

Yale CANCER
CENTER
answers

WNPR Connecticut Public Radio



Hosts

Lynn Wilson MD

Vice Chairman and Professor
of Therapeutic Radiology

Francine Foss MD

Professor of Medical Oncology

Pediatric Oncology

Guest Expert:

Paul Jubinsky, MD

*Assistant Professor of Pediatrics and
Hematology and Oncology, Yale School
of Medicine*

Yale Cancer Center Answers

is a weekly broadcast on

WNPR Connecticut Public Radio

Sunday Evenings at 6:00 PM

Listen live online at

www.wnpr.org

OR

Listen to archived podcasts at

www.yalecancercenter.org

Welcome to Yale Cancer Center Answers with Dr. Francine Foss and Dr. Lynn Wilson. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Wilson is a Professor of Therapeutic Radiology and an expert in the use of radiation to treat lung cancers and cutaneous lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This week, Dr. Foss is joined by Dr. Paul Jubinsky. Dr. Jubinsky is Assistant Professor of Pediatrics and Hematology & Oncology at Yale School of Medicine. Here is Francine Foss.

Foss Can we start off by having you tell our audience what a pediatric oncologist is and what is your training?

Jubinsky A pediatric oncologist is somebody who starts off with full pediatric training, much of the things that you would see at your pediatrician's office, and then gets more specialty training, and so after finishing our pediatric residency in the hospital, we go on to do a fellowship which is a minimum of three years and some people expand that out a little bit longer, where we get clinical training and then research training in the areas of oncology, which as you know, is patients with cancer.

Foss Can you define pediatrics, many of us think about little kids, but I know pediatrics can go up into the early 20s; can you define the age of your population?

Jubinsky That is exactly right, typically a lot of people will think about pediatrics as once they get to be 18 they ought to transition over, people do not want to be in the office with little kids. Pediatric oncology is probably a little bit different, and some of the other pediatric fields are changing because what happens is that within oncology there are actually different subsets of tumors that exist in a pediatric population than also exist in the adult population. So what happens is that boundary between adult and pediatric overlaps for some of these tumors where they are 20, 21, 22, and 23, and end up having a tumor that is more common in somebody who may be 5 or 6. The adult people, who in all honesty see more patients, just do not have the experience in those areas where there is an overlap and so we have treated people certainly up to the age of 27, which is a little bit different than what people would think of as pediatrics. Typically if somebody comes into pediatric oncology and they get diagnosed and they may not get cured really fast, or they may have a relapse, we tend not to overly switch those over to the adult population because there is a bond, because of the nature of pediatrics we do a lot of things and we make big efforts and we have a little bit more time to take care of people when they are outside the standard group.

Foss It sounds like things are probably more fun in your clinic anyway because you have got the toys and the audiovisual things?

Jubinsky I think that is exactly right, and I think it makes a difference no matter what your age group is, as I

**3:08 into mp3 file [http://yalecancercenter.org/podcasts/2012_0610_YCC_Answers -
Dr Jubinsky copy.mp3](http://yalecancercenter.org/podcasts/2012_0610_YCC_Answers_-_Dr_Jubinsky_copy.mp3)**

could tell you the adults would probably be happy having some kids in the clinic playing and running around than, because as I said, as adults, we do not always have a good time when we are doing stuff and I think having kids around makes us think about other problems, so to some degree I think that even though people like age differences, I think for adults they probably wouldn't mind having kids around because oncology people really do associate with each other very strongly no matter what the age group is.

Foss Can you talk a little about pediatric cancers, can you tell us how common cancer is in the pediatric population?

Jubinsky Compared to the adults we are talking about really small change, and we do not think of it that way because we do different things, but in terms of total numbers in the country there may only be about 12,000 cases a year of all of the oncology problems, and if you think about 50 states and everything else, you realize there are hundreds of cases depending on the size of a state of new oncology patients, and when you think of adults you think of lung cancer and breast cancer, where there are 50,000 to 60,000, so we are way down on the spectrum, but obviously, from our perspective based on the age group and because of the impact and because it is somebody in the beginning of their life, we think it is extremely important even though the numbers are not where everybody else's are.

Foss Can you talk about what the most common pediatric cancers are?

