, sometimes to children conceived by different reproductive technologies. But it can be a challenging issue.

It's also important to have conversations with your oncologist about the possibility of being able to collect sperm and egg and have them frozen and stored for future reproductive capacity. In some cases, it's not possible. In some cases, just the diagnosis with lymphoma has already created a situation where there aren't adequate sperm counts, for instance, in a young man, to be able to collect and store. But, all of these things are so individualized based on treatment that it is an important conversation to have with your doctor.

**Lauren Berger:** Thank you. We'll take the next question from the telephone audience, please.

**Operator:** Thank you. Our next question comes from Denise from Florida. Please proceed with your question. Your line is live.

**Denise:** Yes. I have a six-and-a-half-year-old son who had pre-B ALL and he was on treatment for three and a half years. And so, I'm in that phase now of looking for those possible long-term effects. And I was wondering what kind of information would be out there in specific terms of research, so that I could get a better handle and ease some of my anxiety as to what he

**Denise:** may be experiencing. He has more of a percentage of a chance to experience certain things than others.

So far, he seems to be doing well. But, I just want to be prepared and be able to act accordingly. I have had him tested psychologically, and he's fine, and we will continue to monitor that. But I was wondering, where is the data and what would be the best source to go to to get the information about what to expect and what to look out for?

**Dr. Armstrong:** There actually are a number of things that are there. The Candlelighters Foundation with Nancy Keene has published a very nice book on educating the child with cancer. It's in its revision, and I understand a new volume will be out. That's available free of charge. Candlelighters has changed their name, and I apologize to all my friends in that area. I can't remember the name of the society right now. But I think you can still go to [Candlelighters.org](http://Candlelighters.org). That's free of charge for you and teachers. Nancy did a great thing there.

The Leukemia & Lymphoma Society has a very nice booklet on these kinds of issues that can be very helpful. The National Academy of Sciences published a paper in 2003, or actually a booklet and a report to Congress on late effects that a number of us participated in helping to write. And that's a really nice piece. And then there was an article that the Children's Oncology Group neurocognitive group published in the [Archives of Pediatrics and Adolescent Medicine](#), about three years ago. The first author of the paper is Nathan, N-A-T-H-A-N. And it really summarizes most of the things that we've talked about, summarizes the research findings about all of these particular types of issues. And so those would be resources I'd recommend.

**Lauren Berger:** Okay, and for Candlelighters, you'll find that in the resource materials, or you can call an LLS Information Specialist to access the resource information for this program and they can mail it to you, or tell you over the phone. Candlelighters' new name is "American Childhood Cancer Organization."

Okay. We'll take the next question from the web audience. And this is from a parent who says, "My son is in high school and an eight-year survivor of ALL. His 504B accommodates pretty well during the year except for final exams." "We have not had great success with the school in addressing memory issues for subject matter studied for an entire year and the inability to recall some of that. Other than trying to eliminate anxiety and get a good night's sleep, what suggestions do you have for accommodations for final exams in high school?"

**Mr. Gordon:** Yeah. That's a wonderful question. And again, 504s are really designed for kind of the moment in time, you know? So if they need extra time for the exam, that's where a 504 plan makes sense. When you're talking about cumulative exams, which is what this question really refers to, that's really more of a long-term memory issue.

So, the recommendation that I would have, moving forward for a family like this is, you're going to want to see if you can have a neuropsychologist from the treating institution do more of that memory or executive functioning type of testing to really be able to help provide

**Mr. Gordon:** the evidence to the school on why the child needs the accommodation, and then work with the school to figure out how you're going to modify that test based on the need.

It's a common issue that we'll see, because the survival rates are so great and because there has been so much work on minimizing the long-term effects of these survivors, which is wonderful, oftentimes we have a large percentage of leukemia survivors that have more almost, mild types of learning disabilities, that become harder to categorize within the Individuals with Disabilities Education Act. So, on the one side, it's really good news because it's not as severe of cognitive disabilities as we would have seen more in the '70s and '80s. The flipside is sometimes it makes it a little harder to access some of the services.

So, in that particular family's case, what I would recommend is to start to see if there is a way that they can pursue some additional testing again, so that they have that evidence to make the case to the school to modify the testing, if they haven't had luck getting the school to kind of agree to that beforehand.

**Lauren Berger:** Thanks. We'll take the next question from the web audience. "What is the best way to locate or enroll in a study aimed at preventing late term effects?"

**Dr. Armstrong:** Well, the first thing to do is to talk to your oncologist. Almost every children's hospital in the United States is a participant in the Children's Oncology Group (COG) trials. And the Survivorship Committee of COG has actually activated a number of late effects studies. And so the way that you'd get onto those studies would be by having a child who had a particular disease who met the criteria for that particular trial, and then being able to enroll in it. We actually have a large study right now looking specifically at long-term neurocognitive outcomes in children treated on two of the COG clinical trials.

