## WEBVTT

 $00:00:00.000 \longrightarrow 00:00:01.960$  Funding for Yale Cancer Answers

NOTE Confidence: 0.9586961

 $00{:}00{:}01.960 \dashrightarrow 00{:}00{:}03.920$  is provided by Smilow Cancer

NOTE Confidence: 0.9586961

 $00{:}00{:}03.990 \dashrightarrow 00{:}00{:}05.690$  Hospital and AstraZeneca.

NOTE Confidence: 0.96957475

 $00:00:07.730 \longrightarrow 00:00:09.902$  Welcome to Yale Cancer Answers with

NOTE Confidence: 0.96957475

 $00:00:09.902 \dashrightarrow 00:00:12.408$  your host doctor Anees Chagpar.

NOTE Confidence: 0.96957475

00:00:12.410 --> 00:00:14.330 Yale Cancer Answers features the

NOTE Confidence: 0.96957475

00:00:14.330 --> 00:00:16.692 latest information on cancer care by

NOTE Confidence: 0.96957475

 $00{:}00{:}16.692 \dashrightarrow 00{:}00{:}18.204$  welcoming on cologists and specialists

NOTE Confidence: 0.96957475

 $00:00:18.204 \longrightarrow 00:00:20.741$  who are on the forefront of the

NOTE Confidence: 0.96957475

00:00:20.741 --> 00:00:22.487 battle to fight cancer. This week,

NOTE Confidence: 0.96957475

00:00:22.490 --> 00:00:24.145 it's a conversation about sickle

NOTE Confidence: 0.96957475

 $00{:}00{:}24.145 \dashrightarrow 00{:}00{:}26.236$  cell disease and cancer in pediatric

NOTE Confidence: 0.96957475

 $00:00:26.236 \dashrightarrow 00:00:28.091$  patients with doctor Farzana Pashankar.

NOTE Confidence: 0.96957475

00:00:28.091 --> 00:00:30.729 Dr Pashankar is an associate

NOTE Confidence: 0.96957475

 $00:00:30.729 \longrightarrow 00:00:32.554$  professor of Pediatrics in hematology

00:00:32.554 --> 00:00:35.090 oncology at the Yale School of Medicine,

NOTE Confidence: 0.96957475

00:00:35.090 --> 00:00:38.210 where Doctor Chagpar is a

NOTE Confidence: 0.96957475

00:00:38.210 --> 00:00:40.290 professor of surgical oncology.

00:00:40.630 --> 00:00:43.006 Maybe we can start off by you telling

NOTE Confidence: 0.9838451

 $00:00:43.006 \longrightarrow 00:00:45.548$  us a little bit about yourself and

NOTE Confidence: 0.9838451

 $00:00:45.548 \longrightarrow 00:00:48.131$  how you got involved in doing what

NOTE Confidence: 0.9838451

00:00:48.131 --> 00:00:50.675 you do and what exactly do you do?

NOTE Confidence: 0.8281876

00:00:53.180 --> 00:00:57.797 Essentially I had a really long,

NOTE Confidence: 0.8281876

00:00:57.800 --> 00:00:59.261 circuitous career journey,

NOTE Confidence: 0.8281876

 $00:00:59.261 \longrightarrow 00:01:03.291$  but I got involved in doing pediatric

NOTE Confidence: 0.8281876

 $00:01:03.291 \longrightarrow 00:01:07.029$  oncology when I was training in England,

NOTE Confidence: 0.8281876

00:01:07.030 --> 00:01:10.622 after which I did a pediatric hematology

NOTE Confidence: 0.8281876

 $00{:}01{:}10.622 \dashrightarrow 00{:}01{:}12.666$ oncology fellowship in Canada.

NOTE Confidence: 0.8281876

00:01:12.670 --> 00:01:14.290 And after fellowship,

NOTE Confidence: 0.8281876

 $00:01:14.290 \longrightarrow 00:01:18.070$  the two areas that I really loved

NOTE Confidence: 0.8281876

 $00:01:18.172 \longrightarrow 00:01:21.058$  and wanted to focus my career

00:01:21.058 --> 00:01:23.870 on were sickle cell disease

NOTE Confidence: 0.8281876

 $00:01:23.870 \longrightarrow 00:01:25.208$  and solid tumors

NOTE Confidence: 0.8281876

 $00:01:25.210 \longrightarrow 00:01:27.904$  and development of clinical

NOTE Confidence: 0.8281876

 $00:01:27.904 \longrightarrow 00:01:30.655$  trials and improving care for children

NOTE Confidence: 0.8281876

 $00:01:30.655 \longrightarrow 00:01:33.277$  with sickle cell disease and cancer,

NOTE Confidence: 0.8281876

 $00:01:33.280 \longrightarrow 00:01:34.765$  particularly solid tumors.

