

## **Childhood Cancer Survivorship: Challenges, Strategies, Resources**

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**Daniel Armstrong, PhD  
Nancy Cincotta, MSN, LCSW, ACSW  
May 26, 2009 12:00 PM**

OPERATOR: Hello, everyone, and welcome to *Childhood Cancer Survivorship: Challenges, Strategies, Resources*, a free telephone education program. It is my pleasure to introduce your moderator, Carson Jacobi.

CARSON JACOBI: Thank you, Lindsey, and hello, everyone. On behalf of The Leukemia & Lymphoma Society, thank you for choosing to spend this hour and a half with us today. We welcome you to the program, *Childhood Cancer Survivorship: Challenges, Strategies, Resources*, featuring Dr. Daniel Armstrong and Nancy Cincotta. We thank them both for sharing their time and expertise with us today and for their ongoing dedication to serving families touched by cancer.

Today's program is proudly supported and funded in full by The Leukemia & Lymphoma Society.

You all should have received a packet in the mail including an agenda, a biography of Dr. Armstrong and Ms. Cincotta and an order form for The Leukemia & Lymphoma Society's materials. We encourage you to look through those materials at your leisure if you have not already done so. You will also find an evaluation form for you to fill out for today's program. For nurses and social workers, you can receive 1.5 hours of continuing education credit. All participants may visit our online evaluation center at [www.LLS.org/eval](http://www.LLS.org/eval) to complete your evaluation online, or you can mail it in the enclosed self-addressed envelope. I will provide a code for nurses and social workers to use at the conclusion of today's program.

After the presentations we will open up the phone line to questions from all of you. We have over 1,100 individuals registered for our program today from across the United States and some international participants, and they're from Australia, Canada, Mexico, India, Barbados and Kenya. A special welcome to all of you.

If we are not able to get to your questions today, you can call The Leukemia & Lymphoma Society's Information Resource Center. And the toll-free number included in your packet is 1-800-955-4572. This will connect you with an oncology professional who can answer your questions; they can help you obtain information, link you with your local chapter or help you order free materials specific to your needs. The Information Resource Center's hours are 9 AM to 6 PM, Eastern Time, Monday through Friday.

We are also audiotaping and transcribing today's program for posting on the LLS Web site in several weeks. This provides an opportunity for you to read or listen again to today's presentation, especially to follow up on any terminology or therapies, treatments that you may have missed.

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CARSON JACOBI: Before I turn the program over to our speakers today, I would like to introduce The Leukemia & Lymphoma Society's President and CEO, John Walter, who is on the call today to welcome you and share a few words. John, thanks for joining us.

JOHN WALTER: Thank you, Carson.

I'd like to add my welcome to all the parents, patients, caregivers and healthcare professionals on the call today. We are very fortunate to have as our presenters today two individuals who have dedicated their careers to improving the lives of childhood cancer survivors and their families. Dr. Daniel Armstrong and Nancy Cincotta 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 both taking the time out of their busy schedules to help further your understanding of the challenges facing 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 your blood cancers. 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 will manage their illness with good quality of life.

Since its founding in 1949, LLS has invested more than \$600 million in research, specifically targeting blood cancers. We will continue to invest in research for cures and programs and services that improve the quality of life for patients and their families. We hope this teleconference will be helpful to you on your family's journey forward.

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

CARSON JACOBI: Thanks so much, John.

I now would like to briefly tell you a little bit about both of our speakers.

The first one I'd like to talk about is Daniel Armstrong. Dr. Armstrong is Professor of Pediatrics and Psychology at the University of Miami Miller School of Medicine, where he is the Associate Chair of the Department of Pediatrics, the Director of the Mailman Center for Child Development and Director of the University of Miami's Sickle Cell Center. He's also the Associate Chief of Staff for the Holtz Children's Hospital at the University of Miami Jackson Memorial Medical Center. Dr. Armstrong

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CARSON JACOBI: has been an active researcher on neurodevelopment in children with cancer, sickle cell disease and HIV/AIDS. Dr. Armstrong was selected as the second recipient of the Micah Batchelor Award for Excellence in Children's Health Research. And this award allows him to conduct innovative research on the prevention of cognitive late effects in children treated for cancer and sickle cell disease.

I'd like to tell you also a little bit about Nancy Cincotta. Nancy has been a social worker for over 30 years, having begun her professional career as a child life specialist. As a clinician, manager and educator, she has focused on the needs of families of children with cancer and related illnesses and bereaved families. Ms. Cincotta is the Psychosocial Director of Camp Sunshine in Casco, Maine. Camp Sunshine is a nationally based retreat program for families of children with life-threatening illnesses and bereaved families. Ms. Cincotta is interested in demystifying the emotional journey faced by children and their families once diagnosed with a life-threatening illness and exploring the burdens encountered by and resilience of professionals working in this area. And her current research centers on the role of hope in the lives of families with seriously ill children.

We're so very grateful that we have both of these experts with us today. I'd first like to turn the program over to Dr. Armstrong. Dr. Armstrong?

DR. ARMSTRONG: Thank you, Carson. And thank you all for joining us today. It's always a privilege to do a teleconference for The Leukemia & Lymphoma Society and to have the opportunity to have all of you join us to learn about the late effects.

I'm going to try to respond, in the presentation, to an organized review of what we know about primarily cognitive late effects, but also to address some of the issues of survivorship in general. A number of you sent in an awful lot of questions to us in advance. I was going over – this could go four or five hours with the number of questions you've provided – so we'll try to be concise and recognize that we won't get to everything today.

I do want to talk a little bit about why we're talking about survivorship. Within the next few years we expect that about 1 in 900 adults will be a childhood cancer survivor. We're looking at overall survival rates that are rapidly approaching, for all types of cancer, about 80 percent. For many of the leukemias and lymphomas we're now in the 90 percent range. And so we really expect children to be able to survive this disease, whereas many years ago that was not the case.

As we are moving forward and seeing children survive, we're also learning that there are consequences to survival and we call those late effects because many times

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DR. ARMSTRONG: these are the problems that show up years after treatment is finished, when we think we've made it through and have gotten a cure.

There's an awful lot of work going on in survivorship and I'm going to give you a Web site—and I'll repeat this again a little bit later, [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org). This is the work of a number of scientists that are part of the Children's Oncology Group and we meet monthly and review all the literature on the topic of survivorship. And we have at this Web site a very large and detailed reference for all the different types of treatments that are provided to children during the active phase of all types of cancer, what we know about acute and long-term toxicities and side effects, some health links and some recommendations for what kind of surveillance should be put into place, as well as when we know, what kind of treatments for late effects are available. So I really encourage you to know this Web site, to keep up with it, because we are updating it as new information comes out all the time.

One of the things that we clearly know is that there are late effects of childhood cancer. And some people always ask the question, why didn't we know about all of these? Part of the reason is that you have to have survivors who live long enough to tell you what is happening and we are celebrating the fact that we now have many, many children who are reaching that point and many more that are expected to reach that point.

As we move through we find out, however, that cancer treatment, particularly in developing children, can have a number of problems. It can affect growth and development. It can affect reproductive capacity later on. It can affect the bones and bone growth and bone deterioration, the heart, can affect breathing. It can affect almost every area or function in the body. But it's also important to know that the effects are really specific to what your child gets. And so when we talk about any of the late effects, it is really critical to understand that if your child didn't get a particular chemotherapy agent or a type of radiation or a type of surgery or didn't have a particular type of cancer, then the late effects associated with those cancers won't apply to you. It will only be the ones that apply to the treatments that your child gets.

