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Event Started: 3/19/2014 7:00:00 PM

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>> The webinar will begin shortly. Please remain on the line.

>> Welcome everyone and thank you for joining the American brain tumor Association webinar series. Our webinar today will address managing survivorship for adolescents and young adults who have been diagnosed with pediatric brain tumors co-presented by Dr. Goldman and Dr. Reichek. Please note that all lines during our webinar unmuted. If you have a question you like to ask them at please type and submit using the question box in the webinar control panel on the right side of your screen. Dr. Goldman and Dr. Reichek will answers many questions as possible at the end of the presentation. Tomorrow you will receive an invitation to complete a brief feedback survey. Please do take a moment to share your comments about today's webinar and your feedback. It is important for us for future webinar development. We are recording today's webinar that will be posted on the date -- ABTA website shortly. We will also receive a webinar link in a follow-up e-mail them -- e-mail message. Let's pause for just a minute so we can begin our webinar recording.

>> The American brain tumor Association is pleased to welcome you back to our webinar series. Our webinar today will discuss managing survivorship for adolescents and young adults who have been diagnosed with a pediatric brain tumor. My name is Crystal Ward, I am a program manager here at the ABTA and I'm delighted to introduce our speakers today. Dr. Goldman and Dr. Reichek. Dr. Stewart Goldman is the medical director of neuro-oncology and that foundation chair at the and and Robert H Lurie Hospital in Chicago. He is one of the principal investigators of pediatric supported pediatric brain tumor Consortium. And active in the collaborative and [indiscernible] research network, as well as the DOD supported and as treatments coach watching.

>> Dr. Jennifer Reichek is the director of the star long-term survivor program as well as a young adult oncology program. She is actively involved in the children's oncology group survivorship and adolescents young adult committees. As well as a critical mass young adult alliance. Dr. Reichek's research includes adolescent young adult and psychosexual -- psycho outcomes.

>> You may now begin your presentation.

>> Before I turn this over to Jennifer, I want to make a special thank you to Dr. Elizabeth Welch who has shared many of the slides today and we appreciate your input. I am excited to share this podium with a very fast-paced, we have a lot of slides, discussion about survivorship. As Dr. Reichek has taken over our long-term survivor program with her history and social work, she is really in a unique position to make a difference analyze our virtual than that we follow.

>> Thank you for attending our webinar. We are delighted to have you. This is just a little cartoon to get you in the mood. We are very funny people but we will be service about this topic.

>> The objectives for this webinar today are to recognize late effects associated with treatment for brain tumors. To identify special circumstances for the population were talking about, unless in and young adult brain tumor survivors. Do also identify issues that are about transition to adult care for adolescent and young adult brain tumor survivors. Who are survivors?

>> One in 450 adolescents in the United States is a survivor of a pediatric cancer. That makes about 220,000 total survivors of pediatric cancer in the USA at this time. About 75% of all children diagnosed with pediatric cancer will be survivors. And one in 2000 adults alive right now were survivors of childhood cancer. Those are statistics from 2000. We expect that there are more than that at this time.

>> Most common pediatric cancer diagnoses include ALL, brain tumors and Wilms tumor. Brain tumors are the most common diagnoses and more common with a LL, they did a management situation that tracks all diagnoses in the United States and survivor rates.

>> However, the more challenging for children with brain tumors is still higher than the mortality for children who are diagnosed with ALL or leukemia.

>> Late effects are any set-top box physiological or psychosocial problem arising after cancer treatment is finished that can be attributed to chemo, radiation, surgery or the disease process that necessitated the treatment. Late effects also include potential problems that are screened for on an annual basis. Even though somebody did not suffer from a particular late effect, if it is a potential late effect, we talk about those as well. Attention problems identified based on applications that we know that somebody's treatment and screening is standardized through the children's oncology group for all survivors.

>> We talked about survivorship population but let us talk about the adolescent and young adult population. One in 250 young adults age 50 to 45 will be a cancer survivor. Lose 50% of these people are likely to have or develop disabilities that alter their quality of life. This clearly is a subject or niche we need research and attention.

>> CNS tumors or brain tumors plus additional challenges for survivors. And the population of survivors of childhood cancer, two thirds of those survivors are likely experience a late effect from the treatment. Again, I late effect is any doubt,, either chronic or late occurring after treatment so we define that is five years from diagnosis and it is attributable to the treatment. However, with all this being said, 89% of survivors still report that they are in good health.

>> What factors influence late effects? The age of the time it diagnosis. Tumor type and location of the tumor. Cumulative chemotherapy dose and the way in which chemotherapy is given. The cumulative radiation dose and the location of that radiation. Complications experienced during therapy and after therapy. The degree of support received. And that means to the child and family during therapy. The degree to which the child and parents are able to cope with the diagnosis and treatment psychologically. And current health-related behaviors. For example, smoking, use of alcohol and dietary.

>> Essentially every organ in the body is a potential late effect. This is a list of all but not all-inclusive of potential late effects that you can read as well as I can.

>> Let's talk about your. How do you divide your? A biological cure is continuous complete remission until death from unrelated causes.