NOTE Confidence: 0.8281876

 $00:01:34.765 \longrightarrow 00:01:38.230$  So those are the two areas that

NOTE Confidence: 0.8281876

 $00:01:38.316 \longrightarrow 00:01:40.446$  I have focused on in

NOTE Confidence: 0.8281876

 $00:01:40.450 \longrightarrow 00:01:44.473$  my career for the last

NOTE Confidence: 0.8281876

00:01:44.480 --> 00:01:47.792 about 17 to 20 years and my

NOTE Confidence: 0.8281876

 $00{:}01{:}47.792 \dashrightarrow 00{:}01{:}51.380$  passion primarily has been to focus on

NOTE Confidence: 0.8281876

 $00:01:51.380 \longrightarrow 00:01:54.669$  development of clinical trials for children for

NOTE Confidence: 0.8281876

00:01:54.670 --> 00:01:57.118 certain rare types of solid tumors,

NOTE Confidence: 0.8281876

 $00:01:57.120 \longrightarrow 00:01:59.466$  and also in bringing new and

NOTE Confidence: 0.8281876

 $00:01:59.466 \longrightarrow 00:02:01.527$  innovative the rapies for sickle cell

NOTE Confidence: 0.8281876

 $00{:}02{:}01.527 \dashrightarrow 00{:}02{:}03.647$  disease to our patient population.

 $00:02:03.650 \longrightarrow 00:02:04.868$  So maybe we

NOTE Confidence: 0.97506434

 $00:02:04.870 \longrightarrow 00:02:06.370$  can start with that.

NOTE Confidence: 0.97506434

 $00:02:06.370 \longrightarrow 00:02:08.620$  Is there much overlap between sickle

NOTE Confidence: 0.97506434

00:02:08.687 --> 00:02:10.987 cell disease and pediatric cancers?

NOTE Confidence: 0.97506434

 $00:02:10.990 \longrightarrow 00:02:14.246$  I mean, do children get sickle cell disease?

NOTE Confidence: 0.97506434

 $00:02:14.250 \longrightarrow 00:02:16.665$  Does sickle cell kind of lead to

NOTE Confidence: 0.97506434

00:02:16.665 --> 00:02:19.455 cancer or are these just two separate

NOTE Confidence: 0.97506434

 $00{:}02{:}19.455 \dashrightarrow 00{:}02{:}21.975$  passions of yours that happen to

NOTE Confidence: 0.97506434

 $00:02:22.050 \longrightarrow 00:02:24.450$  coincide in the same individual?

NOTE Confidence: 0.9367568

 $00{:}02{:}25.740 \to 00{:}02{:}28.860$  These are two separate passions,

NOTE Confidence: 0.9367568

 $00:02:28.860 \longrightarrow 00:02:31.524$  and because in Pediatrics we

NOTE Confidence: 0.9367568

00:02:31.524 --> 00:02:34.320 train in both hematology and oncology,

NOTE Confidence: 0.9367568

 $00{:}02{:}34.320 \dashrightarrow 00{:}02{:}36.264$  these are two passions which

00:02:38.581 --> 00:02:40.946 developed during my training,

NOTE Confidence: 0.9367568

 $00:02:40.950 \longrightarrow 00:02:44.260$  but it is not connected in any way in terms

NOTE Confidence: 0.9367568

 $00:02:44.340 \longrightarrow 00:02:47.190$  of children with sickle cell disease being

 $00:02:47.190 \longrightarrow 00:02:49.566$  more prone to getting cancer or

NOTE Confidence: 0.9367568

 $00{:}02{:}49.566 \dashrightarrow 00{:}02{:}51.967$  children with cancer more prone to

NOTE Confidence: 0.9367568

 $00:02:51.967 \longrightarrow 00:02:54.205$  having any issues with sickle cell.

 $00:02:56.490 \longrightarrow 00:02:59.496$  Let's talk about each of the two in turn

NOTE Confidence: 0.970355798

 $00:02:59.496 \longrightarrow 00:03:02.222$  and let's start maybe with

NOTE Confidence: 0.970355798

 $00:03:02.222 \longrightarrow 00:03:04.390$  talking about pediatric cancers.