And when we talk about chemotherapy, it's also really important to recognize that we use a lot of different types of medicine that we lump into a category that we call chemotherapy. Each one of those is different and has potentially different late effects. And so it's very important not to talk about chemotherapy, but to think very specifically and have a specific conversation with your child's doctor about what are the late effects that we can expect with what my child got.

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I'm going to focus this morning on neurodevelopmental problems. And these are the problems with a child's ability to learn, remember and perform, either because of damage to the brain and blood vessels in the brain or because the development of the brain is interrupted by the treatment and that can be something that affects the chemistry of the brain, the way that the brain uses oxygen and nutrients, which we call metabolism, the availability of oxygen in the brain. And there are a lot of different things in children treated for cancer that can be affected. And it's a complicated issue.

Certainly genetics, hereditary issues that are in your family can play a role and those may not be related to the cancer at all. So if there's a family history of attentional problems or a reading problem, just having leukemia may not – those kinds of things may pop up even in the face of leukemia. We can have structural damage to the brain, this is what happens with children who have tumors in the brain. We can have damage to the blood vessels, either in the large blood vessels or in the little tiny blood vessels that we can't even see with a regular MRI. We can have disruptions in what we call the neurotransmitters, the chemicals in the body that allow messages to move from one nerve and one area of the brain to another. We can get disruptions in the way that oxygen is used and nutrients are used. There can be endocrine problems that come about, particularly with radiation to the brain.

But frequently what we see are disruptions in the way that a protein, it's like an insulation sheath around the nerve cell, grows and develops. It's called myelin. And as myelin grows, the thicker it gets, the faster the electrical messages on the nerve cells are able to move. What we see with a number of our treatments is that that growth and development of myelin can get interrupted. It doesn't always get destroyed, but it gets stopped and it doesn't grow as quickly and therefore there's a slowing of the electrical transmission that translates into some of the problems that children experience in terms of their learning and school performance.

The other piece that comes about is that our brains, from the time before we're born until we're about 30 are constantly growing and developing. New connections are being made. I think about it as an interstate highway system with multiple cloverleaves that allow you to not have to stop as you move from one road to another. These connections are something that are growing and developing and there's some evidence that some of the treatments that we give can actually interfere with that growth and development. There are connections, but they are not highly efficient connections. And so there can be a slowing down in the way that children learn.

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And then, of course, there are issues of the environment and other learning problems. I'm quick to point out that just because a child has leukemia doesn't mean that they're not going to sit on the back of Dad's pickup truck and decide to be Superman and have a head injury from that. Children are children, whether they have leukemia or not.

We know that there are some very specific things that are related to late effects, particularly the neurodevelopmental or neurocognitive late effects. If there is a tumor, where it is and how large it is can have a lot to do with what kinds of long-term effects a child may have. If there is surgery to the brain, that can certainly have an effect. And we've shown that even in children who only have surgery to remove a tumor that's fairly high in the brain, there can be some long-term consequences.

Radiation therapy we've known for a long time – radiation therapy to the brain can cause learning problems. And it's probably our biggest and most consistent culprit for long-term cognitive late effects.

Chemotherapy certainly can be a problem for us. But not all types of chemotherapy. Clearly the one that we are most concerned about right now is methotrexate in the treatment of leukemia and we have a large study where we're looking at that. And there are multiple concerns about the role that methotrexate may have on children's long-term cognitive late effects. But it has proven historically to be a backbone medication for improved therapies for leukemia. So there are some trade-offs there.

Certainly also the dexamethasone that we use, one of the corticosteroids, has some implications that children may have a greater risk, also with some orthopedic problems with that drug. But it has also been associated with quite possibly better long-term survival. So once again, tradeoffs.

Vincristine is one that causes acute problems for children because it has an effect on the ability to have good fine motor speed. It can also cause foot and hand drop and pain in the jaw and things that you may have known about. And we've clearly seen children's performance in academic and on neuropsychological tests really be adversely or negatively affected when the child is getting the vincristine. But typically after vincristine is finished and the child's no longer getting it, within several months most of the functions return to normal at that point.

There are many other chemotherapy agents and it's hard for us to pin them down as to which ones are going to have neurocognitive difficulties. There are some we think may contribute, but as you know, we give a lot of different medications, particularly in children with leukemia. So when we're giving one that we are pretty sure causes

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late effects, it's hard for us to separate out whether the others are also contributing. So for instance, when a child is getting methotrexate, we don't know whether cytarabine, for instance, or Ara-C, is going to have complications because very few children get cytarabine alone. And that's true of many of the different drugs that we use and that makes it a little difficult for you as a parent to be able to know what's the exact culprit. It's probably a combination of many of the things that we're dealing with.

When we think about factors that are associated with cognitive outcome, these are questions that I get asked an awful lot. And let me run through some of the things that we know.

Number one, we have clear evidence from a number of different studies that younger age is associated with a greater likelihood of long-term problems. So children who are under 3 or 4 at the time of their treatment, we have to take a really special look at because they're more likely to have more serious long-term problems and they're likely to have them in more specific areas than children who are older. But children who are older can still have some problems and I'll talk a little bit about how that falls on a continuum in just a minute.

In children with acute lymphoblastic leukemia, there is some evidence to suggest that girls are more likely to have long-term cognitive problems than boys. Now boys are still at risk, but girls have a slightly greater risk. And we're not exactly sure why that is right now.

If a child gets radiation therapy to the brain above about 18 gray or 1,800 centigray, depending on what numbers you may have heard from your oncologist, those children are likely to have cognitive problems down the road with that cutoff. Below 1,800 it's not as clear and some children really don't seem to have any difficulties with lower doses of radiation therapy.

I mentioned some of the chemotherapy medications a minute ago.

If a child has to have a shunt or has seizures, their risk for long-term problems go up, as do those children who have an infection of the brain at any point in time.

Now one of the things that is really important for us to think about is the treatment seems to have its biggest effect on the part of the brain that develops after treatment is started. So the parts of the brain that develop before treatment seem to be relatively safe and those things that we would expect to see develop after treatment are the ones that we're concerned about.

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And so for instance, we know that language development and gross motor ability is rapidly developing during the first two to two and a half years of life. But things like attention and fine motor skills and visual motor skills, those develop later on in time. So if a child has treatment around age 2 and 3, what we find is that often their gross motor skills and their language skills are relatively intact and they tend to stay pretty much on track in terms of the developmental course from that point on. However, a child's ability to sustain attention, their ability to do fine motor skills, to do handwriting and to process visual information, which is something that is developing between 4 and 6 years of age, may really be impacted. And as a consequence, some of the learning problems that we see for children in school wind up having a greater impact in those children.

It's a complicated picture. We've been developing some real models that look at the relationship between types of treatment, what happens in the brain, what happens to the really precise neuropsychological ability like visual, memory and attention and processing speed and then how those impact school performance in the classroom. And there are some nice lines that go from the treatment to the things that we need to be able to do to be successful in life.

One of the questions that I'm frequently asked is for neurocognitive late effects, who are the children who are at greatest risk? Well, any child who has a malignant brain tumor is at high risk and we are concerned about those children. That would also include children who have lymphomas that occur in the brain. Children who are treated for acute lymphoblastic leukemia or ALL, that get the intrathecal chemotherapy, the spinal tap chemotherapy, with or without radiation therapy, and those children who get higher doses of methotrexate during consolidation periods of treatment are at significantly high risk. Children who have ALL and then relapse or have a high risk that makes them go on to get bone marrow transplant that uses total body irradiation, they get sort of a double whammy because they're getting the chemotherapy up front and then the radiation and transplant on top. So we look carefully at them. Any child who gets radiation to the head or the face, whether or not they have a brain tumor or ALL, is of concern. This would include children who have bone cancers or soft muscle cancers of the face, the eye and the head that would get radiation.