Jubinsky The most common pediatric cancer that people see is probably leukemia, and leukemia is a cancer of the blood cells and as people know is a little bit different than the solid tumors that adults usually get, where the tumor is everywhere, and so that is the most common and there are two major types, one is lymphoblastic which is from a lymphocyte, and then other ones are myeloid cells. I do not want to get technical but altogether those are a little over 40%, and then after that the next most common are brain tumors which are around 25% and then we have all the other tumors and we have more populations of tumors than the adults have, they have more numbers, we have more kinds, and so then we'll have a smattering where there is 5% or 6% neuroblastomas, Wilms tumors, and bone tumors are all in that percentages. Then we get down to the other oddball population where there are 20 or 30 cases that have ever been reported and they exist in the pediatric age group. One of the challenges and one of the things most of us like in the field is that even though you may not have a lot of cases, it gives you an opportunity to learn about new things, and because our volume is less, we have the advantage of being able to spend a little bit more time with patients because I know my adult colleagues work extremely hard, but we work hard in a different way and they work harder in volume and we work harder in making sure that when it is an unusual disease, we spend more time making sure that we have everything covered and we know how to take care of these kids. We call colleagues to actually figure out what the

**6:21 into mp3 file [http://yalecancercenter.org/podcasts/2012_0610_YCC_Answers -
Dr Jubinsky copy.mp3](http://yalecancercenter.org/podcasts/2012_0610_YCC_Answers_-_Dr_Jubinsky_copy.mp3)**

absolute best therapy is because if there are only a few kids and if the last case was five years ago, you try to put it together, so those are some of the differences between the way adult and pediatrics take care of patients.

Foss Are you alluding to the pediatric oncology group and national groups that look at how pediatric cancers are being treated, and establish some standards for them?

Jubinsky That is right, for the common stuff, we know how to do it, but for the less common, we look to the pediatric oncology group, which is essentially all the hospitals in the country plus Canada, plus most of Australia and a bunch of other countries where we try to learn what we can because of the less numbers of patients we value each patient and try to learn what we can, not so much as an experiment, but to collect data and say can we utilize how people are treated to try to make things better? We can't afford to get the field moving by not collecting data on every patient that comes in.

Foss So the pediatricians are much better at doing that than the adult oncologists, in terms of getting patients on national clinical trials?

Jubinsky That is right and it is multifactorial, a lot of it is because we know if we do not do it we are never going to get anywhere. The other part of it is, for most of pediatrics, with rare exceptions and they are getting rarer and rarer, things are in academic medical centers, it is not like you can open up a practice in the middle of Connecticut away from a hospital and say I want to see a lot of patients, there are just not enough patients to do it as there are in the adult populations. And because of that we are academic, there is a huge academic function, and when you go through pediatric training, they really emphasize some kind of way of making an improvement in the world, whether it is clinical studies or a little bit more basic, and it isn't always collecting data, but trying to make things better for patients and improving services, so if you are not doing actual research, there is a big emphasis on making where you are and what you are doing a better thing, and that is supported.

Foss So most of the patients that are seen here at Smilow Cancer Hospital in pediatrics are referred in presumably they are diagnosed by a community pediatrician?

Jubinsky What happens, and this is another difference between adults and pediatrics, people come with different problems and depending on the severity they typically will get seen in the clinic if we have an idea of how ill they are, from the pediatrician's office they call in, or if they are little bit more ill they come into the emergency room. The thing that is a lot different is that only on extremely rare occasions when they come to see me or any of my colleagues, do they already have a diagnosis, and so what happens is a lot of people do not have a lot of experience with cancer, and when you start off in the beginning, it is devastating. As an adult you go to your internist and they say, well I feel a mass in your breast or something, you may have breast cancer. In the

9:45 into mp3 file [http://valecancercenter.org/podcasts/2012_0610_YCC_Answers -
_Dr Jubinsky copy.mp3](http://valecancercenter.org/podcasts/2012_0610_YCC_Answers_-_Dr_Jubinsky_copy.mp3)

pediatric population, those families, most of them do not know a child who has cancer, at school there may be one or two kids but they're not in the same grade and they do not know them and so they basically come in thinking that their kid will never have a problem, is never going to get cancer, and they aren't expecting it, and because of that, pediatricians do not really know how to approach it, you cannot just say, I looked at the blood smear, it looks terrible, we've got a big problem. You have to understand where there are going from, you have to understand their feelings and their knowledge and their home base and then try to tailor it because the families are critically important and if they have an issue, not even educationally, but if they have a major breakdown from the diagnosis, because it is a devastating diagnosis, it really impacts on the kid. The kid coming into the hospital thinking that they are the cause of why mom is crying and it makes the dynamics a little bit more difficult and certainly the other part of it is that on occasion, somebody thinks they know what the diagnosis is and even us, we are extremely careful, we say here are the possibilities, but we do a pathology and we try to define it the best we can, but even then we say, sometimes it takes other people in other places to help us look at it, because when you tell somebody it is "X" and if you have to go back and say it is "Y" it is really hard to take, because they just cannot believe that medicine still has some difficulty in making a diagnosis and it is a tough thing. So, we take that into account and try to be very careful.