 $00{:}03{:}06.982 \dashrightarrow 00{:}03{:}09.440$  Any time we hear about children getting cancer,

NOTE Confidence: 0.970355798

 $00:03:09.440 \longrightarrow 00:03:10.988$  the uniform emotion that

NOTE Confidence: 0.970355798

 $00:03:10.988 \longrightarrow 00:03:12.893$  people feel is heartbreak.

NOTE Confidence: 0.970355798

 $00:03:12.893 \longrightarrow 00:03:15.364$  So tell us a little bit more

NOTE Confidence: 0.970355798

 $00:03:15.364 \longrightarrow 00:03:17.590$  about how you get involved.

NOTE Confidence: 0.970355798

 $00:03:17.590 \longrightarrow 00:03:20.894$  I know so many medical

NOTE Confidence: 0.970355798

 $00:03:20.894 \longrightarrow 00:03:23.787$  students come up to me and they say,

NOTE Confidence: 0.970355798

 $00:03:23.790 \longrightarrow 00:03:26.604$  how can you possibly dedicate your career

NOTE Confidence: 0.970355798

00:03:26.610 --> 00:03:29.277 to doing something that is so heartbreaking, 00:03:31.518 --> 00:03:34.226 but honestly after doing this for over 20 years

NOTE Confidence: 0.978117600000001

 $00:03:34.226 \longrightarrow 00:03:36.512$  this is such a rewarding journey.

 $00:03:36.520 \longrightarrow 00:03:39.192$  It is the time that a lot of

NOTE Confidence: 0.978117600000001

00:03:39.192 --> 00:03:41.089 families are going through

NOTE Confidence: 0.978117600000001

 $00:03:41.090 \longrightarrow 00:03:43.772$  probably the most intense and difficult

NOTE Confidence: 0.978117600000001

 $00:03:43.772 \longrightarrow 00:03:46.663$  time of their life and to be able

NOTE Confidence: 0.978117600000001

00:03:46.663 --> 00:03:49.968 to be a part of it and to help them

NOTE Confidence: 0.978117600000001

 $00:03:49.968 \longrightarrow 00:03:52.512$  navigate and think about the treatment

NOTE Confidence: 0.978117600000001

 $00:03:52.520 \longrightarrow 00:03:54.837$  decisions for their child and to be

NOTE Confidence: 0.978117600000001

 $00:03:54.837 \longrightarrow 00:03:57.528$  able to treat their child effectively,

NOTE Confidence: 0.978117600000001

00:03:57.530 --> 00:03:59.130 honestly, I don't think

NOTE Confidence: 0.978117600000001

 $00:03:59.130 \longrightarrow 00:04:01.130$  there's a substitute for that.

NOTE Confidence: 0.978117600000001

00:04:01.130 --> 00:04:03.530 I think it's so emotionally rewarding.

NOTE Confidence: 0.978117600000001

 $00{:}04{:}03.530 \dashrightarrow 00{:}04{:}06.330$  It is also heartbreaking at times.

NOTE Confidence: 0.978117600000001

 $00{:}04{:}06.330 \dashrightarrow 00{:}04{:}09.050$  I mean, we do have children who could

NOTE Confidence: 0.978117600000001

 $00:04:09.050 \longrightarrow 00:04:11.950$  have a recurrence and it is

NOTE Confidence: 0.978117600000001

00:04:11.950 --> 00:04:14.914 a lot of intense time thinking about

 $00:04:14.914 \longrightarrow 00:04:17.836$  not only the management but also

NOTE Confidence: 0.978117600000001

 $00{:}04{:}17.836 \dashrightarrow 00{:}04{:}20.190$  supporting these families through that.

NOTE Confidence: 0.978117600000001

00:04:20.190 --> 00:04:22.980 But the relationships I've built with

NOTE Confidence: 0.978117600000001

 $00:04:23.060 \longrightarrow 00:04:25.460$  even the children that we've lost,

NOTE Confidence: 0.978117600000001

 $00:04:25.460 \longrightarrow 00:04:26.270$  the relationships

NOTE Confidence: 0.978117600000001

 $00:04:26.270 \longrightarrow 00:04:28.295$  built with those parents

NOTE Confidence: 0.978117600000001

 $00:04:28.295 \longrightarrow 00:04:29.510$  is just unbelievable.