>> There is no evidence of physical disease.

>> A psychological cure accepts -- when somebody accepts having cancer as a past event and does not continue to interfere with normal development is going.

>> And a social cure incorporates the person cure to cancer into society without consideration of past history of cancer and/or his treatment. This is very important because we cannot talk about the

psychological cure without having a biological cure. It is impossible to talk about the social cure about the patient accepting him on her challenges having a cancer at -- as a normal past event.

>> We would we study late effects? I think this is really a current question. One we really want to be able to improve what we are doing for rehabilitation. We want to make sure we are getting better the long-term care and new treatment designs include looking out for late effects.

>> Just for a couple of examples. The research on near oncology has made a difference already. In the first that is that many of you know if that predecessor a 9961 is blessed, studies. In these, we reduce the amount of radiation in an effort to decrease late effects while still maintaining cure. It is a conformal this is of whole brain radiation. We use intensification of chemotherapy for blood stem cells in order to afford radiation sometimes. And a very hot topic out there that we may talk about your question about, the use of proton beam radiation. We? Because kids with brain tumors have neurologic [indiscernible].

>> Sometimes is about the tumor itself and sometimes it is about the treatment, what we call the director and director of the two men treatment. These really can be from any of the different modalities that we use, whether it is chemo, radiation or surgery, they're all equally important. Just some examples.

>> Radiation neurotoxicity. Some people are sleeping up to 16 to 20 hours a day. Inability to walk is only. Late effects like roses of the brain, myelopathy injury premature aging of the blood vessels like vascular injury. Near psychologic's sequelae. And it can issue, bone into the issues, I issues, hearing issue. I think one of the hardest ones to deal with, the risk of second cancers. It is really important that we study these things.

>> One example, this is a very ugly looking picture but we know from radiation therapy to the brain it makes it more difficult to acquire the knowledge. Specifically working numbers. And decrease processing speed. Sometimes memory deficits. All of these can be another challenge of the kids.

>> One thing I think is so important because there's a positive spin here is we are now aware of these issues so we can intervene earlier. Awareness leads to better therapies and better outcomes.

>> I think I talked about some of these things already. In an effort to move forward we will go to the next light.

>> We know that there are neurocognitive interventions during and after therapy. One of the best ways to identify whether a young person is having issues it through neuropsychology address neuropsychological testing. We also advocate for children and young adults to have differences in their learning environment whether it be an elementary school, high school or college, by asking for non-timed testing. For tape-recording sometimes if people have hearing or difficulty writing things. And resource assistance. For special help to make sure that everybody knows with their assignments are, remember to bring their homework.

>> Most important way, there is research out there for people with special learning needs, Inc. learning -- including the IDEA and section 504 of the rehabilitation act of 1973. We encourage of your child have issues with earning to talk with people at your treatment facility to get help to be able to get increased assistance at school.

>> We will move on and talk a little bit about the childhood cancer survivorship. Which is a huge study looking at lots of children, adolescents and young adults. And actually older adults who were treated as goods in the United States.

>> This is an angle relative study looking at the timing and incidence and adverse neurologic outcomes with people with brain tumors. We are looking at the effects of age at diagnosis, prior treatments, and earlier late effects on development of subsequent neurologic toxicities. This is looking at patients from as early as 1994, up until 2007.

>> And the way in which they gather data was by self-reported neurologic and neurosensory abnormalities. Meaning that there were questionnaires sent out to people who agree to participate in the study and they filled out whether or not they were having certain symptoms. It was looking at the time of onset, the time that the symptoms occurred, and new symptoms. Looking at the overall incidence, altogether how many people experience particular side effects. And then use complicated statistics to look at late effects. They were all looked at five years after diagnosis.

>> This is the graph showing the most common neurologic outcomes. Including coordination problems, that Dr. Goldman was speaking about, seizures and motor impairment. As you can see, they get more frequent the more years from the diagnosis.

>> Unfortunately, having a brain tumor is a gift that keeps on giving.

>> This is looking at hearing and deafness and hearing loss, tinnitus and ringing in the really -- ringing in ears and dizziness and vertigo. We see that it continues to increase over time since cancer diagnosis.

>> Talking specifically about hearing loss, I think it is everything else at Dr. Reichel showed you. Tells us that we need to be involved in late effects programs because you have to continuously follow-up to look for the symptoms. Something close to my heart, hearing loss. Of our kids get cisplatin or Carboplatin and some hearing loss. Radiation itself will give hearing loss to her percentage of patients. It is normally seen in the high-frequency, sometimes out of normal range speeches. But consequences can be communication difficulties, difficulty in a noisy environment, difficulty with consonants. When you think about it, we talk about some of the straight neurocognitive types, now there's a situation where hearing is difficult, it is just one of the things the child has overcome. Once again, awareness is a struggle. Follow-up a struggle.

>> Here is a standard audiogram. What this shows is before the circles, some cisplatin, some hearing loss, 40-40 dB range and the more plan we get, the more noise. For many of the parents that I see, they get this kind of graph when it comes to the clinic. We really should give you a this Graham. Where we see difficulties. The telephone ringing, piano playing, hearing loss down here you may not be able to see her, and airplane going over your head or a drum suddenly playing.