We don't know about neuroblastoma. We've not had enough children who have survived stage 4 neuroblastoma to know. But we are getting reports from a lot of parents that they're seeing some of the same consequences that we described for ALL and brain tumors in their long-term survivors of children with neuroblastoma. So this is a new area of interest for us.



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And then the other group is very young children who have to be hospitalized a lot. We don't think that this is a primary neurologic condition, but it's a developmental condition because they live in a hospital, they don't get the same kind of social interaction opportunities as other children. So we're looking at that really carefully.

So what are the common late and emerging effects that we see? Well, the most common one is slow processing speed. If it takes the other children in the class 30 minutes to do their homework, it may take three hours for the child who has late cognitive effects. And parents see this in many areas of life, including social processing. Sometimes the children are a little slower with interactions, they tend to like to be with adults and older children who are more tolerant of how they process information, and they often feel uncomfortable with their peers.

We have problems with attention, typically not hyperactivity, but just problems with being able to sustain attention for long periods of time.

Memory difficulties come up. These tend to be mostly memory for visual information.

There's some difficulty with fine motor coordination and speed, so handwriting is often a problem. As is the ability to plan and organize, to plan a project over multiple weeks and do all the steps and stay up with it, to stay on track with anything that involves sequencing. We call these executive function problems. They're the executive piece of our world, running our entire life. These things often kick in around 11 or 12 years old and can persist through high school.

Children will frequently have problems in math. The problems are in the calculation area. They often show up around third grade and are heavily related to difficulty memorizing and using multiplication tables, and then the reverse of that, division. But children's ability to understand how math works, the application component, tends to be pretty good and not terribly affected. Similarly in the reading areas, children are often able to recognize what they're reading, they can read it out loud, but comprehension is a real problem. So a child may read all the material, be able to say all the words, but then when asked questions about what they understood, there's just so much work in the processing of that information that their comprehension tends to drop.

And those are very common problems that we see in children treated for brain tumors, for leukemias and lymphomas, for children who get radiation to the head or face and, as I mentioned, some parents are starting to say my long-term survivor of neuroblastoma is having similar problems.

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How do we pick these things up? Well, the thing that everybody becomes familiar with is neuropsychological testing or the short piece, neuropsych testing. And people ask the question, "Can I get that done at school, do I need to see a psychologist? It's expensive, my insurance company won't pay for it. Should I get a baseline?" Let me answer a couple of those questions.

Schools are typically equipped to do very good evaluations of IQ, some basic processing abilities and academic achievement. But they typically don't have people who are trained to do the tests or to interpret the tests in specialized areas related to memory, processing speed, computerized tests of attention and executive function tests. And since those are the areas that are most often affected, you can wind up having difficulty being able to get an evaluation in the schools. Mainly because many of the school psychologists, while well-trained to assess for academic achievement issues, are not well-trained to be able to look at, well, what's the effect of methotrexate and is this child on vincristine or not and are they taking a steroid and did they get radiation therapy and all the questions that go into the cancer background.

And so we do recommend if you can find a neuropsychologist, to be able to have an evaluation done, it can be incredibly helpful, not in saying what your child can't do, but in defining the scope of their abilities and being able to provide the school system with really good information about how they can best help your child.

We do recommend, at least I recommend, getting a baseline evaluation as early as possible after diagnosis. With ALL, for instance, I do ask that you delay until after induction and sometimes after consolidation. If you can get it done in the first year of treatment you're usually in pretty good shape. What that does is it gives us a good picture of where your child is before we get any late effects. And that's important because one of the things that we've seen over time is if we have a child who's very bright and we test them when they begin to see problems emerge, their scores may still fall in the average range, but we've seen enough cases where a child may have had a test in school for a gifted program and prior to their diagnosis might have had, let's say, an IQ of 133, and then they come back and they get their evaluation when they're having problems with late effects and their score comes out to be 105. And the school looks at this 105 and says that's in the average range, we don't need to provide any services. But if we have that baseline and show that that child went from 132 to 105, that's a very significant decline and is clear indication of their learning problem.

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That also is issue because an IQ, when it drops, often means that there are very specific areas of function – processing speed, memory and things of that nature – that are really giving the child a lot of difficulty and need to be addressed.

We do suggest that neuropsych testing be repeated. Because this is a developmental phenomenon, you may not know whether your child is able to do something until they can't do something that other children the same age will do. So we don't expect a 4-year-old to be able to do multiplication tables, nor do we expect a 9-year-old to be able to do trigonometry or to read Macbeth. Those are skills that are acquired with increasing age.

So repeating an evaluation every two or three years or any time you or your doctor or the teachers notice that there's a change is a good idea, because then you can track what's going on and intervene as early as possible.

We also recommend that you have this done around the eleventh grade because that will help with being able to get accommodations for standardized testing like the SAT. And if your child needs disability services when they go to college, that evaluation will help to qualify them for services from the Office of Students with Disabilities.

Now what are we doing in terms of intervention? Well, there are several things that are being looked at. One, are stimulant medications for things like ADHD, and there's one big study funded by the National Cancer Institute that has shown that children can have a significant improvement in attention and possibly memory with some of these medications.

However, there are some warnings from the Food and Drug Administration for the stimulant medications. They're called black box warnings. Because some of these in the general population increase the risk for depression or anxiety and there's also a risk of sudden heart failure.

And in children who've gotten anthracyclines as part of their chemotherapy regimen for ALL, and these are things like daunomycin and Adriamycin®, we know that those things can damage the heart, so extra special care and conversation with your oncologist needs to take place before you use any of these medications with children who have a heart risk.

Another component is cognitive rehabilitation. This is a strategy that's built on doing a lot of repetitive skill learning, with the idea that having a child engage in a particular task will exercise the brain and build muscles and in this case build nerves. And

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The question that exists right now is, are we waiting too long before we do this kind of cognitive remediation or should we begin this right when a child is diagnosed, because if we wait until a child is showing difficulty, we may have missed an important window of opportunity. The world is still out on that particular issue, but that's work that is going on.

Most children will come into contact with the school and the Individuals with Disabilities Education Act or IDEA or the 504 regulations, the Rehabilitation Act. And these are federal laws that provide supports for either special education services under IDEA or for what are called accommodations under the 504 plan. And these are things that provide support, special education, intensive help for children who are having difficulty. And many children who have late cognitive effects clearly meet the criteria under either other health-impaired or traumatic brain injury or one of the other classifications for either IDEA special education services or 504. You should really have a conversation with your special education folks in your school system to make sure they are aware of these connections and are providing the services.

The availability may depend on whether the school is public or private. If they're public and receiving federal funding, then IDEA automatically kicks in. If it's a private or parochial school, some schools follow IDEA completely, others don't. You'll have to have that discussion with your school. But you can get everything from simple accommodations like extended time to complete homework assignments to reduced homework, all the way through to having aids, having speech and occupational and physical therapy and a variety of different things.

There are accommodations that are available for standardized testing like the SAT. That requires, however, a neuropsychological evaluation completed within three years of the request, so that's why I said make sure around eleventh grade you get your kids tested, so that you've got that for them. And it requires a letter from the professional involved in the case saying that your child meets the criteria.