And those kinds of things come up every so often. The group meets twice a year and new protocols are activated. That would be the best trial. The other thing to do is anything that's a clinical intervention trial, whether it is a drug therapy trial or a behavioral/educational trial, has to be registered with [clinicaltrials.gov](http://clinicaltrials.gov). And you can go to that. It's a federal website, and people do register on it because they can't publish their results in a journal if they've not registered with [clinicaltrials.gov](http://clinicaltrials.gov). You can go on there and it will give you a list of all of the open, available clinical trials. And you can see where your child might fit in order to participate. The other thing is to look and pick up the ones that are done at the major institutions that have large populations and do their research on their own.

**Lauren Berger:** And I'll just add to that, that for clinical trial information or for information on any of the other topics we're talking about today, you can call an Information Specialist at the Leukemia & Lymphoma Society and they'd be happy to help you. And that number is 1-800-955-4572. And we'll take the next question from the telephone audience, please.

**Operator:** Thank you. Our next question comes from the line of Michelle from Washington. Please proceed with your question. Your line is live.

**Michelle:** I'm wondering about the types of things that families can do at home, just in their everyday lives to try and lessen some of these late-term effects that might happen in the future. What are just some everyday things that families can do in their home environment?

**Dr. Armstrong:** David, you want to take a stab at that, or I?

**Mr. Gordon:** Sure, I can start off on that one. You know, I think what's helpful for families to do at home with kids that are of school age is just to encourage them and to work with them to continue to be active learners. One of the things from my experience when I worked in a hospital setting for a number of years is, when a child gets sick, they don't feel well, and oftentimes people will kind of downshift and say, "Oh, you know, they're not feeling well. I don't want to push them too hard," And it's understandable for short periods of time. But what happens for some of our learners is, that can get stretched out for months at a time. And if they learn that habit of being a passive learner, it's like any other habit. It's kind of hard to unbreak.

So, one of the things that we've done, and something that I do now with my foundation, is we try to provide students and learners with opportunities for engagement, regardless of whether they're at the hospital, inpatient, outpatient, or home. And that's really one of the things I'd recommend for families. So with kids, since they're not going to be in that typical classroom environment, I think if you make it interactive and fun and interesting, you're more likely to engage them in becoming active learners and staying motivated in relation to just interacting with the world around them, even though they're sick.

One of the things I'd encourage people to do is, if you're really going to start to take some of this on yourself, which I think is great, take a look at some of the museums and science centers and informal learning places around the country. Many of them will have sections of activities within their education department within that museum or science center that you can do at home. And so, this way, especially if you have a child, if you're like, "Hey, we're going to go do math homework now," then that's not going to be so motivating, as opposed to, "Hey, you know, let's do this experiment on solids, liquids, and gases." And that's something that you could do at home with just ice and water and water vapor.

So, I just wanted to try to give you a couple of ideas of places to look to start to explore that. And I think if you do that, you keep them active, you keep them engaged, you keep their brains sharp, and I think that becomes really helpful for them to reintegrate back into school. There's a number of things that can be done just parent and child, and there are also a number of ways to use technology to keep that student active and engaged in some learning opportunities. And if you're lucky and fortunate and you have a school district that's willing, I'm starting to hear of a lot of school districts that are allowing students who have chronic health issues to either Skype into the classroom or do other types of video conferencing into the classroom to stay active. And I think that's a wonderful way to go, as well.

**Dr. Armstrong:** Yeah. And David, I'd add a couple of other simple things that I think you can do. Probably what we find is, in those children who do develop cognitive late effects, the effects are often in slow processing speed, and ultimately, in the ability to quickly take in information visually,

**Dr. Armstrong:** recall it, organize it, and do handwriting. And so, the reading/writing approach that really predominates in schools, winds up often needing to be approached or supplemented with a high language, and as I mentioned, an oral, verbal, auditory approach.

So one of the most important things you can do with your child is engage them in language tasks. Do storytelling. Do deductive reasoning, not just repetition of words, but do word games with them. Do word problems that are fun. Have them tell you stories. Start a story and each person in the family picks up the story and tells another section, and then the person next picks it up and goes around. Those are simple tasks that you can do around the dinner table. Everybody gets to participate and contribute, and it can really help to strengthen language skills.

Fine motor task is another area that's affected. And while we've not looked at it in the cancer area, it has actually been shown in some interesting research, much to the dismay of many families, that video games can actually improve some of the fine motor dexterity and skill. And so, video games in moderation, and not necessarily the violent ones, can be a good thing. And then, play memory games. "Do you remember this?" You remember the old games of flipping cards over and Concentration, trying to remember where did I flip that card? As David is saying, anything that's fun develops active learning, but really builds around language, fine motor skills, and memory.