>> If you remember from the previous slide, we have common hearing loss. Where people can have difficulty determining between the GNF sounds. This can be an educational roadblock.

>> But we can do something about this. We can use constant surveillance. We cannot hearing aids, make sure the kids have preferential seating. Make sure the environment is correct. Something called the FM session where the teacher will wear a microphone wherever they sit so they do not have to sit in front if they do not want to. And also we need to make sure the epidemic of hearing loss that is happening teens and young adults from earphones, loud music -- I really sound old right now, don't I? All these things where we try to avoid those environments to practice for family members and the patients.

>> And this is just an example of new work that is being done looking at protection such as amifostine. It has been used in the past to protect kidneys. In some studies it may show that it will decrease the more the hearing loss. Changes on the way. Wheeze as possibly focusing on what people all already faced -- facing.

>> As Dr. Goldman said we really encourage the patient to follow-up and copperheads of survivorship clinic's causes clinics are expert of following all of the different side effects that can happen. There are routine screenings.

>> There are certain the -- chemotherapy medications are know that caused momentary fax like bleomycin, which is often used in different types of tuners. Boss yourself and for stem cell transplants, BCNU, CCNU are all common a brain tumor central cause Boman are effects. And those are likely pulmonary fibrosis, meaning that one is unable to expand or contract the Raiders busted. Which leads to a restrictive pattern of lung disease.

>> The Ray that we screen for these things is by doing test X so take a look at the lungs themselves. But also by pulmonary function tests to see what the ability of the person comply with breathing.

>> Interventions that we can do after they have been detected, our counseling people to stop smoking and encourage people not to start smoking I have not. Making sure that if the patient or young person is getting a Caesar, precautions are taken. And sometimes medication such as a Bureau.

>> We know that brain tumors can cause discretion and endocrine function. Sometimes that is from the tumor itself and sometimes it is from the therapy they receive. The waves in which receive these are growth, the function of the thyroid, and on fertility, as well as other things.

>> Thyroid banalities are often caused by radiation therapy in that radiation therapy or other to the brain caused with the problem with the hypothalamus the church I access or with the head and neck which can shut the thyroid as scattered. It can cause primary or secondary failure of the thyroid. And a clinical caused the nine gross on the thyroid.

>> The way that we screen for thyroid out amount is our first of all through a thorough history and physical exam. But we also measure the thyroid hormones in the blood. If we feel any nodules or see anything unusual on thyroid hormones, we can do a thyroid ultrasound.

>> If there abnormalities in the thyroid, there is treatment that can happen. Sometimes people need replacement thyroid hormone. Sometimes people need surgery to the thyroid and sometimes I need radio oblotion to the thyroid. All of this is fixable.

>> The reason which thyroid dysfunction can happen again is data from radiation therapy. It can be disruption of the pituitary axis from cranial radiation therapy or radiation to the brain. And they can lead to changes in the thyroid that can become cancer.

>> We know that if the thyroid works too hard to prove use the hormone, it can cause itself to grow nodules that can intimately be cancer. So it detection of thyroid dysfunction early is really very important. And replacement thyroid hormone is incredibly important.

>> The ways in which we learn from history whether somebody's having a problem with the thyroid to be asking questions if they're more tired than usual, having difficulty learning, feeling cold, stop growing as well as they were growing before, constipation, is their skin cold or dry, is their weakness of muscles that should not be there. People also often experience a round puffy face with very dry skin.

>> Again, evaluation after treatment is key. And it must be routine. Even if you check it once, you must make sure that you continue to check thyroid more month to make sure they're working appropriately.

>> There are lots of people who have hyperthyroidism or decreased thyroid hormone. There is an article in the Journal of clinical endocrinologist at and metabolism that it about 50% of patient had CSI had several hyperthyroidism. So perhaps without symptoms. 90% -- 92% of this patient had central hyperthyroidism, meaning from the thyroid itself, and 27% had mixed hyperthyroidism, which would have been undiagnosed if there had not been testing at baseline. So before the changes.

>> Let's talk a little bit about growth now. We know that there are effects on growth from therapy for brain tumors. Radiation kinking -- can cause effects and the effects that people experienced include growth hormone deficiency, or coaches puberty, meaning going into pure realign age, and short stature.

>> As we all know, being very short can have tremendous psychosocial and emotional consequences. I know you cannot see this but I happen to be a pretty sure person. I promise you, it gets in the way sometimes.

>> They can be affected by hormonal effects. That period -- that can be direct their preset cause a short stature. We know the growth hormone replacement is important. But in the past it has been really controversial because there was some concern that giving growth hormone to people would increase the risk of a relapse of the disease or a secondary malignancy.

>> We no longer believe that that is true. We know that with growth hormone deficiencies starts in childhood, it can lead to short stature. But in addition to that, it can change the walls of the heart and they can make the heart less able to respond to exercise. So unable to pump blood quickly and strongly to the rest of the body during exercise.