But we have to be thinking about the fact that these evaluations may be needed well into young adulthood because sometimes the issues show up when you're trying to do school work.

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We've developed an organizational or strategy that we call compensatory intervention, for children who clearly have long-term learning effects. And basically recognizing that most of the problems that children have involve visual processing, memory and speed and a translation into their fine motor skills. We shift them from read and write to listen–speak. And so many of our programs now involve having children do their reading by listening to digital or disks or books on tape, using voice recognition software that allows them to have their speech converted into text on the screen that they can then edit and turn in a written piece of information. Using text capture, calculators, using oral rather than written testing. These are all things that have been very, very important.

We've followed a group of children for 10 years with this particular model, all of whom had brain tumors with significant impairment, were in special education programs. Of those 10, nine graduated from high school with regular diplomas, five went on to college and two of them are now in graduate school.

We've got a lot of work to educate and there are a number of materials from The Leukemia & Lymphoma Society – *Learning and Living with Cancer*, a great book from Candlelighters called *Educating the Child With Cancer*, the National Academy Press at the Institute of Medicine did *Childhood Cancer Survivorship*. These are all great references for parents as you move through.

We need to recognize that late effects are important and being aware of what can happen to your child, not worrying about them, but being aware of them, making sure that you have access. And so once again I recommend to every parent that I run into, go to [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org) for access to the kinds of treatment that your child got.

We are hopeful that within a very short amount of time we will have access to where your child can put in their treatment and get an individualized passport that will describe what late effects they need to be concerned about. That's an essential issue because when your child is no longer a child and is an adult, the adult world is not really well-versed in what the late effects of childhood cancer are, so your child will have to be a strong personal advocate for his or her health, letting the doctors in cardiology, in pulmonary, in internal medicine know what they need to know about the treatment that your child has received.

So with that, I'm going to wrap up just by making one final point. We're really lucky that we expect so many children to be able to survive this horrible disease and go on and live fruitful and exciting lifestyles and lifetimes. We expect them to grow up and have families of their own, to be productive in the world.

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DR. ARMSTRONG:

We have a special program in Florida that the American Cancer Society supports, a scholarship program. We've learned something important about our survivors. Nationwide, about 20 percent of children who complete a bachelor's degree go on to professional or graduate school. What we've learned in Florida is that about 50 percent of our college graduates go on to graduate or professional school and what is even more overwhelming is that those children are going into fields in medicine and nursing and psychology and teaching and the clergy. And we have folks that are going into fields like law and accounting. But what we're finding is that whether it is a direct health profession or if it's the accountants or the attorneys, they're often going into advocacy law, they're doing work for 501(c)(3) charitable organizations. By and large, our survivors of childhood cancer, as they grow into adults, are giving back to our society. Not just to cancer, but to our society in general, in a way that none of us ever imagined and in ways that we can only benefit at a far level. So we're very, very fortunate.

So if you have a young child, you can look forward to the time when your child will be one of those who's making our world a better place.

With that, I'm going to stop and turn this over to Nancy Cincotta.

NANCY CINCOTTA:

Thank you, Dan. You know, listening, probably like many people in the audience, I feel like okay, now, let's just go to the millions of questions and I appreciate that your clarity and knowledge is remarkable. And I'm so grateful for both The Leukemia & Lymphoma Society and their efforts and your efforts in helping families to kind of understand what the world of late effects is and how it affects children going through all different types of cancer treatment.

I wanted to just start by suggesting the context from which I am coming. My connection to Camp Sunshine, after 25 years of also being kind of hospital-based in oncology, allows me to have the privilege of working in the only facility in the country that's dedicated to a retreat-respite model for families of kids with life-threatening illnesses, and predominantly families of kids with cancer. And so what that means is that I often find myself sitting in the room with anywhere from 30 to 70 parents who have a tremendous amount to say about what the lived experience of having their child go through treatment and be off treatment is all about. And I think that some of what I hope to do today is to be able to respect and reflect their wisdom in the things that they have said to me and I have heard.

And I appreciate it, it sounds like there's about 440 parents on the line and about 660 professionals, and I do believe that part of what we have all seen in this

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movement forward in the survivorship for childhood cancer patients and their families is really about the partnership between all of the healthcare professionals and parents pushing forward to learn more and to understand more.

I wish that everybody who came and sat in the room, who had any concern that there was something going on with their child post-treatment, had access and knowledge and even just the understanding that all of the resources are out there and that the research is out there. And I think that there's great variability for families in their treatment centers and so I still hear the struggle from families, often on a regular basis, that they perceive there is something going on with their child, but they're not sure what it is, and they're recognizing certain losses and certain issues. So it is my hope that the more availability of information, the more apparent it is to every parent of a child going through that, these resources are there, it will make in fact the journey better for everyone.

You know, when you think about childhood cancer and from the diagnosis on, I think that people are often heard to say that the diagnosis of childhood cancer is a family affair. So when a child is impacted, everybody in the family is impacted and that is true whether you're talking about the initial period when you're learning about cancer or you're talking about the late effects and the implications of those late effects down the road and how they change what is a family's journey forward in life, from that date of diagnosis on, and I think that families are so changed in the experience of having a child diagnosed with cancer, that that date stays imbedded in the family's mind forever. People will always be able to tell you when they learned that their child was sick, where they were, what happened and how life changed for them at that time.

So you think about kind of the powerful things that families do together and have together and their emotional well-being and their growth and their cultivation of the lives of their children. And cancer is bigger than most of those things that you encounter along the way. And the cancer journey is unlike any other one from which you have had the experience. So you enter into this world and you're struck by your lack of knowledge in this area. And unless you are a health professional, you may not have ever encountered somebody with cancer, lived through chemotherapy, lived through the treatments, and you are plagued by some of the stigmas and the things that you know about cancer treatment and some of the problems that you anticipate.

So one of the interesting emotional parts of this journey is how you, once your child is diagnosed with cancer, you embrace that diagnosis and live and learn with the

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diagnosis. And I think that it's kind of learning while living and living while learning. You live in two different worlds. You're living in that world both that you had been in and then you're living in a – there's the world of the healthy and then there's the world of – the cancer world, if you want to call it that, that you come to know and come to love and become an expert and gain tremendous expertise in. But at the beginning can be quite daunting and quite challenging to understand, you know, again, is this a club you really want to be part of. And although you may not have any choice, once you're there what do you do and how do you learn to live there comfortably and how do you even thrive there?

If the context of your family life has changed, it's possible that, at least in the immediate time frame, your family's aspirations and goals may be changed. Your financial and future planning may be changed. And for many people, you hear not necessarily as negative, that some of the context of day-to-day living and your philosophy as a family changes. That people learn to embrace the moment and maybe not sweat some of the little details and really learn how to live life to the fullest in each day. And if the diagnosis of leukemia is not what you would choose to have, to give you that perspective on life, but for many people that perspective can be an asset in other places in life.

One of the interesting things when you think about living with cancer is that the energy within a family changes. Like if you think about family life and you think, for any of you on the line with children and think about the amount of energy required in the course of the day from when you get up to when you go to sleep at night, in what you need to do with work and caring for your children and taking care of life, there's really truly only a certain amount of energy that each person in each family embodies. And the treatment and the diagnosis take with them a certain amount of energy. It changes the physical and emotional energy that a family has. It changes the homeostasis for a family. And again, it's not just about the child with cancer and I'm not just talking about when a child is tired, I'm talking about when the whole family is tired, when everybody is affected. The energy kind of realigns, I guess, is a way to look at it. And it suggests, it changes how you spend your time, who does what, who needs what, who helps who.

