Pediatric Brain Tumors 101

Please stand by for realtime captions. [Captioner is on hold, waiting for event to begin.]

>>Welcome everyone and thank you for joining the series today, it will address Pediatric Brain Tumors 101 presented by Dr. Corey Raffel. If you have a question you would like to ask please submit it using the question box using the webinar control panel on the right-hand side of the screen, Doctor Raffel will answer as many questions at the end of the call. Tomorrow you will receive a survey asking to presenter feedback for today's webinar, we are also recording today's webinar posted to ABTA website look for it in a couple of days. Feel free to share with your family and friends that were unable to be on the call today. We will pause for a moment and we will enter the recording right here.

>>We are pleased to welcome you back to our webinar series, we will discuss webinar pediatric brain tumors 101, my name is Jillann Demes, I'm delighted to introduce our speaker today Corey Raffel. He is a board certified pediatric neurosurgeon, at good Samaritan Hospital in San Jose California. His current laboratory work is the use of viruses in the way of killing cells, he has received his empty and PhD from the University of California San Diego, in addition he has served in the scientific advisory board of the ABTA for many years which we are very grateful, thank you so much for joining us Dr. Raffel, you may begin your presentation.

>>Good morning everyone, it is my pleasure to give a primer on pediatric brain tumors, for allowing me to do this -- let's get started.

>>I would like to talk a little bit about brain tumors in general, in children in general. No parent wants to find out that their child has a brain tumor. Most of the time when I tell families there is a brain tumor in their child they do not believe me or they are confused.

>>A lot of this support is available from the ABTA.

>>What are the signs and some to, then I will talk about what kinds of tumors and how they are treated, I will talk about the chance of survival with the quality of life is for each of these tumors.

>>When a child has a brain tumor, the most common symptom is headache. Now children can get headaches not related to brain tumors. You will have to differentiate which headaches our brand -- brain tumor and which is something else.

>>If they are associated with other neurologic systems, some other indication that the brain and spinal core are not working perfectly amongst those symptoms, we also have sleepiness, personality change, clumsiness of hands, difficulty of walking, the heart rate slows, Blood pressure control what.

>>I think it is really important to emphasize that children can get headaches not
associated with neurologic deficit and still have a brain tumor. These headaches are worrisome, if the child wakes at night, or has a headache when they wake up in the morning, especially worrisome in the headache is associated with vomiting, the most common thing is the child wakes up with a headache, throws up and feels better.

Some other things that we worry about, what we see child with headaches, worsening when they lie down, worsens when coughing, straining, on the back rather than the front of the head, when there is a distinct onset of the headache, the parents will say it started three weeks ago, when they have been going on for less than six months, children will have headaches, and then get a different headache related to a brain tumor, a change in pattern, or severity of a pre-existing headache syndrome. That is also a warning sign. If the headaches get worse over time, we are also worried about the headache.

Another symptom is vomiting as I mentioned previously associated with a headache, it is worse in the morning, but improves later in the day, vomiting is usually a new symptom -- symptom and leads to weight loss.

In addition children can have new onset of epileptic seizures, they can have a symptom of a brain tumor, especially true if the child has never had Caesar's -- seizure before. We worry when it is not associated with a fever, sometimes it is associated with a high fever.

Unfortunately brain tumors can occurred in children of any age. Sometimes very young children, who are less than two years of age get brain tumors, these are hard to identify. And infant may show a sign if they lose previously acquired milestones, or their head grows faster than normal if it has been growing normally.

Sometimes when a child has a worrisome sign of symptoms, the eyes, the pressure is transmitted to the back of the I and we can see that pressure, this condition is called Captain. Medina -- M Dema --

This condition is [Indiscernible], in our imaging it is a study, MR scans are best at tumors, they do not require x-rays we like to use the MR scan whenever we can. However if the scan is not available, a CT scan may be obtained, they are also good at looking at the brain it is a study that requires x-rays, the child is radiated we try to avoid that.

Let's talk about the Types of Tumors that children get. It is important to know brain tumors in children are not common, it is to say in the United States there are about three cases per 100,000 children, every year. That is not very common. If we look at the population in the United States let's say that means 1500 new cases per year in the United States, in the overall span of a child's life, one in 2700 children will get a brain tumor, of those types, brain tumors are very common, the only type is more Coleman --, and is leukemia, tumor of the but -- of the blood.