>> We know that giving growth hormone replacement not only until the child is finished their growth curve that also through adulthood can help with lipid profile. So we know that metabolic syndrome is a common inter vivos of pediatric cancer. It can decreased fiber Jenin levels which lead to blood clots. Increase cardio function me to blood costs and continue to increase a function of the heart.

>> What is the radiation effect on further broke high-gloss? We know that spinal radiotherapy changes the height loss based on age. If you are one years old at the time of your radiation therapy, you can lose up to 9 cm of vertical growth. At the age of five years at the time of radiation debris, 7 cm. And even at 10 years all, 5.5 cm of vertical growth.

>> We believe that proton beam may help to decrease invertible high-gloss because the scatter is different.

>> There is also growth that happens too early. It leads to decreased amount of growth. Precocious puberty is the appearance of physical signs of puberty prior to age 8 in boys and nine in gross. It could be due to a variety of things, including tumor itself, surgery and radiation. It happens more frequently with females. And some start puberty at a normal age but progress rapidly.

>> Surveillance, again, is the most important thing we can do. We stage people by physical exam, GnRH development, secondary characteristic. We test hormones in the blood, we can look at bone age by x-rays. And we can treat this condition with hormone analogues to block continued hormone development and growth hormones so that people continue to grow to the point that they are supposed to grow.

>> Growth hormone therapy can increase the height. It only works if those bones are still able to grow. So we have to look on an x-ray to make sure that the bones are not fused so there's a potential for growth. Permanent loss of growth potential in the spine means that you are sitting

height is too short. So we have long arms and legs and a short torso. They later you start, the less time it takes to work. So we really try to start really very early.

>> This is a pictorial about growth hormone replacement therapy in children with medical us,. It is the 11 bit -- 11 biggest brain tumor -- sorry, this is the 11 biggest brain tumor program in North America. This is compiled from therapy at least five years and treated with growth hormone prior to the age of 15. It looked at the GH uses and the time starting therapy. And it match the recurrence of tumors rates using GH versus no GH.

>> If you look at the years post therapy, and the probability of a recurrence, --

>> No difference.

>> What? No difference at all. If you look at the growth with no GH therapy and GH therapy, you can see that kids who got growth Ormonde therapy were able to grow better than their peers who did not take GH therapy. Again, we believe that using GH therapy in children is important.

>> No difference in recurrence rate or new tumors.

>> Gonadal failure or futility. We know that high-dose cyclophosphamide can cause gonadal failure particular board. We know that radiation in the spine and lower abdomen and pelvis can cause failure. We know surgery involving the gonads can impair fertility. We also know that of all the kids that retreat, that prepubertal girls are the ones who preserve their fertility throughout therapy.

>> Radiation to the brain also can cause premature menopause, by many -- primary and mentoring, meaning that it's don't get the periods and low-cost run -- testosterone.

>> Water interventions we can do? Really, prevention is the most important thing. So we have been talking a lot in the adult community about preserving fertility prior to starting chemotherapy. And if it is not emergent to start chemotherapy or radiation therapy, the push is now to preserve fertility by collecting semen from boys who can do it and produce a sperm sample or preserving covariant and testicular tissue in order to be replaced after chemotherapy radiation has done to allow children to have reproductive tential.

>> We can also use hormone replacement therapy and other reproductive technology.

>> We know that, particularly in girls, at the hormones are networking, it has an effect on bone health. These girls when they take vitamin D supplements like women do after menopause.

>> There are familiar -- familiar cancer syndromes. Outside of this particular population, there is no - there is no increased risk for children who have had some sort of a tumor to have babies. It is not war likely for a child with a brain termer to have a child with a brain tumor that it was for their parents to have them.

>> There are large studies regarding the situation in the key media and smaller studies that been done in solid tumors and CNS tumors. In addition, the offspring from patients of different types of tumors have no obvious increase of congenital malformations or illnesses. Even though it is scary to think about, it is not more likely for the young person with a brain termer to give birth to somebody who has that problem.

>> Again, we talked a little about fertility preservation. We covered these things. We are happy to answer questions about this one me open up the questions.

>> What about second -- secondary malignancies. It is very hard to talk to a family that treating a child's character and say 0 By the Way, secondary their break could cause cancer in another cell.

Both radiation and chemotherapy continue to her risk of secondary malignancy. This is part of the reason that we want long-term surveillance and all of our patients. Whether in an oncology or Nero college he clinic or survivorship clinic just so we can watch out for this lightning striking twice.

>> There are many radiation-induced second tumors including meningeal met, GBM and osteosarcoma. For chemotherapy, the most likely secondary malignancy is in the form of leukemia.

>> Again, here are the different types. We talked about thyroid carcinomas. In addition, if you experience radiation, there is skin cancers and breast cancer depending on where the radiation field was.

>> This is work by cicadas looking at secondary tumors following RT for medulloblastoma. Of the 200+ kids who were treated from 1985 to 1994, in that population, there were eight secondary tumors in seven kids. Of the kids who got a secondary tumor, 4/7 of those tumors. Three of them have leukemia and to receive chemotherapy. So the cumulative rate of secondary malignancies from this population was 20%. Overall, 30 years post diagnosis, only 10% of patients had had an issue.