If you think about it, you can think about a situation where you have a mother whose kids have just gotten old enough, who's about to go off and launch her law career and then her child is diagnosed with leukemia and she makes the choice to stay home and – of necessity also and desire to be near her child and with her child, to help. And everybody helps. And there is a way in which the family life course has



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changed. And five years later, it may not be that that mom goes back to that activity because in fact the world will have brought her to a different place.

You think about the 18-year-old who's diagnosed with Hodgkin's disease right after they get their college acceptance and they're ready to be on their own, going in a particular way, only to find that they're going to become reconnected, and a little bit less independent, with their family and that maybe it will change their whole course of where they will go and what they will do.

We hear the phrase that there's this "new normal" for families. And we've talked about that I think for a long time, that things do change and you adapt to them and that you come to live and love and thrive in this new normal. But it's an interesting question of what does it really mean?

I often have the privilege in my group to be able to say to people, "So how has your life changed, where has life changed?" And I get to ask questions about just even how the sleeping patterns in the house have changed. And I think that it would be stunning to know how many people whose children have cancer are really not sleeping at all or not sleeping well. And there are so many things that we don't talk about in life and people don't talk about, but they live feeling as though oh, my, what's wrong with me, why am I not coping in this way or maybe I'm not doing well. And sometimes it's opening up those discussions to realize that everyone struggles or struggles a little bit in trying to figure out how to cope and how to live with this diagnosis.

So we often think about survivorship as the survivorship of the illness and getting past the medical component of the illness, the scientific component, and then the late effects if they are affected. And as Dan mentioned, there's also the social part, there's the peer part, there's the family part, there's the emotional part. And the emotional profile within a family is a very significant part of the treatment and the outcome and even the success of survivorship. Because in fact, two people can survive cancer in very different ways. But if you cannot survive and live and enjoy life and see the joy in life, it is a very complicated survival experience.

So some of the questions become how do you survive any crisis? How do you help people survive crises? And in the cases of cancer, they're complicated survivals because it's not surviving a crisis for a day, a week, a month, a year, it is often surviving for the long time, for the long haul.

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You hear some of the late effects which are increasingly being learned more about and being learned how to both help and to help kids cope, compensate, relearn, rethink, maybe get over, but maybe live their lives with certain late effects.

So again, when you think about kind of realigning a family's energy and focusing on becoming empowered to take on whether it's the late effects or the treatment effects or any impact, you learn how to become empowered with information. You learn about treatment. You learn how to put everything in place to follow a treatment plan. And then you even have a road map that you're given by your center to help you follow the treatment plan. And the question, is what is the emotional road map, what are the tasks, when do you even stop to think about what the impact of this illness has been to you as a parent, to your children, to the people in your family? When do you let yourself react? And I think that we are seeing that sometimes people react very emotionally at the very beginning, but then they move into a soldier mode where they are fighting this illness and they are fighting to survive. And that there are times when people need to fall apart, to react, to rethink, to reach out to other people for help. How do we help people recognize that it is okay to get help and it's okay not to just get help in diagnosing a problem and in the treatment of that problem, but then in your emotional reaction to that problem? Who do you seek out for help in making peace with yourself in the process and when does that happen? Does that happen in the first year, does that happen in the tenth year? We're really seeing that it happens for different people at different times in the same way that your kids are different and late effects may be different. Coping as a parent and a child is also different.

We kind of have the privilege, being 25 years in operation, we now have a tremendous number of kids in their 20s, and I'm going to call them kids in their 30s, who are kids that have come through the Camp Sunshine program and who are off-treatment, who are back volunteering and being part of a mentoring program and helping parents. And really teaching us what it's like to live down the road. And to learn to compensate both in the careers that you choose, in your aspirations and really living full lives and letting the world know that they are cancer survivors and the things that they have been through.

Parents rely on each other often in this journey, but they also may encounter some roadblocks because, as roles emerge for each parent and as each parent reacts to what's going on for the child, you do come to learn that there are times, whether you call it that mothers and fathers react differently or people with different personality profiles react differently, but there comes a sense of needing to

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NANCY CINCOTTA: understand the strength of given individuals and how people can help and work in this process.

When you hear from lots of moms that they want to talk and process and have the time to cry and to listen. And you hear from, sometimes from dads, who want to fix the situation. You realize that families need help in just being able to meet each other at a place where they can hear and listen to each other and deal with kind of the issues in front of them.

This new age that we're living in has also brought other interesting avenues of coping to people. Dan and I have been doing this for long enough that there was a time when there was not an Internet, there were not CaringBridge sites, there were not ways that people got information about certain things that are going on for their child, in other families. And what is interesting is that some of the advance of those things has created some different ways of coping for families within the context of their children's illnesses.

And I'll give you a quick example that, quite often CaringBridge sites, which many of you know are an opportunity for families to post what's going on with their child in a site on the Internet where other people can go and look and it's a way of giving information that people record on their child's situation. I have come to know many, many mothers who read hundreds of kids' CaringBridge sites and actually meet other parents, talk to other parents. And maybe talk a little bit less in their own household about some of the issues. Whereas before, you see in mothers' groups, many concerns that dads were not talking to them so much. Now I'm hearing concerns in fathers' groups that moms are at the computer and not talking to them so much. So it's interesting to see how technology has influenced change.

Someone sent in a question and talking about, kind of, what the experience of—how do you tell your kids, what do you tell your kids about cancer, about late effects? And I think that for kids you really want to be able to provide them information that is consistent both with their developmental thinking, their cognitive ability, what they understand about the illness and about the treatments that they are going to encounter. And that there is a big lesson in understanding that if a child is diagnosed at 3 and is on a three-year protocol and also has other effects that will last beyond that, the children need at different ages explanations and information about their illness and treatment that is consistent with the age that they currently are. And that changes over time and that developmental knowledge and presentation to children needs to change over time, in keeping with them and what they need and where they are and where they're going. That you really want to be able to normalize this

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NANCY CINCOTTA: experience for children and provide them information and to enable them to both understand and be prepared for what's happening. And to have some degree of control.

It may be that your child is a child who you assess, with your child, does not want to know about certain treatment components or different things before they happen. But you may have a child who wants to be prepared and know about them before it happens.

The element of choosing, of working together with your child, of making and working on treatment plans enables both children and parents to be empowered to help each other and to get through. I think for everybody, you look to find things that find support and create support, both for your children and for yourself.

We got a question about siblings and it's something I'd like to spend a couple of minutes on because in fact I think that one of the things that we have all learned over the years, that this, the impact of a child's diagnosis on a sibling, is great.

And I was sitting with a child over the weekend and I heard him talking with me and I even sat back for a minute and thought, you know, this is not what you would have thought that you would have heard this young man say. But he basically said, "My sister got diagnosed and my sister is now blind and I really hurt and I hurt so much and nobody understands how I hurt, and sometimes when people don't understand me or they make fun of me, I just want to make them hurt, so they will understand how much I hurt."

And when I went on in the discussion with him he talked about having been to detention 17 times and it was clear that he wasn't being completely clear with everyone around him about what he was feeling and what he was thinking and it just again brought to the fore the reality that siblings feel the experience very intensely. And that often during the course of treatment, it's a little bit harder for siblings to be always present with their sibling as they're going for treatment, as they're doing things, and often support is brought to bear so that siblings may be relocated to another house during some course of treatment. But as you talk to siblings, it becomes important to even think about within the context of a family, what some of what you might call late effects for siblings from an emotional point of view may be. And those actually may be and may have academic consequences, social consequences. Because in fact it has so shaken the homeostasis of that sibling's life. So I think the trigger there is to have the resources in place to hear what your kids are thinking, but also to recognize that siblings may fare better by being more available and present in their sibling's treatment. And the more information

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that they have, the more in fact they are able to be part of the family and feel like they are part of what's happening. And that sometimes it doesn't matter who it's happening to in the family. It just matters that people are able to feel as though they're a family going through this together and experiencing this together.