NOTE Confidence: 0.978117600000001

 $00:04:29.510 \longrightarrow 00:04:31.540$  And after losing the child,

NOTE Confidence: 0.978117600000001

 $00:04:31.540 \longrightarrow 00:04:33.076$  they still think of

NOTE Confidence: 0.978117600000001

 $00:04:33.076 \longrightarrow 00:04:36.799$  us as being part of their family.

NOTE Confidence: 0.978117600000001

 $00:04:36.800 \longrightarrow 00:04:39.327$  And I think that bond is

NOTE Confidence: 0.978117600000001

 $00:04:39.327 \longrightarrow 00:04:41.260$  so valuable and precious.

NOTE Confidence: 0.978117600000001

00:04:41.260 --> 00:04:44.500 So yes, it can be heartbreaking at times,

NOTE Confidence: 0.978117600000001

 $00:04:44.500 \longrightarrow 00:04:46.520$  but it's also extremely rewarding.

NOTE Confidence: 0.978117600000001

 $00:04:46.520 \longrightarrow 00:04:48.998$  And today I would say that we cure

NOTE Confidence: 0.978117600000001 00:04:48.998 --> 00:04:50.650 about 85%

 $00:04:50.650 \longrightarrow 00:04:52.530$  of children with cancer very successfully.

NOTE Confidence: 0.978117600000001

 $00:04:52.530 \longrightarrow 00:04:54.665$  So clearly we have done a really

NOTE Confidence: 0.978117600000001

00:04:54.665 --> 00:04:57.120 good job at trying to make advances

NOTE Confidence: 0.978117600000001

 $00:04:57.120 \longrightarrow 00:04:59.322$  and improve the life of these

NOTE Confidence: 0.978117600000001

 $00:04:59.399 \longrightarrow 00:05:01.547$  children diagnosed with cancer.

00:05:03.430 --> 00:05:06.438 And I think that's such a key point is that

NOTE Confidence: 0.98242605

00:05:06.438 --> 00:05:08.574 whereas many people will

NOTE Confidence: 0.98242605

 $00:05:08.574 \longrightarrow 00:05:11.330$  think of cancer as a death sentence,

NOTE Confidence: 0.98242605

 $00:05:11.330 \longrightarrow 00:05:13.244$  now more and more what we're

NOTE Confidence: 0.98242605

 $00:05:13.244 \longrightarrow 00:05:15.876$  finding out in a variety of cancers

NOTE Confidence: 0.98242605

 $00{:}05{:}15.876 \dashrightarrow 00{:}05{:}18.432$  is that really we're beginning to

NOTE Confidence: 0.98242605

 $00:05:18.432 \longrightarrow 00:05:20.847$  discover that many of these cancers

NOTE Confidence: 0.98242605

 $00:05:20.850 \longrightarrow 00:05:23.280$  are treatable and with good outcomes,

NOTE Confidence: 0.98242605

00:05:23.280 --> 00:05:25.710 but you're interested in solid tumors,

NOTE Confidence: 0.98242605

 $00:05:25.710 \longrightarrow 00:05:28.782$  so tell us more about the solid tumors

NOTE Confidence: 0.98242605

 $00:05:28.782 \longrightarrow 00:05:32.119$  that occur in Pediatrics and what kind

 $00:05:32.119 \longrightarrow 00:05:35.430$  of treatments we have to offer these kids.

NOTE Confidence: 0.98242605

 $00:05:35.430 \longrightarrow 00:05:36.902$  What the prognosis is,

NOTE Confidence: 0.98242605

 $00:05:36.902 \longrightarrow 00:05:38.742$  and the other thing that

NOTE Confidence: 0.98242605

 $00:05:38.742 \longrightarrow 00:05:40.699$  I'm always curious about

NOTE Confidence: 0.98242605

 $00:05:40.700 \longrightarrow 00:05:43.340$  on this show, we spend so much time

NOTE Confidence: 0.98242605

 $00:05:43.340 \longrightarrow 00:05:45.559$  talking about personalized medicine.

NOTE Confidence: 0.98242605

 $00:05:45.560 \longrightarrow 00:05:47.990$  The fact that now

NOTE Confidence: 0.98242605

 $00:05:47.990 \longrightarrow 00:05:50.937$  we've begun to really unlock the

NOTE Confidence: 0.98242605

 $00:05:50.940 \longrightarrow 00:05:52.364$  genomic abnormalities that

NOTE Confidence: 0.98242605

 $00:05:52.364 \longrightarrow 00:05:54.500$  occur in cancers we're able to

NOTE Confidence: 0.98242605

 $00:05:54.561 \longrightarrow 00:05:56.577$  better target these abnormalities.