So now that we have said tumors can occur in children, we talk about symptoms, and in general let's talk about specific Types of Tumors.
The first tumor I would like to talk about is Medulloblastoma, this is the most common minute look brain tumor -- Mende glint --

Mende glint playing tumor --

In the back part of the brain we call posterior what about some -- they have signed consent of related increase pressure, the to or prevents the normal pressure of the fluid made in the brain, it is made in the brain and it circulates outside the brain, this blockage of the fluid causes pressure, we call this hydrocephalus, water in the brain, because the fluid space get bigger, you may be told your child has a brain tumor and hydrocephalus, that is what it is.

When you do have increased pressure in your head, it comes with headache and throwing up, that's why it is so common in children with brain tumors, others symptoms caused double vision, loss of coordination balance problems.

Here is an MR scan of a child that has Medulloblastoma, I will circle around to see the tumor Sitton in the back part of the brain, here is a Midline cut of the child's head, this MR is sliced from the nose to the back of the head, we can see the tumor in the bottom of the back of the brain, the part of the brain right here that the tumor is involved with is called the cerebellum, it is responsible for balance and ordination. That is why we have problems with those things if a child has a Medulloblastoma.

When we see a child with Medulloblastoma, the first step which treatment is an operation, that is the first thing that is going to be done. We have three goals, when we do an operation for a tumor in the back of the brain. The first goal, we want to find out what type of tumor it is, we want to establish the diagnosis. We take a piece of the tumor out send it to the pathologist so that he can look at it under the microscope to tell us what kind it is, children with high for stock Douglas -- children with hydrocephalus, -- our last goal is to see if we can get as much tumor out as possible, to get as much out as we can see.

The reason why we try to take out the tumor, or as much as we can see, there's many studies that say removing the tumor, can better the outcome, the doctor has to remove the tumor, without neurologically -- neurological injury.

Interestingly, recent research has shown Medulloblastoma, is really not one tumor type, if there are at least four subtypes that occurred, the meeting shims that happened -- the mutations that happen that make cells grow in that unrestricted fashion, each type has different teams involved, even though they look the same, they are different tumors. One of the things that is very different, the subtype of given tumor, really influences the outcome.

Today and someone has a Medulloblastoma, studies are done to see what subtype the tumor is, it gives us an idea of the outcome, and may direct therapy.

After the operation, patients with Medulloblastoma art they -- they are treated with irradiation and chemotherapy -- radiation and chemotherapy.

It depends on the type. The reason it varies somewhat, radiation therapy may have a bad effect on the brain, that is developing in a child, there are a lot of
studies to show if you give radiation to a young child, you get young -- you get more damage to the young child. We try really hard not to give radiation to children less than three years of age, currently the problem with radiation therapy, will -- our goal is to lessen radiate -- the radiation in therapy.

>> The fluid around the brain, this is an MR scan, that is cunning through the neck - - cutting through the neck of the child, here's the top and the bottom, this tripe is the spinal court, you can see this white layer on the outside of the spinal core, that is a tumor that has spread in the flume or -- in the fluid, this is cerebral spinal fluid or CSF, it is present -- dissemination, it is present and leads to the most aggressive therapy that we have.

>> We have given our therapy now, how do we do this in children with Medulloblastoma? Currently using our best available therapy, we have survival rates of five years, about 70%. The survival is really determined large part by the sub type of the tumor, some have better outcomes in some have worst outcomes.

>> When a child survives, we have to be careful, sometimes they have cognitive deficits their brain does not work very well from the radiation therapy, from this reason I personally believe we need new types of therapy for treating Medulloblastoma, to completely take out radiation therapy.

>> The next tumor I'd like to take out is called up Ependymoma, this counselor 70% of tumors, in the same -- Pentella MOMA has -- Ependymoma has signs and symptoms, they also called hydrocephalus, increased pressure inside the head to get increased vomiting, because they are near the vomiting center they have the prominent feature of Ependymoma, here is an MR scan showing the Ependymoma, this is a similar picture were slicing from the top to the bottom, through a child's bottom of the brain of a spinal court, here is a tumor sitting in the similar location to the Medulloblastoma, pushing him cerebellum, it is typical for Petaluma -- Ependymoma to look at this scan and see that this is Ependymoma, here is a similar picture, here is the front and the back, here's the tumor sitting in the back of the brain, it is running out this way and that way, those are normal places for cerebral spinal fluid to leave, Ependymoma's have a tendency to go through those holes also, a sign that this tumor is Ependymoma and not Medulloblastoma.