So when you think of all the different things that a family can encounter and the different needs that people have, you think about what are the kinds of interventions that are out there to help people. And you think about The Leukemia & Lymphoma Society has a tremendous group work program and I look at the group work program at Camp Sunshine and I think that what groups do that are harder to do in individual interactions are they really do help families feel less isolated. Help parents and kids feel less isolated. And sometimes that is all you need in the course of development, to be able to enable you, to inspire you to move forward and deal with the things that you need to deal with.

So you think about – we all need natural helper environments and social environments to connect on the issues of our life. And it is not always easy for a parent of a child with cancer to hang out with another parent of a child with cancer and to do that the way you would do in the playground near your home for your other children in other situations. But by creating environments where people can get to know each other, they can see a range of coping skills, they can learn from what other people's experiences are, they can be connected to each other, is something that enables and facilitates the journey forward for families.

I'm looking at the time and I'm thinking as we move forward, that there's just a few more things I want to be able to talk to you about before we open up to questions.

I think that sometimes you – I don't know how many of you on the line – this is where I'd love if we were in conversation and I could say how many of you have had group work experiences and have they been positive for you? There is some sense that it's also true that as people help each other, they help themselves as well.

I think that one of the features to get through this process is about hope. It's kind of when your child is diagnosed, what do you hope for? Often you hope that the diagnosis is wrong. But once it's clear that the diagnosis is not wrong, you really hope that this illness will go into remission, you hope that treatment will be manageable, you hope that everything will get better. You hope that – there may be late effects, but that your child won't experience them. Or if your child will experience them, that they will be minimal and managed. You hope for a normal life and that your child will grow up and will have a family and keep growing.

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NANCY CINCOTTA: But hope is the kind of thing that it often and at times needs to be refueled. It needs to be realigned with that energy and it can be found in any of a number of places. But when you think about hope as a concept, it rekindles the spirit for people. It enables functioning for many people. And sometimes as a parent, you need to find hope and joy when you're feeling exhausted or emotionally depleted. And you can find it in simple places. You can find it in an ice cream cone, in a conversation. You can find it in an assessment of your child when you finally learn what's going on and that you're not crazy that those things were going on. And that you do think that your child's memory is failing or that your child is having more trouble doing things and that the reality of information can make you hopeful.

Children are innately hopeful and helpful. And I think that, in this process, they are also inspiring and that sometimes when you're on this journey and you look at kind of the partnership with the members of your own family and your healthcare team, you realize that it is that partnership that enables you to do everything you need to do when you feel like you are at wit's end.

And the reason that I mention this is because we have heard countless numbers of families talk about their frustration and feeling as though their children are struggling during treatment and post-treatment and that they have gone to the professionals who are treating them and they have gone for testing and that they've not always been acknowledged or their problems have not always been recognized. And I think that some of the message here today is that testing is important, testing with people who know the kinds of issues that your children are facing are important and that being able to reach out to people for help and to programs that are able to help people are important.

I think that when you look at your children and you look at some of the issues that they face, you think about how their lives have changed, what has happened over the course of time, how they understand things differently, how you understand things differently for them. And you do wonder, is this not a life-long commitment that you as professionals have made and as families have made, to help your children both overcome all the obstacles that they face during the way and to be people who go out, make friendships, learn how to negotiate for themselves, learn how to advocate for themselves.

I think that as we proceed in this cancer journey and on to questioning, I think that we want to both thank you all for your input and your connection. And again I want to thank The Leukemia Society and Dan for all of his input. And I hope that we are able to now move towards questions.

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- CARSON JACOBI: Thank you so much, Nancy. Thank you so much, both of you, for such passionate presentations and information for all of us.
- It is now time for the interactive part of the program, the question-and-answer session. So before Lindsey gives instructions for all of you to enter the question-and-answer queue, I would like to remind you because we have so many participants on the line, and for everyone to benefit, if you can please keep your questions general in nature and try to be brief and our speakers will provide an answer general in nature. Your phone line will be muted after you ask your question, so Dr. Armstrong or Ms. Cincotta can respond. Lindsey, if you can please give instructions so our audience can queue themselves to ask a question.
- OPERATOR: To participate in the call by asking a question, please dial star-1 on your keypad. We will take questions in the order they are 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.
- CARSON JACOBI: Thank you. We'll take our first question, please.
- OPERATOR: Our first question comes from Sue from Oregon.
- SUE: Yes, hello, thank you so much, both of you, for the work that you do with children. I work for The Leukemia & Lymphoma Society in Oregon and my son is a survivor. My question alludes to something Dr. Armstrong said at the beginning about social issues. I find more and more in dealing with kids who are long-term survivors that their socialization with peers is really impacted and that they have such a struggle and a difficult time making and keeping friends. And I wondered if you had any information about research or anything that's being done on behavioral issues to help these kids integrate back after their treatment, so that they can establish friendships.
- DR. ARMSTRONG: You raise a really important point. And for years we've seen, particularly with children who were treated at younger, preschool to early school age time, that there can be some what we would best call maturational delays. The classic description that we've seen has been a child who gets along very well with adults and gets along very well with younger children, but is a wallflower with peer group, not quite sure how to fit in completely, doesn't have that same level of comfort. And it certainly doesn't apply to every child who's been treated for cancer, but they are missing out on some really critical periods of time, when they're learning the give and take of social interaction. And they're also learning something that's quite abnormal and that is how to deal

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DR. ARMSTRONG: with doctors and nurses and technicians and all the people that occur in the hospital. And all of the really abnormal adult attention that you get when you have cancer.

There are some studies that are going on and folks who are looking at the whole issue of socialization for children with cancer. The good news is that as the children are growing up and reaching young adulthood, the social difficulties tend to diminish as they find their stride as young adults. But it is a real challenge, a challenge for a number of children during the school age years.

NANCY CINCOTTA: Can I react as well?

CARSON JACOBI: Absolutely.

NANCY CINCOTTA: I just wanted to note that because I work in an environment where we are constantly creating kids' groups for kids with cancer and their siblings, while their parents are in parents' groups, we have also seen that children, and we've heard from parents, the kind of issues that kids have with socialization. But what is really interesting is I would really recommend that the whole body of kids' cancer camps and family camps that are out there, are a great environment to help children begin to socialize more frequently in a place where they are very comfortable and have a normal experience in that environment, that they then are able to take to the other environment and even to be able to talk about issues of how much easier it feels to be in a group of kids with cancer or siblings with kids with cancer. And then we really have seen that kids feel as though this environment helps them be able and feel stronger going into other environments.

The other issue that I would just want to note is that for kids who were treated within close proximity to going off to college, we really have heard a lot about how kids get to college and they don't feel in the normal culture of kids who are drinking and smoking pot and smoking in general, because they feel like they've survived cancer and they don't want to do those things. And I think that again a network for kids to be able to talk to other kids and find support and find encouragement, to find other kids on campus like them, that they may need a little bit of help finding those social networks, but when they find them, they are able to make that adaptation. So that in some ways I think kids get to those college years a little bit more mature in some ways than some of the other kids. So in some places where they are a little bit less mature, sometimes they are a little bit more mature, but both of those things make them feel as though they don't fit in. Talking about it really helps.