**Lauren Berger:** Thank you. Very good information to have. We've received a few questions on the web related to Down's syndrome, so I'm just going to read you two of them and see if you can respond to those. "We're struggling to separate Down's syndrome impairments from long-term effects. Can you offer any suggestions?" And the other is, "My daughter is a leukemia survivor and has Down's syndrome. Is there special testing to see if she has late-term effects of treatment versus Down's syndrome effects?"

**Dr. Armstrong:** Boy, those are very difficult questions. I was fortunate to be a member of a cross institute task force the Director of the NIH put together a few years ago on Down's syndrome, and I was asked to participate on this particular issue. I think clearly what we can see is that children with Down's syndrome have a trajectory of growth and development that you as parents will know fairly well. If there are additional complications because of the treatment that they get, then that trajectory gets thrown off. It's very similar to what we see with a typically developing child. And so, being able to track that development forward and recognize the changes that occur, those are things that may develop or may be related to cognitive disabilities. Unfortunately, there's no way to guarantee that, and we really don't have a lot of research. I think one of the things that's next on the docket is a study of cognition functioning in Down's.

**Lauren Berger:** Thank you. I'm going to take another question from the web. And this question is, "My daughter is a leukemia survivor and will be looking at colleges and possibly vocational schools next year. What issues should we be considering?"

**Mr. Gordon:** If it's okay, I'm going to jump in on that one. I think, for the college search process, my recommendation is you want to account for the main variables that any student who does a college search process would, and then add a couple more on. So, with any student that's thinking about college, you want to be clear on geography, what part of the country, assuming they want to stay in the US, that they want to go school, and the cost, which is always a family factor that's really important to consider.

And the one piece I'll add in relation to cost is, in working with a number of families on this issue, oftentimes families are like, "Oh, we don't have a lot of money. I'm going to send them to a state school." But, sometimes you can have a student that can go to a private school and receive enough in scholarship and financial aid that the costs become almost parallel. So just doing your homework on the cost piece becomes important. Making sure they choose a school that has the major that they're interested in, and if they're not sure what they're interested in, making sure that it's a school with a robust liberal arts program so they can get exposure to a number of different areas. The setting of the school: is your child most interested in being in a rural setting, a city setting, or a suburban setting? The size of the institution: are they somebody that wants to be at a really large institution, or are they somebody that's going to really benefit from a smaller school with smaller class size? And then, the competitiveness of the school.

And then, for our population of learners, I think you have to add on to that, "What do they have for student support services?" So if the student or learner is currently on therapy, just a couple things come to mind. They're probably going to look at schools either close to their treating institution or close to another treating institution, which means proximity near a city or a major metropolitan area. And then, the other piece is, "What does that school or college have for disability supportive services?" So, if it is a student that has had some late-effects issues or some cognitive issues, picking a school or a college or a post-secondary program that has good disability support services becomes very, very helpful.

And there's a number of schools out there, colleges and universities, that really promote their disability supportive services. So, if you do some homework, depending on what area of the country and those other factors I mentioned in the beginning, you can find colleges and universities or post-secondary programs that are going to have the supportive services that your child needs.

I guess my last takeaway on this question is be really clear on what your child needs, find schools that fit that learning need criteria and that also meet those other five or six criteria that they're interested in, and then you're going to have a good match. And then, also make sure that your child's willing to share that information with the college, because they are not under any obligation to provide supportive services unless the student coming in self-discloses before they come to that college or university.

**Dr. Armstrong:** And I would add into that, keep hope and keep expectations high. I've been fortunate to be part of a college scholarship program for children treated for cancer for about 13 years. And about 50 percent of the kids who are able to complete their bachelor's degree, and most do,

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**Daniel Armstrong, PhD**  
**David Gordon, MS**  
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**Dr. Armstrong:** go on to graduate or professional school, and they wind up in the professions of medicine, nursing, psychology, clergy, education. Some enter law or accounting, and they're doing 501(c)(3) charity work or advocacy law. What winds up happening with this is, it is worth every struggle to go through what David described to get through the front door, to get through college, and have them be successful, because as a group they wind up making the world a lot better place.

**Lauren Berger:** Thank you so much. That was so much information that you provided and so much hope. Things are really going well and we appreciate all of you listening today. We have a lot of resource information. We know the one hour goes by quickly. If you have not received or accessed the slides from the program or the separate resource documents, you may do so now. A number of organizations, websites and telephone numbers are listed, as well as supporting information, and additional information on the topics that were covered today. Please call our Information Resource Center at 1-800-955-4572 and they can either help you find it on our website or they can mail you a packet, if that works best for you.

Please help me thank Dr. Daniel Armstrong and Mr. David Gordon for their time. We hope that many of your questions were answered and this will assist you and your family in your next steps.

Please complete the evaluation form for today's program. We listen to all of your feedback and it's most important as we plan future programs. On behalf of The Leukemia & Lymphoma Society, thank you so much for sharing your time with us today. Good-bye and we wish you well.

**Operator:** Ladies and gentlemen, this does conclude today's event. You may disconnect your lines at this time, and we thank you all for your participation. Good day.