>> Here's a similar picture showing the top of the tumor pushing on the cerebellum.

>> Just like for Medulloblastoma, when we see a child with eight tumor Ependymoma, we think operation, in this case we want to get a radical recession -- resection, there is no factor that matters more in a patient on how a patient with Ependymoma will do with surgical inception, the amount of tumor that is taken out is the most important thing. In Ependymoma, we try hard to take out all tumor, if we do so then we have a good chance of the child doing well.

>> The problem is, the same problem, for Ependymoma, with Medulloblastoma, you have to be careful not to cause bad newer logic deficits, -- neurologic deficit, when you take the tumor out.

>> After the tumor is out, radiation therapy is recommended, special types, sometimes you will hear Gamma night therapy, or stereotactic, may be used, and
fortunately we do not have chemotherapy that works very well, we do not have a role of treatment in therapy, for it and Obama, -- for Ependymoma.

>>We have a high expectation the prognosis, it goes some places where you can cause very hard to balance the possibility of causing deficit that is permanent and difficult to live with, when we are trying to get a total reception, in Ependymoma's, patients who get tumors when they are younger do a little bit worse, tumor that looks aggressive under the microscope is a little harder to treat.

>>The next tumor that I'd like to talk about is Astrocytoma, the problem with this name, it covers a wide range of tumors, they differ greatly on depending where they occur, and how aggressive they are. The treatment and outcome is very different even though we call all tumors astrocytomas -- the symptoms and the location -- the symptoms occur, in reference to the location, they calls -- cause Heisel specialist --

>>They cause hydrocephalus, these tumors can occur elsewhere in the brain, they cause deficit related to their location, or sometimes they cause seizures.

>>The astrocytomas, in the back of the brain, they are clear, --, and tumors and they are often called pilocytic, the world health organization, sometimes the who classification of the tumors, these astrocytomas, can occur anywhere, some are more men a glint, -- some are more Malignant, and they occur in the back of the brain -- occur in the front of the brain.

>>You can see in the back of the brain in the cerebellum here, they often have a cyst, this tumor is this little thing sitting right here. The next slide shows you can see this is just fluid exist, the tumor nodule itself, given contrast for this can, which makes the tumor show up more.

>>Pilocytic astrocytomas, just like the others we talk about in the first step is surgery this is what we call a surgical disease what I mean by that if I see a child, I take all the tumor out, the chance of the child being cured is high.

>>The problem will need no additional therapy the only thing that will him be needed -- that will be needed is surgery.

>>We try to remove all the term a -- all the tumor.

>>Unfortunately the location of Pilocytic Astrocytoma, we can often get all the tumor out without causing a significant neurologic deficit.

>>When we operate on a Pilocytic Astrocytoma, after the operation, we have it MR scan, and we be sure that we take out all of the tumor, if it all has been removed, we still get additional scans to make sure that it is not coming back, the likelihood that it comes back the scans are clean, is small. If we get a scan and we see tumors still there, then we need to decide do we go back in to get it out, or do we think it is too dangerous to get it out, and that case we will not do another operation, what we leave tumors behind we will get frequent scams to watch to see if the tumor occurs, this time we have interoperate it -- this day we have Intra-operative, we can put the scanner in the room, weakens -- we can we -- see if we got the tumor out before the end of the operation, not having to take patients back
because we left tumors behind.

>>Another type of Astrocytoma, the world health organization, you can see this picture the area, it is much hazier that we saw with the pilocytic Astrocytoma, it is still in the cerebellum.

>>Just as patients with Pilocytic Astrocytoma do well, when all the tumors go out patients with -- Grade II tumors can also be taken out.

>>We can recommend radiation or therapy.

>>If we look at these diffuse astrocytomas, in the back of the brain, even if we see residual tumor, over the next 10 years only a third will grow, for this reason we follow with symptoms and scans, this is especially true for pilocytic astrocytomas, another type of Astrocytoma, occurs in the brainstem, these tumors grow in the brainstem, and you may hear them called brainstem gliomas, they are astrocytomas, we use the word glioma, which is more inclusive to describe Basil Thai soma -- to describe the Astrocytoma.