Foss It sounds to me like you really need a multidisciplinary approach to this. In your clinic at Smilow, what different components are available to help families with this issue?

Jubinsky I have to say, we as physicians do the best we can, but what I would say is that as much as I think the families love us, or will get to like us in the long term, I think that they feel, for whatever reason, more comfortable talking to the nursing staff, and some of it because they do not want to feel like they are wasting our time. But the nursing staff is massively important for education and support, they are huge, just like anywhere else, but even more so in pediatrics, because moms will typically bring the kids in more often can connect with them, but then we have all the other people, and so one thing is to get the educational part down, but the other part that is critically important are the services such as social work and there are so many things that families worry about, like how to get this taken care of, is there a way to divvy up the work in the household, what do we do about school, and getting resources because people are out of work and even people who have great insurance never have coverage for a lot of the things that we need to do. I mean there are things that are absolutely positively medical that have to get done and then there are things that make people do better, such as in school they adapt better. They are able to still function and the family is intact and those things do not get covered by insurance companies. They do not care as much, and those things that are critically important are supported by the Cancer Center and before we move on, we have people like the Child-Life people and what they do is they create an environment where kids play, where the clinic ends up being a fun place and a not a scary place and people like to come in and they socialize, and the kids themselves socialize and everybody has their part and they all do it independently and they do not like going to the hospital for admission as much, but going into clinic, the kids, by in large, like to come in and even the older kids where

13:43 into mp3 file [http://yalecancercenter.org/podcasts/2012_0610_YCC_Answers -
_Dr Jubinsky copy.mp3](http://yalecancercenter.org/podcasts/2012_0610_YCC_Answers_-_Dr_Jubinsky_copy.mp3)

they want to go out and do their own thing, they are comfortable and that's where the comprehensive approach takes out the stress and makes it easier. As physicians we have to sometimes do what we call firefighting, where an issue comes up that may not always have to do with us, something does not go smoothly, or the family is unhappy, and we have all these other people to help.

Foss That is very extensive and I would like to talk a little bit about how you actually tell a child that they have cancer, but we have to break for a Medical Minute before we can get into that. This is Dr. Foss and this is a break for a Medical Minute.

*Medical
Minute*

There are over 12 million cancer survivors in the United States right now, and the numbers keep growing. Completing treatment for cancer is a very exciting milestone, but cancer and its treatment can be a life changing experience. The return to normal activities and relationships may be difficult and cancer survivors face other long term side effects of cancer including heart problems, osteoporosis, fertility issues and an increased risk of second cancers. Resources for cancer survivors are available at federally designated comprehensive cancer centers such as the one at Yale Cancer Center to keep cancer survivors well and focused on healthy living. This has been a medical minute brought to as a public service by Yale Cancer Center. More information is available at YaleCancerCenter.org. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.

Foss Welcome back to Yale Cancer Center Answers. We are here today discussing pediatric oncology. Paul, you talked a lot about the multidisciplinary approach that is available at Smilow, can you back track and address that really important question, which is how do you actually go about telling a child that he or she has cancer, what do you tell them?

Jubinsky As we talked about, a lot of things in pediatrics are age dependent, and what I talked about and what I am going to be talking about is mostly the way I do it. Obviously, there is a little bit of variation between other people, but the approach that we like to take is to get them into a comfortable circumstance. We bring in other people who are going to be involved in their care, and so typically people will get followed by a nurse, most of the time in clinic and a lot of the time inpatient, so if we know what nurses are likely going to be assigned to them we bring them in to try to get the group together because there is a big bonding process in the beginning. The way I usually start is I go back into the history, and I already know based on the history what has been going on with the patient and so I ask how they have been feeling, are they feeling good and just get an idea of where they are. And some patients come in really healthy, and those who come in through the emergency room are obviously coming in with a lot more symptoms, which we can talk about later, but depending on what it is I say, do you know why you are in the hospital? And they usually say to get me better, and I say that is right, you are in here because you have some things that are going on with you that do not make you feel very well and we are here to make it