>> We wanted to talk a little bit about direct central nervous system toxicity.

>> This is again, to me, one of the things that keeps [indiscernible]. We know that surgery, tumor radiation chemotherapy has an effect on the central nervous system. We worry about people having cerebrovascular disease or being in risk for heart and stroke. We can do this and just from radiation, usually between 2-20 years post radiation. The very common type is about five or eight years out. This is really taken the blood vessels and having them age quicker.

>> Anytime we see a sign of a transient ischemic attack, stuttering of the words, loss of memory, transient weakness, we have to take this seriously and needs to be seen by a physician immediately.

>> We know that brain tumors, patients have survived brain tumors are at increased risk of late strokes. We see that one of the things most associated is higher dose cranial radiation where we are trying to avoid this for gliomas and other tumors like Ray Neil and Jonas that patients routinely get over 30 G we. This shows there is a Q incidence of different spirit of patient having a brain termer and a brain tumor and cranial radiation. There is an example.

>> This is very important because as we know, as the years go on, we still need to be vigilant.

>> We have this talk, I was thinking we must be scaring people left and right about the future. That's not the point. In fact most people define. But this is the reason that we have to have continue surveillance.

>> As our patients survive and grow, there now is a problem where there are many adult physicians who are not aware of some of his concerns. That as we transition clinics, that Dr. Reichek is running, and survivor clinics are vastly important to your child and your future.

>> Intellectual outcome. We know that the location of the tumor is extremely important. Patients with posterior fossa tumors do better than those than those with supratentorial, meaning in front on top of the brain. A little more difficult for some of the outcomes.

>> We know that lesions that are deep in the brain at increased risk of having some intellectual problems, even prior to any the therapies themselves. The tumor itself can cause intellectual problems, radiation can cause a, Nero cognitive Robbins. We have done a lot of changes in our protocols to try to be aware of this and maintain survival rates. Here's an old study but I think a really critical study.

>> A little bit of history here. For any families that have childhood medulloblastoma we talk about standard radiation and reduced radiation. When I started my career, standard radiation was 3600 ramp to the entire cranial access and reduce was 23. There was a study that said it was safe to reduces radiation kids as opposed to giving chemotherapy at full does or at team of therapy with reduced radiation. This study, which did not improve really well because people were unwilling to have the child randomize without chemotherapy, still gave important data.

>> Of the kids who were tested 6-10 years posttreatment for schooling and intellectual outcome, them up to the quality of life, and a stratified them when they were before age 9 or after age 9. And they had some health-related quality of life issues and all of the patients at large. Very few to the point of where they could not take care of themselves, but most still had some issues.

>> This hard-to-reach slide, the take-home point is those patients who were younger, less than nine, were able to get reduced radiation, did better in their spelling and reading scores. These IQ scores. As compared to those who were younger who got the higher dose.

>> As you get older and the brain is more mature, you can see there is a difference, it is not as significant. I think this is an important piece of information.

>> Now we will talk a little bit about cerebellar mutism, which is a consequence of having a brain tumor. Scene at the beginning of therapy, usually postoperatively for brain tumor. It usually starts about six 6-72 hours after surgery happens. They can be seen starting with actual hypotonia, meaning some [indiscernible] sitting and difficulty walking and wobbling back to fourth. Changes in emotion like being upset, happy, and changing very quickly. And some difficulty in making sure that you are saying the right thing.

>> In red under her, you can see a quote by Dr. Robin Humphreys describing the onset of cerebellar mutism.

>> What does it do? It is involved in higher cognitive functions. It is very important distinction in abstract terms. It helps in early detection and ability to learn from errors. So if you do something wrong, you learn not to do it against. It helps other areas of the brain perform functions more efficiently.. Without the cerebellar input, motor and thinking performance is slower, in accurate, difficult and changeable.

>> Who gets CMS syndrome?

>> Most kids -- most cases involve kids. There are reports of cerebellar mutism in older patients. It happens most commonly in kids who have had a brain tumor at the back of the brain. So medulloblastoma is a must, diagnosis, file by appending Mona, Corey plexus, rhabdoid and rarely astrocytomas. Is often tumors that are in the middle of the brain, meaning along the spinal axis.

>> Other people who get cerebellum mutism syndrome who had trauma to the brain, and infection or bleeding in the brain, a blood caught and kids who have abnormal blood vessels.

>> The resume you talk about this now is that we know that if a child has CMS, it is associated later on with worst global neurocognitive outcomes. As you can see in this graph here, with orange being that CMS negative kids and blue being CMS positive kids, that IQ is lower than -- after having CMS.

>> In addition, special education services were more frequent when needed. The blue here is kids who have had CMS and the red is kids who had not had CMS. It is a doubling of the number people who needed special education services.

>> Importantly, for the star, there is research going on. Looking at neurocognitive interventions to help prevent these long-term effects. We can do cognitive assessments. And there is a new protocol or website and a bunch of interventions call CogState . There is computer Dars cognitive training to CogMed. There is pharmacotherapy, so different medications can be given to increase alertness and the ability to concentrate.