>>The brainstem is critical part of the brain, it connects all of the brain with all of the rest your body. That means all of the information that your body sends to your brain, and all of the information, goes through the brainstem. In addition, the brainstem controls the movement of your eyes, swallowing, movement of the muscles in your face, the movement of the muscles in your tongue, so when we have a tumor in the brainstem, we often see many types of symptoms, so many things can be affected.

>>Some of the tumors that occur in the brainstem's are vocal, meaning -- focal, meaning when you look at this camp, they'd demarcated, from the brainstem, they call the mid-brain and the bottom of the brainstem called the mobile, --, balot, -- medulla, or outside the brain and the next.

>>Sometimes they come out of the brainstem and Philip one of the places inside of the brain -- they fill up the brain, one of the places inside the brain, -- what we see these focal tumors usually they are pilocytic astrocytomas, or diffuse astrocytomas, or Grade 2 tumors, or other tumors called gangliogliomas, and maybe make neglect -- they may be Malignant.

>>When we are working in the brainstem we need to be careful on how aggressive we are in taking tumors out, there is a high probability -- sometimes they are treated with chemotherapy, if there is residual tumor left behind, what we see a patient with the focal brainstem tumor, there is no rush to treat the tumor, often they cause few symptoms, and often they grow slowly, sometimes we will do a biopsy, to figure out what type of tumor, and decide whether we need to do anything at that time, if it is slow growing, we may just watch with scans, to see if there is tumor growth, or if they progress, which pushes our hands to do something.

>>The other type of tumor that occurs in the bring them -- brainstem, is a Diffuse Pontine Astrocytomas soma -- Astrocytoma, sometimes you will hear them called Astro PAG's, -- PG's.

>>The characteristics if they are diffuse and infiltrate the brain, they usually occur
in the middle of the brainstem, which is called the ponds, these tumors are unresectable, the reason they do not play a role in these tumors it means that they are infiltrated, areas of the tumor have normal tissue, if we take out normal tissue in the brainstem, we caused unacceptable deficit, sometime we will recommend biopsy, for these tumors it will lead us characterize genetic events, what mutations are happening, which are causing them to crow event understood it fashion -- unrestricted fashion.

This is an MR scan showing what a diffuse tumor looks like, it is just filling the whole brainstem, you can see the edges are hazy, it is diffusely filled trading the brainstem.

It is filling up the brainstem area. This is an unfortunate term, we also including the focal legions, they are most common, and account for 70% of the tumors, I do not like to call the focal Brainstem Tumors gangliogliomas, because of the difference in treatments.

It is often recommended that radiation therapy gave -- be given.

Only transmissible -- the patient will improve and the tumor will come back, they may lead to transient improvement. Unfortunately when a child has a Diffuse Pontine Astrocytomas, we need radical effective new chemotherapy, -- new therapy that attack them in different ways, that is why we like to do biopsies on these tumors. We hope we can identify drugs that will attack the specific changes that will allow it to grow.

In the future, we are hoping that we will have therapy based on the genetic mechanism that has caused the tumor as to say, we can identify specifically -- mutations that are active or not active at all, the drugs that will attack that problem in addition as mentioned in the introduction, I am interested in using viruses to treat these, we are trying to investigate ANGO angina this therapy -- Anti-angiogenesis therapy, we are trying to have them attack the tumor well helping the rest of the body, I will sum up by saying Brain Tumors in Children are not common, we must keep in mind, children do get tumors, they have headaches, neurologic symptoms or signs, we will need to be pretty aware, that all findings may be important.

You will not find out a child has a tumor unless you are looking to see if they have one.

I will say, the outcome of pediatric brain tumors are not as bad as people think, when a child has a brain tumor, as I mentioned, if we can get it out, the prognosis is very good, -- there are some Types of Tumors I did not talk about because they are rare, so such as gangliogliomas, these can all be treated, we did talk about some tumors that are more aggressive that are such as NGO plus soma --

NGO plus soma --

We took to --

We did talk about other tumors, we do know it radiation is that for the developing brain, our research is trying to find out known about the irradiation, which is bad for
the brain.

>>I would be happy to answer any questions.