16:56 into mp3 file [http://yalecancercenter.org/podcasts/2012_0610_YCC_Answers -
Dr Jubinsky copy.mp3](http://yalecancercenter.org/podcasts/2012_0610_YCC_Answers_-_Dr_Jubinsky_copy.mp3)

better. I tell them that a lot of the time they go to the doctor and we can get you better in a couple of days, but for the problems that we think may be going on with them, it is not going to be a couple of days, and unfortunately, it may end up being years, but I tell them that is what we expect and that is what we do. We introduce the idea that it is a problem, we do not start off with cancer, but just that things are not right and that we want to make it better, and then you evolve over and say well it is not like pneumonia, these things could go longer, and they say, what is it? Obviously the older kids know what cancer is, but with the younger ones we use an analogy that I use for a lot of things, is a garden and weeds, and I say we have good things that grow in the soil, if it is for bone marrow, and then we have things that we do not want to grow. I tell them that sometimes your yard overgrows and certain parts of your body are not behaving themselves, just like we do not behave all the time, other parts of your body do not behave. It is like weeds in a garden, if we let that go it will get too big, they affect the rest of the garden and we need to get those things to go away, so your good tomato plants are happy and that is the stuff we use on the lower level just to get them in.

Foss Do you use the word cancer?

Jubinsky I do not right off the top use the word cancer. Once they know where I am going with the analogy that is when I say, so what I am telling you is what is going on with you, and everything that we do has a name, when you have an ear infection you call it an ear infection, and the name that you have for this is, if it ends up being a bone tumor, I say it is called a Ewing sarcoma and a Ewing sarcoma has a lot of these things that we call cells that make up your body and they are bad and what they make up is a very large group of medical problems that people call malignancies, which they may not know what that means, or a cancer, and then I just stop. There are on occasion a few families who do not want to use the term cancer, but typically, we do not like to encourage that because it is like any other terminology, the kids know it, and if they see they are on the same floor as other kids with cancer, you just cannot hide it and it is better just to be honest. And unless people force our hand, because we can't predict how everybody from the beginning is going to do, we go in with the impression that there is always something to offer and that we work really hard to get rid of the bad cells, and in the beginning if they do not ask me, are you going to get rid of it, I do not usually bring that up. When things go on a little bit more and we start to go into more of the details, we bring up that sometimes things do not work one way and that we have to switch gears, but usually on a lot of these really difficult questions, we wait for them, they have an understanding and kids typically will ask what they want to ask and there are things they do not want to hear. There are things where even a 15 year old will say to me, I am tired, my mom loves me, she is going to take care of me because I cannot understand all this and they defer and so some people want to be in a room and some people do not, but we typically let them decide what they want to know because our feeling is that if they aren't told, I think it sets up credibility issues.

20:32 into mp3 file [http://yalecancercenter.org/podcasts/2012_0610_YCC_Answers -
Dr Jubinsky copy.mp3](http://yalecancercenter.org/podcasts/2012_0610_YCC_Answers_-_Dr_Jubinsky_copy.mp3)

- Foss In the research area we have the age of assent, when a child is old enough to make their own decisions, how does that play into your practice in pediatric oncology and when do you feel that a child is old enough to say what you just said, which is I do not want to hear anymore of this?
- Jubinsky I think at any age they do it. We have got to realize that it is like everybody, especially in the beginning, we all have our ups and downs there are probably days I go to work and I do not want to talk to anybody either, and so they do the same thing and what we have to do is that when they want to pull back, you let them pull back. You do not want to disengage somebody who is old enough to comprehend their care and get involved in their practice and in the treatment because it is totally essential that they are onboard and they understand and know what you are doing because it is scary enough coming in and getting therapy, but they are old enough to know the long term.
- Foss Can you go back and tell us a little bit about some of these common pediatric cancers? Are the kids symptomatic when come in and how do we treat them? I think you said leukemia was the most common and brain tumors were the second most common.
- Jubinsky What happens to most pediatric patients is not that much different than what happens in adults, something shows up, it could be big and it could be small, the boy or girl may be a little bit tired or they may have aches or pains, so in leukemia it typically ends up having to do with the blood counts because the leukemia outgrows it, but they typically have anemia, which means they get tired easily. Sometimes the blood cells that are involved in keeping you from getting bruises, the platelets are low, so they end up bruising a little bit easier or they get low grade fevers or, because of the leukemia inside the bone marrow, they get aches and pains and what happens is everybody gets these problems but they go on and because a lot of cancers aren't up and down in one day, it is usually a gradation of the process, there are usually several weeks where things are just not right but it's not enough to put a finger on, so they will go to the pediatrician. The pediatrician looks, and says they have a virus and mom comes back and says well it is not like the other viruses, and that can go on for quite a while until oftentimes somebody else looks at them and says, your kid is pale and because of that gradation they come in, and for leukemia, get blood work done that shows abnormalities to confirm it. For a lot of the other tumors it's another physical sign such as with a bone tumor, it is typically pain and occasionally swelling. What usually happens is they get kicked, because everybody gets kicked at that age, and it takes six weeks, so the average time for a bone tumor after onset of symptoms is about two months of presentation of rather severe bone pain that is localized and sometimes with swelling because most pediatricians only see, one or two diagnoses maybe in their lifetime, they just do not think oncology and so a long period goes by and after a while people say, well it has been, you know, three months with a problem, don't you think that is a little bit weird, and then everybody gets the radar going and all of a sudden it goes from nothing to everything getting done in a short period of time, but other things present as masses,