>> We also have now written into all of our protocols Nero cognitive assessments both during the therapy and afterwards so we can increase awareness and have early intervention. One example of an early intervention trial, again, it was not promoting anything in particular, just to show that there after, is the study of modafinil to improve neurocognitive deficits. Not to go to the did all this, this shows that we have a trial now that is ongoing that not only during the time to have therapy get -- sorry, I got page. Make sure this is a change for the positive in the future.

>> Let us talk a little bit of that social so cool effects. We know that having cancer in general P disposal psychosocial effects. There's been a lot of literature about posttraumatic stress disorder in patients who have had cancer. As a direct result of cancer being life altering event. The fact that kids go through lots of painful procedures during the therapy. That kids no longer have control over themselves or control over what is happening to them and what is happening to their family. This is an experience of an immediate consequence but may also feel like a lifelong consequence. As secondary effects,.

>> There's a separation of family and friends and what is safe and known during therapy. This posttraumatic stress can impact both parents and the patient.

>> More interesting to me is that most people when survey at least a year post cancer therapy report that although they may have had symptoms a poster manic stress during treatment, they feel that they have had what is known as poster manic growth. Meaning a clarification of what is important in life, of who is very important to have relationships with in life, and other things that they see as beneficial ultimately as a result of having had cancer.

>> Additionally, having cancer can change a life trajectory, especially if you're a teenager and working on separating from your family and becoming more independent, being ill may make you more dependent on your family. Can also change her social situation, they may have to come back and live with her family during therapy. And can change current employer mint and the ability to be employed in the future.

>> Again, it is not all that. Psychosocial reaches a shown that survivors words and insiders are not actually greater than age matched controls. And are actually less focused on the health then people their own age who have not undergone therapy for cancer.

>> Despite the fact that many late effects can happen in kids with a brain terms, these children and adults are mostly satisfied and happy with their lives. Again, most report post meta-growth as a result of the cancer therapy.

>> What specific psychosocial effects to look out for in adolescents and young adults? If we can all think back to being a teenager, it is really important to be liked and accepted by your peers. Cancer therapy change that and pulls you away from your peers and isolates you during therapy. And sometimes because of changes that are associated with therapy. Again, cancer diagnosis treatment can make yourself confident in your self-image and self-esteem change because of those physical changes and physical abilities or change during treatment.

>> Additionally, as I said before, like task of separation and individuation that is so critical at this time of life can be changed by the diagnosis and treatment. Because they're working toward

independence, young adults and adolescents become more -- when they become more detached -- depended on the family a feel infantilized or regress.

>> There's a really important when issues of cognitive and physical ability a change by treatment. And in this age group, fertility are of utmost importance.

>> What about relationship issues? Isolation from peers at this crucial point can affect some long-term ability to form relationships. There are many relationships that may and during high school due to the stress of illness because peers cannot cope with the thought of somebody very -- having cancer. Changes in body image can affect the sexual development and sexual relations in the present and later on in life. And we know that sexual drive, sexual function and fertility may be altered by treatment itself.

>> This is a confusing picture about different factors that have been identified that affect marriage injury to -- brain tumor survivors. There have been a lot of data regarding how many survivors of pediatric brain tumors are married, worse is their age matched control. In general, boys who have a lot of neurocognitive challenges are less likely to get married then boys their own age who have not undergone cancer therapy.

>> What about social skills? We know that development in near cognitive changes in therapy and that may affect social development. Social development may also be change because parents is so worried about their kids during therapy that they do not set the same limits that they would step before and do not allow the kids independence and privileges that they used to have before they were receiving therapy.

>> What about education? Education and the outcome of education is really dependent on some of these Nero cognitive status. Survivors of brain tumors are more like to of special education needs because of the side effects of their. And are slightly less likely to attend college. However with early intervention of the time of onset of this neurocognitive changes, survivors of brain tumors certainly can go on and get an education and do what they want to do.

>> What about employment? Again, depended on somebody's neurocognitive abilities. Survivors of brain tumors are more likely to be employed. But this is more related to their physical abilities or disabilities necessarily then in neurocognitive ability.

>> We have alluded to transition of care for adolescents and young adults and this is close to the end of our talk. I just want to spend a moment talking about change of care as people age.

>> We know transition to adult care is difficult to anybody with a chronic health problem. It is a process over time. Right now, we define it as a purposeful movement of the AYA, or adolescent or young adult, then the pediatric system to the adult setting. Our goal is for the AYA to achieve successful engagement in the adult system. So that they can receive developmentally and medically appropriate care. And we know that this transition should be coordinated, centered on the family, in particular the family itself, and planned.

>> We know that there are several stages of transition. Initially we talked about envisioning a future. So we start talking about future planning. So that gives hope that there will be a future. But also gives time to adjust to the changes. And we start this transition process we before it actually occurs.

>> Then the age of responsibility where the survivor takes over some autonomy in their own care. Where is maybe parents have been making most decisions, the survivor of themselves takeover.

>> And then there's the age of transition. It is divided into adolescence and young adulthood. The tasks change depending on where you are in this continuum. It gives increasing levels of decision-making ability with regards to healthcare to the survivor.