>>Thank you Dr. that was wonderful, I would like to remind people how to type in questions, if you look at your control panel again, you can type in the question box, at the right hand side of your screen, type in the question and I will ask Dr. Raffel the question, we will start with the ones that have been submitted.

>>You have mentioned someone asked, that there is no chemo for append a mama -- Ependymoma, why not chemotherapy for Ependymoma?

>>That is a good question I didn't mean to give the Impreza -- impression that we have not tried, there are many people actively investigating the use of chemotherapy, the point I was making was none of the therapies that we have used have been effective, the tumor does not respond to the chemotherapy, if it's not that we have not tried, we continue to try, we do not have a minute if therapy.

>>-- We do not have an effective therapy.

>>That make sense.

>>Another person is concerned there brain -- child has a brain tumor, should they be concerned about the siblings, should they have them tested? Is there any connection of other siblings having them also?

>>That is a great question.

>>While there are, inherited condition, that cause Brain Tumors in Children, they are extremely rare, I would -- when I talk to families and they have one child, it is strangely -- extremely unlikely that another has a brain tumor.

>>There are conditions as I said inherited syndromes that do have brain tumors associated, but we usually know about those problems because of other signs that the child has of this condition for example type I neurofibromatosis, or to furlough stereo system, -- to plurals neurosis -- they have the syndrome -- and the sibling will have the symptom but have other signs that is one way we know.

>>That makes parents feel little, knowing that they would know.

>>It is very hard to worry about other children -- hard not to worry about them, the chances one of the other children has a brain tumor it is very small chance.

>>As a neurosurgeon can you tell just by looking at a tumor, if it is Manila glint -- if it is Malignant or benign?

>>We can look at the stands -- the stands we have, certainly in the operation, we can determine whether the tumor is sharply demarcated, what I mean when I look at the tumor I can take my pointer and say this is tumor, and it stops right here. And this is now brain. When I see that it may be a tumor I can take out, it blurs into the brain, I worry it is a more aggressive tumor, the bottom line, the pathologist tells us what kind of tumor it is, doesn't matter what the neuroradiologist thinks it is, it doesn't matter what I think it is when I'm operating, what matters is what the pathologist sees when he looks at the tumor under the microscope. It is very
important to be patient, everybody wants to know what kind of tumor it is right away, we will not know for sure until the pathologist tells us.

>>Perfect.

>>Team-based approach is important.

>>Absolutely.

>>You talk about not wanting to use certain treatment on children until a certain age, which led someone to add -- ask about long-term effects, I know we are getting some advanced -- advancements in long-term effects, this person is questioning how they would find out how they would find about clinics or survivorship clinic’s? What should they be looking for? Do know that answer?

>>If I am understand the question, someone is asking why do we think radiation therapy causes long-term effects?

>>That is of course because the children who survived their tumors, we watch them over time, we can see they are not developing cognitively, that development you expect to see in terms of learning abilities is less. It is less for a child who has a brain tumor, and has had radiation therapy, and a child who has not had radiation therapy. We are pretty confident that radiation therapy is the problem. We are trying to see if there is a way we can give drugs for example that will mitigate that problem, and protect the brain while eliminating the tumor.

>>If you do have a child with a brain tumor and you’re wondering what is happening over time these long-term clinics are great.

>>You are also mentioning about certain tumors -- definitely they were ones that recur -- recur, someone --

>>Reoccurrence, is that gangliogliomas one that reoccurs?

>>I didn’t talk about them because they are a rare tumor, I was wanting to focus on common tumors, of course there are many types of tumors that I did not talk about, gangliogliomas is one I did not talk about, it depends on where they occur, in the temporal lobe, the outcome is very good, with just surgical reception, if they occur elsewhere in the brain, often again, if the entire tumor can be taken out, the long-term prognosis is good. If the tumor is residual, and decisions have to be made if it progress, -- is progressed, some look more aggressive under the microscope, they are more aggressive and the chance of occurrence -- reoccurrence is higher.

>>Refrain about Diffuse Pontine Astrocytomas -- the radiation helps -- but it comes back how many times would you radiate?

>>With Diffuse Pontine Astrocytomas, we always do this because it makes them feel better and their symptoms improve, we almost always give it, the problem we know it will be palliative, it will make them feel better but not alter the outcome.