CARSON JACOBI: Sue, thank you very much for the question. Let's take another question, please.



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OPERATOR: The next question comes from Jeannie from Florida.

JEANNIE: Hello, it's good to be here again. I have a question with Dr. Armstrong. The question would be I'm experiencing some late effects. I am a over 30-year survivor of Hodgkin's disease. And at first I forgot to say it's so wonderful to hear that the programs and the research, especially with the childhood survivors, is really coming together. I've experienced a little different, because there wasn't any groups or a lot of information for me or my family and, of course, I also have my own children. And I kind of wonder if they are going to get any of the neurological effects. And then with my different diagnosis between ulcer and heart things, are the doctors really going to be aware when I tell them I've had treatment in the 70s? And I do live in Florida and I'm getting ready to face the heart surgeon and I have concerns. Is there any direction you can point me in, is there any group for older childhood survivors, that might help me?

DR. ARMSTRONG: There are a lot of points to your question. And first, congratulations on being a 30-year survivor. You're the cutting edge. And everything that you go through is the information that all the folks who are coming along now will glom onto. Recognizing, of course, that since 30 years ago, treatment has changed a lot.

You raised a couple of really important questions. One, no, what we find is that in the general world out there, most of the folks who take care of adults don't know anything about late effects of childhood cancer, current or 30 years ago. And so one of the things that's really crucial, and I would recommend that [survivorshipguidelines.org](http://survivorshipguidelines.org) for you, is to go through, pull that information out and consolidate it for yourself and take it to every doctor you see. Because it will be crucial that they know what you got, what we know about the late effects of what you got and what they need to look for. Because at the time you were coming through, of course, we had mantle radiation and different drug combinations than what are used now and they might not be aware of that issue.

The second component is, is there some place you can go? The first place to start is with the comprehensive cancer centers in Florida at the universities, to just see, what do they have in terms of programs for long-term survivors? Many of the children's programs, and being 30 years out, you don't quite fit the Dino the Dinosaur exam table any more, but the oncologists there will be able to let you know what exists in your community. There is a Florida group called the Florida Association of Pediatric Tumor Programs, that is trying to develop a systematic program for long-term adult survivors of childhood cancer, as are several of the cancer centers. But they're really

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- DR. ARMSTRONG: in the early stages because we just were prepared to take care of acute problems, not the long-term problems. So you are part of an emerging and growing field, that sharing your story is crucial to helping everybody else realize that this is not only possible, but it's real.
- CARSON JACOBI: Nancy, I didn't know if you wanted to add anything.
- NANCY CINCOTTA: No. Thank you so much for calling in because we really need people like you to come forward and share your story. So thank you.
- CARSON JACOBI: Jeannie, from The Leukemia & Lymphoma Society's perspective, we have several locations throughout the state of Florida, chapters we call them, that you can call the Information Resource Center after the program and find out where those chapters are. We have in-person support groups, we have bulletin boards on our Web site, and we have a program called *First Connection*, which links patients who have been diagnosed, who are trained peers, who can talk to someone who's been through a similar experience. There's many forums and avenues for emotional support. So I don't want you to feel alone. So there's definitely people that are out there that want to talk to you and that will talk to you. So please reach out to us if you choose to.
- We'll take the next question, please.
- OPERATOR: The next question comes from Jerry from Kentucky.
- JERRY: I'm the mother of an ALL survivor. We just completed our full treatment odyssey. He's 9. And my question is, is this, We didn't have a cognitive assessment done when my son was diagnosed at age 5. Would you recommend we go ahead and get one now as a baseline? Sounded like kind of the gist of what you were saying, was get it done whenever you can and then he'll have some kind of baseline.
- DR. ARMSTRONG: Good, I came through cleanly, thank you for that. Yes, I would go ahead and get a baseline whenever you can, and particularly if you're just finishing therapy. Many times – I mean, we do see new problems begin to show up in children who are anywhere from two to five to seven years away from completion of therapy. And so if you have a snapshot to show he was once at this place and now he's here, then that really helps tremendously in being able to get access to the services, whether those are in middle school, in high school or even in college.
- CARSON JACOBI: Thank you to Jerry's family for the question. Let's take another question, please.
- OPERATOR: The next question comes from Daniel from Washington.

## **Childhood Cancer Survivorship: Challenges, Strategies, Resources**

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***Daniel Armstrong, PhD  
Nancy Cincotta, MSN, LCSW, ACSW  
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- DANIEL: Hi, thank you very much for the presentation. I have another question about the cognitive assessment subject. I wondered if you could offer some general suggestions about where to go to find that service and what to ask for.
- DR. ARMSTRONG: Oh, boy, that is the tough question. Most of the programs now in the Children's Oncology Group have a psychologist identified with their program. One of the first places to look is at the academic medical centers because they often have faculty members who are there and graduate students who can do the testing and other things of that nature. There's a lot of efforts trying to train psychologists to be able to do this, but we recognize that there's a workforce shortage. But I would start with your local Children's Oncology Group program, ask the oncologists there what recommendations. If they can't answer, then go to the closest major academic medical center and ask them if they have someone available for you.
- CARSON JACOBI: Daniel, thanks for the question. Let's take another question, please.
- OPERATOR: The next question comes from Julie from Pennsylvania.
- JULIE: Hi. My son was diagnosed with ALL in October of 2005 when he was 2. He didn't have radiation or high-dose methotrexate, but he did have 25 intrathecal methotrexate spinal taps over that three and a half years. After reviewing a lot of Dr. Armstrong's previous courses and noticing some indicators in his behavior, we decided to go ahead and have neuropsych testing done in December. And I was really glad that we did. His test scores ranged from high average to superior, except for the processing speed section, which was average. And the psychologist made recommendations for the school allowing extra time, minimizing speed tests, that kind of thing. He'll actually be starting kindergarten in the fall and he finished his treatment in January. But does that mean that we actually need to make sure he has an IEP going into kindergarten, even though we might not be seeing significant issues until a few years from now when he starts multiplication and that kind of thing?
- DR. ARMSTRONG: It depends. With his scores and his range, this is one of the things that happens, is you can have a child who's very bright and doing well and their low area of functioning is low compared to them, but not to other children. So they may not qualify for an IEP under IDEA, but they would qualify for a 504 plan. And I would go ahead and move toward having a 504 plan, so that there are regular reviews. And accommodations can be made and everyone is aware that this is a child that we need to watch as he progresses and be aware of some of these late effects that come along. But I would have the discussion and go ahead and the earlier you can get the service designation, whether under an IEP or a 504, the better off you are going forward. You don't have to fight the battle again later.