>> What are the barriers to this change? Change is hard. If you been treated by people for years and years you do not want to leave them and you may feel abandoned when Julie them. It also has a change in a role for the adolescent or young adult, which changes dependence on parents help to decision-making on adolescents and young adult.

>> Sometimes adult survivors are even people as China's 19, no longer have health insurance, which makes transition difficult. It is also hard to find an appropriate medical home for adult survivors of pediatric/adolescent/young adult cancer. We know that adult providers are not used to taking care survivors. As more more survivors are in the population, they will need better education about late effects. However, at this point, you know it requires multidisciplinary collaboration and communication, which is again, we we encourage everybody in the survivorship clinic by can coordinate transition to adult care.

>> What can the survivor due to maintain health? The same day we can all do. Exercise regular, get enough sleep, eat good foods, drink alcohol in moderation, do not smoke and wear sunscreen.

>> We need to talk about the future. We know multidisciplinary teams of focusing on survivors and the issues. Using quality-of-life assessments now to better understand this. We are getting new therapy, writing new studies. We want to have time for questions. We have things are doing and hearing. We know the psychosocial research have shown survivors are more focused on the health and some of the silly things people think about.

>> In conclusion, these eight effects are real and they are substantial. Our new treatments are aimed not only at survival but to minimize late effects. Late effects need to be dealt with by multidiscipline or teams. Evaluation and early intervention are key. Despite this, patients are satisfied and happy with their lives.

>> New awareness is to better preparation and coping. New research to understand risk and images. New multidisciplinary emphasis to improve quality of life. With more research and advocacy. And I think the ABTA is one that they've been showing to do at this receipt for so many years now that we can change the future for survived -- survivors of childhood brain tumor.

>> Now it will be happy to take questions.

>> And Cuba so much for the presentation. Dr. Goldman and Dr. Reichel will not be taking questions. If you have a question you would like to ask, please type and submit using the question box in the webinar control panel on the right-hand side of your screen.

>> We do have a couple of questions that have come in. The first one, which chemotherapy are cyclophosphamide?

>> Is also called Cytoxan. Is an alkylating agent and used in many of the brain tumors we treat.

>> Okay. Our next question is are there any interventions that are then found helpful for young adult survivors, particularly to cope with stress and and anxiety as they move further into survivorship?

>> Specific interventions they're looking for.

>> We know that her support is very important so pure support ribs I helpful. Meditation and yoga and even sometimes talking therapy can be helpful to manage stress as a young adult moving into adulthood as a survivor.

>> I think it is really important that people seek a therapeutic group or individual therapist to help them with this coping.

>> Great. How often do you think survivors should be seen in a survivorship clinic walk so

>> The standard of care and comprehensive multidisciplinary survivorship clinic is one time per year.

>> It is dumb on the individual -- it is done on the individual's needs. There are survivors that though once he year are indicated they may have significant needs this adult limited to once year.

>> What makes it difficult to survivors of brain tumors is that disease [indiscernible]. So a child may have a recurrence later. Is it really two years of therapy with a transition into a leg effect clinic? Or someone with an astrocytoma or medulloblastoma? I think the real answer is that as we need coordination between you neuro-oncology is, neurosurgeon, neurologist and lead effect specialist. If we can work as a collaborative team, we can make sure that we are looking at the awesome and important issues of quality of life relate effects and also during screening for recurrence.

>> Additionally, other people neither other services as well so it does not mean that you see your endocrinologist was once year or your kidney specialist once year. There is a coordination of care that happens so that everybody is being taken care based on their particular disease with the specialties.

>> Great. Another question. Are there any physical signs of brain imaging that would imitate cognitive deficit.

>> That is a great question. I was going to ask I will myself. This is an extensive field of research and even ourselves here at children have studies that are ongoing, looking at changes in white matter in track changes. We have a study that is tracking changes on MRI scan overtime as we follow our patients. This is a very hot field that is developing and in the very new future, I think this will lead to some potential areas that we will be able to identify another early intervention. This is a developing field and, yes, we are finding areas.

>> Okay, another question. We have a few questions regarding whether or not to disclosure diagnosis to employers and whether you have any recommendations for that.

>> I think that is a personal decision. I think that people's medical health information is private. If an individual believes that their employer needs to know about their medical history, then it is perfectly appropriate to disclose that. There are always concerns about discrimination based on prior medical condition. In fact, we have some slides and I think Dr. Goldman is pulling them up -- there are resources. So if it failed -- so someone discloses they had a brain tumor to an employer, there are resources of the thought they were being discriminated against the can help with that and those are currently on the screen, I believe.

>> Great, that is a great resource for patients and families.

>> How many slides could they possibly have had? [laughter]

>> There all good. Another question, what are some of the late effects with [indiscernible] and cargo -- Carrboro Latin -- Carrboro -- Carrboro plan.

>> One of the ones we mentioned on this earlier slide were hearing loss, not near as much as can be.

>> It can also cause difficulties with kidney function, but during therapy and after therapy.