>>That is a perfect lead into the next question. You say you cannot treat, what then do you as a physician do as initial so -- as a so-so --

>>As a social worker, when you mentioned palliative care, I really appreciate you
are open to that, that is not always a conversation that to does have.

>>I think for -- it is really important -- let me back off, different doctors have philosophies and different approaches, my philosophy is that I am pretty blunt and honest guy, I tell the families that from the start, if they want bluntness and honesty, they can talk to me if not, they have to find someone else. I will tell them what I think is true. For the Diffuse Pontine Astrocytomas, but the chance that it will cure is very small, we will have to plan ahead for things when the tumor progresses, you mentioned the palliative therapy group, which is appropriate, in that regard we use them extensively here.

>>Great.

>>When do you transfer your patients to adult care? How long do you follow them for?

>>That is a big controversy, the ones that establish themselves within surgery, that transfer of care is difficult, here at UCSF, the Children's Hospital has the cut off and it is less than 18 years old, I am happy to follow patients in my clinic for longer than that, if you need to -- it is one advantage when you see CSF, adult and pediatric facilities that are available.

>>We have time for maybe one or two more questions.

>>What about clinical trials? Is easy for families to enroll their families in clinical trials? Is it difficult?

>>That is a great question. It happens all -- almost all children with the brain tumor are entered into a clinical trial, that is because they are very strong clinical child groups, there are groups were number of children's hospitals participate so that we can get more patients into the trials, children's oncology group, is one of the big ones, in this country, that many cut trees -- many children are treated under COG -- we also participate in the specific pediatric oncology, where we are trying to use molecularly used therapy, to direct their P.

>>Yes almost everyone gets enrolled. It is very easy to do.

>>It is not hard, the thing I want to emphasize, sometimes when the parents are told about these trials, they say you are experimenting on my child? When we do this, it is not true, this is the best therapy we have for the tumor, can we make it better by trying this therapy? We compare this with MP, we want to know which is better, we have to therapies we want to know which is better. -- Your child is not experimented upon. There are trials where we are asking more experimental, we call those Phase 1, or phase 2 trials, you will be asked if your child can be enrolled, those types of trials are only used when best available conventional therapy has not worked.

>>It is not something that they would have to worry about bringing up?

>>No almost every child is entered into a cooperative study.

>>Is it something that insurance covers it?

>>Yes it does.
It is not a worry.
That is good for families to know.
I like how you clarify they are still receiving treatment, that is still a fear, that they are not receiving treatment.
That is correct.
We have it on tape recorded, for everyone to know. As you mentioned, especially for something like this just views Partain astrocytomas, if we -- just like what you have said, with Diffuse Pontine Astrocytomas, how are we going to have any answers?
Until we have 100% cure, with no problems afterwards, what we want to do is cure every child, and have them live a normal life afterwards.
That would be a perfect world.
So.
That is what we want.
Okay thank you so much for answering all those questions, we buzzed right through them, we will wrap up with conclusion, and introducing the next webinars we have. Thank you so much, I'm sure people really appreciate all of their questions are answered, your presentation was wonderful, thank you so much.
Obviously my pleasure, thank you for the opportunity.
For more information, you touched on a lot of topics today, a lot of pediatric tumors, clinical trials, you can find information at our website which is ABTA you can find information@ourwebsite which is ABTA.org, we also have nurses --
You can check out things on our website which is, ABTA.org you can also call our care line at 800-886-2282.
We invite you all to continue to check back, Thursday, February 5 from 1:59 PM, we have men that killer testing for path knowledge he -- we have molecular pathology testing, we have investigator from the Dana-Farber Cancer Institute center for molecular pathology -- oncology -- oncologic pathology, we will discuss testing and how testing is performed, topics covered will include the latest approach is, I DH mutations, integrated reporting by pathologies of these new tests, Dr. Ligon, will discuss how these test Improve braver tumor -- brain tumor diagnosis.
There is a follow-up from this on Wednesday Wednesday, February 18, there is an increase in availability for testing, for patients, in this webinar, Dr. Patrick Y. Wen, professor of neurology at Carver Medical School will provide the information. -- Also discussed in this webinar both standard therapies and participation in clinical trials will be discussed.
Please complete the evaluation survey, you will receive this in your e-mail tomorrow, you may all disconnect.
Thank you again, have a great day.
[Event Concluded]