24:14 into mp3 file [http://yalecancercenter.org/podcasts/2012_0610_YCC_Answers -
Dr Jubinsky copy.mp3](http://yalecancercenter.org/podcasts/2012_0610_YCC_Answers_-_Dr_Jubinsky_copy.mp3)

liver tumors, and some lymphomas present with nodes, and people always worry about lymphomas and Hodgkin's disease and then belly masses, but usually some of it is just not feeling so good, weight loss, not eating, moping, sometimes if it is a brain tumor you will see nerve findings, your eyes do not work right, and some of the kids, as much I do not like to say this because it is not a common thing, but I have had a couple of patients where they were absolute A students. They were A students their entire life, they get into eighth grade and they go from A to B, it took a year and then they go from B to C and they were seen by pediatricians, nothing showed up upon exam, and they say well, the kid is having a hard time, he does not feel good, it's a new school, and some of those kids end up having some bad. The range in most of that is extremely uncommon and for brain tumors it is extremely uncommon, but it just goes to tell you the difficulty with diagnosing some tumors in some people, and why it is hard. One of the luxuries we have is that when somebody comes to us, we assume they have bad stuff until we prove otherwise, and so we go through a lot of tests and they come in and we can say, you are clear, but even then we have to sometimes bring people back if tests are not definitive.

Foss Do you sometimes see kids who turn out not to have cancer?

Jubinsky Yes, I mean there are some things that you think with experience you have a good idea, or based on symptoms and things that can look like leukemia can sometimes be things that are extremely bad infections. So infections can do a lot of things to your body, we know people who have EBV infections, or mono, where people get big nodes and some of those end up being bad lymphomas and some of those get big and go small or solitary, or things that we call adenoiditis, which are bacterial infections, and so there is a whole series of things, people get distensions and everything else, and a lot of times based on clinical experience, we do get an idea from feel, but no one can predict the future and so there are things that look bad, or when we get things that look like blasts or other things and they go away and in fact there are some tumors that we know do go away, and one of them is neuroblastoma where it can be a malignant tumor in the beginning and with age with or without treatment it can turn itself back into normal tissue and so there are a lot of things where the cut and dryness that we always think about with malignancies are not as clear as you would expect.

Foss Do you anticipate from most of your patients with pediatric cancers curing them, or is that your intent when you begin the treatment?

Jubinsky When the numbers are low enough you can never know for a fact, if there are only 10 cases, but we believe that everybody is potentially curable and that everybody deserves a chance of at least the optimal therapy. After that, with difficult cases, it gets a little bit trickier depending on symptoms. The treatment that we decide on in difficult cases is obviously done with the family's wishes as 100% the guide, and also by what we know and what we do not know, and based on

27:54 into mp3 file http://yalecancercenter.org/podcasts/2012_0610_YCC_Answers_-_Dr_Jubinsky_copy.mp3

difficult cases we tend not do things that make people uncomfortable and with the advent of more targeted therapies and antibody therapies and small molecule inhibitors, we can do things where a lot of people almost function like they are not getting any chemotherapy or oral agents, which hopefully will have an effect, but what you have to realize is, and this is another difference between us and adults, when you are 85 and you live another six months, people say, well what does that mean? I have had people where for whatever reason I have been able to extend them where we knew it was a very bad prognosis where you thought they might live a year, and you get them to live three years. When these kids go to Disney World and the family pulls together and they do their activities, it might be that the outcome is bad, but that is worth so much stuff, you cannot believe it has anything to do with cure or not cure rate, which shows up in the papers, it is just part of being people and that is what we want to do.

Foss So, you would say overall that there is hope for patients with pediatric cancers?

Jubinsky The cure rate is extremely high. The cure rate for all cancers is up to 75%. There are difficult things, but there are always new things in the pipeline. We work hard, we try to recombine, change thing and do things that will often, but not always, give you a surprise, and so with kids we always think it's worth it.

Dr. Paul Jubinsky is Assistant Professor of Pediatrics and Hematology and Oncology at Yale School of Medicine. If you have questions or would like add your comments, visit yalecancercenter.org, where you can also get the podcast and find written transcripts of past programs. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.