>> It can be near as impressive. That is why, when children get a low-grade glioma can get Carrboro together. That is why you are getting this but that -- blood test so frugally during the time of administration. It can cause neuropathies, constipation, of Vern, if it hits into the tissue. And most of those we say a temporary. Unfortunately, when I am a patient, temporary means when I go to bed tomorrow morning it is better. In the medical world, temporary means not permanent but can be a long period of time. If we're not careful with our dosing, we can have prolonged neuropathies.

>> I have been doing this a long time. I have never lost my respect for the seriousness and potential toxicity that of these agents. Why are they always getting examined? Why the getting talked to? And it is because we have to be very careful on how we administer the medicines to prevent as much as possible these late effects.

>> Great. I have a couple of questions. Patients were surprised by the pulmonary Effexor talked about and wanted a little bit more information on the effects on the long.

>> It is easy to say that busulfan is not used as much as it used to be in pediatric brain tumors, maybe for it better maybe we should have left this out. Was at one point a, therapy was included in high-dose chemotherapy with some stealth brain tumors. It is under those regimens for the most pulmonary difficult as Whitaker.

>> When we do cranial spine radiation where we get higher doses and not controlling the beam as much that has a radiation affect. Then again, even with CCNU, it is a risk but not commonly seen. Again, we try to make this talk to people who have been long-term survivors that might have had therapeutic given a distant, go.

>> For many of you, PFT may not be a routine function, it depends on the history and amount of the drug you got. Once again, we want to make sure people are aware of the potential toxicity to all of the organ systems.

>> Great, I think that is very helpful. We had a couple of questions come in about coping with the long-term impact of this diagnosis on their personality and social skills. I know you had a couple of slides on that, but if you could elaborate a little bit more.

>> I think that is really individually based. Some of it is based on where the tumor is, what the therapy was, and what the potential changes are. As we said earlier, I think support is crucial, both during therapy and after therapy. And trying to get back to the business of living as much as possible. A regular life, the life that they were living before the diagnosed is really helpful.

>> I want to add, here is we believe are really can make a difference. I think this is dependent on and really important that the medical team caring for your child or you as a survivor, as well as your family, your self and your community, make sure we do not have people become isolated. That we do not focus on what this abilities, may they be small or significant and maintain a lifestyle that is the mainstream lifestyle.

>> I cannot tell you -- I've been doing this a long time and some of this is not based on studies, the patients and families who continue to interact in a normal manner, who have interactions with friends and family, will help them in the long winter coat and look forward. That is easy to say until you are the person in the situation where you spend much of your time coming to the hospital or you do not feel that you can go to school as easily. It is easy for me to make this comment, I realize that there

complex. But as much as possible, we believe during the treatment, you do not want to be someone who is a medulloblastoma. It you want to be a child who happens to have a medulloblastoma.

>> We are not cheating tumors, we are treating children with tumors. As long as you make sure we push forward to help children to understand, and young adolescents and adults, that this is a part of their life but not the defining moment in life, that may help them to cope. And then all of the resources that Jennifer talked about I think a very important in helping them cope with their disease.

>> That is fantastic. I think something that everyone needs reminders and reassurance for. Thank you for the comment.

>> We have time for just one more question. Regarding any studies on young adults for sexuality and development in the survivorship stage. If you are aware of any or have any advice for that.

>> I will have to take I guess at what is meant by sexuality. Again, it depends on the person's particular situation. There are some studies that of childhood cancer survivors should studies looking at sexuality, sexual interaction, marriage, having children, things like that, in the survivorship population as a whole, I am not aware of any studies particularly with this -- with regard to brain tumor population. There is a spectrum, there is a continuum of function that happens because of a person's neurocognitive abilities. I think as we continue to have more people survive different diseases, all aspects of psychosocial function, including sexual function, will be looked at with this rich population.

>> I think the bottom I is -- the bottom line is we learn from our patients and families. There is no topic that is taboo that we should not try to study so we can give you information so that people can move forward with their lives.

>> Great. You have been wonderful. That is all the time we have for today. I just want to thank you all for joining us and thank you once again to Dr. Goldman and Dr. Reichek. We will just pause for just a moment to stop I were recording.

>> We invite you all to continue to check back at our website.

>> We invite you all to continue to check back@ourwebsiteABTA.org for other brain tumor related topics in our webinar series.

>> Our next webinar so Thursday, March 27, them 2 PM to 3 PM central time, metastatic brain tumor, treatment and therapy. Learning about the standard an experimental treatment options, we will also discuss the quality-of-life concerns that are related to these types of tumors.

>> Join Drs. Duane Mitchell and Marion Robin of the department of neurosurgery at the University of Florida as a cool present this ABTA webinar.

>> We also have one on Wednesday, April 1, from one from 1 PM to 2 PM central time, a discussion of treatment options and associated quality-of-life concerns. Joined Dr. Eric Boothbay, director of the brain tumor program, hematology oncology of the hospital of six children as he discusses a different type of treatments available for pantomime. Including radiation and the possibility of chemotherapy or.

>> You can also explore what is on the horizon.

>> This concludes our webinar. Thank you so much for joining us and please be sure to receive the feedback -- please be sure to fill out the feedback survey that you will receive an a few minutes.

>> [ Event concluded ]