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- CARSON JACOBI: Julie, thank you for the question. Let's take another question, please.
- OPERATOR: The next question comes from Janice from California.
- JANICE: Hi, thank you for taking my phone call. I wanted to ask Dr. Armstrong if he could elaborate a little bit more about the intervention using stimulants, to help with the attention and the memory. And again, with the qualifications that some of these come with the FDA black box warnings. If you could elaborate a little bit on what some of those are. As well as any natural alternatives along those same lines. Thank you very much.
- DR. ARMSTRONG: It's a good question. There's a whole host of stimulants. They all basically involve dexedrine or methylphenidate. And you hear them, things like Ritalin® and Concerta® and Metadate® and Strattera® and things of that nature. These are commercially available drugs that have been approved by the FDA for use in children who have attention-deficit hyperactivity disorder. There was a clinical trial done a few years ago that was sponsored by the National Cancer Institute for children who had late effects of either brain tumors or leukemia, that were in a double-blind, randomized, placebo-controlled trial, which is sort of the gold standard for how to do a clinical trial. And what they found was that between 60 and 70 percent of the children showed a positive benefit in terms of improvement in memory and processing speed in some academic areas.
- The issue that came through was that the children were far more sensitive to those drugs and had to be often treated at lower doses than one might expect in the general population. And then the black box warnings came along. And so I think we do have to really be careful about children who have a heart risk because this could be a very serious and life-threatening complication if that's not considered. But that's a discussion that needs to happen with your oncologist and in consultation with pediatric cardiology and others in your community.
- In terms of the natural approaches, there are a number of things that you could – probably hundreds of things that you can go out, that will be discussed – the difficulty that comes in that very few of them have really been evaluated. They're evaluated because someone says I tried this and it worked for my child. The difference between a marketed pharmaceutical and a natural approach is that the marketed pharmaceutical has been required by the federal government to undergo safety and toxicity and efficacy trials. So I'm hesitant to make any recommendations on natural approaches.

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- DR. ARMSTRONG: There are some behavioral strategies that can help. If a child has difficulty sustaining attention, there's some stuff out of a program in North Carolina that suggests that having a little rubber ball or something to squeeze and manipulate in the hand can help to focus attention. There are a variety of these types of things that are out there, but none of them have really been studied very well.
- CARSON JACOBI: Janice, thanks for the question. Let's take our next question, please.
- OPERATOR: The next question comes from Julie from Minnesota.
- JULIE: Good afternoon, thank you for doing the program. I just have a question about the cognitive therapy. My son – I found a company here in Savage, Minnesota that is doing some cognitive training, but the price tag is very, very, very steep. And so I was just wondering if you really feel that that is a method that's worth taking advantage of.
- DR. ARMSTRONG: It's a really interesting question and I hope somebody will ask Nancy a question because I'm answering all of these right now. But they tend to be right down the line on the cognitive. The one program is a cognitive remediation program that Robert Butler and his colleagues put together. It was funded by the National Cancer Institute and was subjected to all the rigors of a clinical trial. That one has really shown that there are some positive effects, they're moderate, and there is a fairly significant cost associated with the intervention. I think it winds up being about an hour and a half a session and can run anywhere from 25 to 50 sessions to be fully implemented.
- There are a whole host of quote-unquote cognitive interventions that are available on the market. And unfortunately very few of them have been subjected to clinical trials, even in children that don't have cancer-related learning difficulties. And they are very, very expensive.
- What I would suggest that you do is make sure that your child has a good neuropsychological evaluation and then sit down with the psychologist who did the evaluation, show them the program that you're considering and really make sure that it's something that looks like it may have a good match. There seems to be some indication that doing those kinds of programs or doing interventions, period, earlier in treatment before there are significant problems, may be more beneficial than doing them after there are significant problems.
- But like I say, there's only been one major clinical trial that's been done and the others we really just don't know. It's a discussion that comes in and fits into your finances, what's available, and the best advice you can get locally.

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CARSON JACOBI: Julie, thanks for the question. Let's take another question, please.

OPERATOR: The next question comes from Sherry from Virginia.

SHERRY: Hi. I have a question. My granddaughter was treated when she was just 1 year old and she went through her treatments and she's finished all those. It's been over three years now. And right now she got her first baseline testing done and she did really good on it. She's getting ready to enter into a gifted program for next year. I was thinking that we were going to have all these learning problems. How far out are we looking to having these problems come about, or are they always going to be there, always watching for these situations for the different learning disabilities to become available? She was diagnosed with ALL and she was high-risk and then they lowered her down to medium-risk. So she went through a lot of the regular treatments they went through for all of that.

DR. ARMSTRONG: You've asked the question of the millennium. What we basically look at is many times we don't see that a child is going to have difficulty until they get to the age where other children are able to do something. And so, for instance, your 1-year-old now, almost 5-year-old, is engaging in the kinds of activities that 5-year-olds would be working in. But that doesn't tell us how she's going to do when she gets to third grade and has to memorize multiplication tables or how she's going to do when the print size and the amount of text changes in the third and fourth grade in the readers. And so the outcome of this is that, especially given that she is a child who's being considered for a gifted evaluation, she may be compensating or at least not using the skills that could be affected. And so unfortunately, you're going to have to watch for a long time. And in fact, many families wind up watching until their children are in the 20s. And I actually have some kids who come back to see me now who are in their 20s in vocations and saying, "This never showed up before, but in my job I'm having this particular difficulty," and we're able to identify it.

It's not something to be hyper-vigilant about, but it is something to be aware. And just know that if you see something that's really different from what you've come to expect in your gifted child in the past, the first thing when you're in the forest and it's an oak tree forest, look for the oak tree. This is one to look for and say okay, I need to jump on this and make sure this isn't something that's associated with a late effect. Because the other part of this is some kids just adjust a little slower as time goes through, but they do adjust. It's when they don't that we have the concern.

But you will need to keep an eye on it pretty much across your child's probably first 20 years or so of life.

CARSON JACOBI: Sherry, thanks for the question. Let's take another question, please.

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OPERATOR: The next question comes from John from Texas.

JOHN: Hello, my name is John and thank you for the program. My son was an ALL patient when he was 9 months old, similar to the last caller, and has been six years off-treatment. My question is, where do you go for guidelines whether he is better off in the public school system or the private school system? We've got both him and my daughter in a private school right now. Not sure if there are more specific programs for someone with some learning issues. I actually went through the checklist. He had the sequencing issues, he's got all the issues of the late-term effects that you would see. He's delayed a year in school and he's doing average in school I would say, with some real big concentration issues. Who can help us determining whether the public school will offer us more or if we should be staying in a private school?

DR. ARMSTRONG: That's one of the top ten questions that I get. And the answer is there are no guidelines. Especially during the elementary and middle school years. Public schools tend to often have, in a general rule, more resources because they fall under federal guidelines and they have to provide special education for children who qualify. And so they will often have a more full group of speech and physical therapists and occupational therapists and the like, supports, if your child needs those kind of supports.

However, when it really comes down to it, what we find is what are the qualifications of the teacher your child has and what are his or her abilities to implement the plan? And that's not a public or private school issue. It's very much, what is that school and that teacher able to do? And you have to really be able to assess that and work with the schools.

I've had children who have done phenomenally well in private schools, in parochial schools and in public schools. I've had children shift from one to the other. And in almost every case it comes down to what's the attitude toward providing the services, what is the ability to offer the kinds of services that are needed and what's the dedication and skill level of the teacher in terms of what works. I wish it was a little bit easier and we could make it more technically sophisticated, but that's where we are with human beings who are both teachers, administrators and children and parents.

CARSON JACOBI: Thank you, John, for your question. Actually, thank you all for your questions. Our program has come to an end. If you can please help me thank Dr. Armstrong and Nancy Cincotta. We are so very grateful that they have donated their time to us today and we thank them again for all of the work they do every day in supporting families touched by cancer.

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CARSON JACOBI: We hope that many of your questions were answered and that this information today will assist you and your families in your next steps.

Our Information Resource Center is open. The number is 1-800-955-4572. And our specialists are ready and available to speak to you and answer any other questions you may have.

So on behalf of The Leukemia & Lymphoma Society, Dr. Armstrong, Ms. Cincotta and I would like to thank you all for sharing this time with us today. Good-bye and we wish you well.

DR. ARMSTRONG: Thank you.

NANCY CINCOTTA: Thank you.

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

END