NOTE Confidence: 0.98242605

 $00:05:56.580 \longrightarrow 00:06:00.470$  Can we do the same thing in kids and

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 $00:06:00.567 \longrightarrow 00:06:04.354$  is that resulting in higher cure rates?

 $00:06:04.860 \longrightarrow 00:06:08.820$  Great question and a lot to unpack.

NOTE Confidence: 0.84232676

 $00:06:08.820 \longrightarrow 00:06:12.131$  In terms of solid tumors, they

00:06:15.970 --> 00:06:19.210 really change across the age spectrum,

 $00:06:19.210 \longrightarrow 00:06:21.989$  so the solid tumors that we see

NOTE Confidence: 0.84232676

 $00:06:21.989 \longrightarrow 00:06:25.144$  in the much younger child are

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00:06:25.144 --> 00:06:27.628 tumors such as neuroblastoma,

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 $00{:}06{:}27.630 \dashrightarrow 00{:}06{:}29.606$  Wilms tumors, retinoblastoma so

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 $00:06:29.606 \longrightarrow 00:06:32.076$  much more embryonal based tumors,

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 $00:06:32.080 \longrightarrow 00:06:34.640$  and then as you gradually

NOTE Confidence: 0.84232676

 $00:06:34.640 \longrightarrow 00:06:37.400$  advance and you're coming to the

NOTE Confidence: 0.84232676

00:06:37.400 --> 00:06:38.780 prepubertal young adolescence,

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 $00{:}06{:}38.780 \longrightarrow 00{:}06{:}41.080$  we start seeing more tumors

NOTE Confidence: 0.84232676

 $00:06:41.080 \longrightarrow 00:06:44.097$  such as the sarcomas, so the osteosarcoma

NOTE Confidence: 0.84232676

 $00:06:44.097 \longrightarrow 00:06:47.060$  the soft tissue sarcomas

NOTE Confidence: 0.84232676

 $00:06:47.060 \longrightarrow 00:06:49.355$  which have an overlap

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 $00:06:49.355 \longrightarrow 00:06:52.120$  with the adult population as well,

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 $00:06:52.120 \longrightarrow 00:06:54.420$  and in addition, we see,

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 $00:06:54.420 \longrightarrow 00:06:55.863$  besides these sarcomas,

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 $00:06:55.863 \longrightarrow 00:06:58.268$  of course we see Rhabdomyosarcoma

 $00:06:58.268 \longrightarrow 00:07:00.644$  which occurs across the age

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 $00{:}07{:}00.644 \dashrightarrow 00{:}07{:}02.874$  spectrum from childhood onto the

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 $00:07:02.874 \longrightarrow 00:07:05.029$  adolescent young adult population.

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 $00:07:05.030 \longrightarrow 00:07:07.376$  So in terms of solid tumors,

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 $00:07:07.380 \longrightarrow 00:07:09.564$  really the main areas or the

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 $00:07:09.564 \longrightarrow 00:07:12.351$  main types of solid tumors we see

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 $00:07:12.351 \longrightarrow 00:07:14.436$  would be the embryonal tumors.

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 $00:07:14.440 \longrightarrow 00:07:16.400$  As I already mentioned and

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 $00:07:16.400 \longrightarrow 00:07:18.360$  then sort of the sarcomas

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 $00:07:18.360 \longrightarrow 00:07:21.097$  and the bone sarcomas.

NOTE Confidence: 0.84232676

 $00{:}07{:}21.100 \dashrightarrow 00{:}07{:}23.518$  Those are the two big groups

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 $00:07:23.518 \longrightarrow 00:07:25.809$  of solid tumors that we see.

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 $00{:}07{:}25.810 \dashrightarrow 00{:}07{:}28.882$  We also see interestingly a lot of rare

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 $00:07:28.882 \longrightarrow 00:07:31.620$  tumors and one of my particular area

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 $00:07:31.620 \longrightarrow 00:07:34.429$  of interest has been in rare tumors,

 $00:07:34.430 \longrightarrow 00:07:36.440$  and I've been very involved

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 $00{:}07{:}36.440 \dashrightarrow 00{:}07{:}38.048$  in developing clinical trials

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 $00:07:38.050 \longrightarrow 00:07:40.534$  for these children with rare tumors

NOTE Confidence: 0.84232676

00:07:40.534 --> 00:07:42.630 through the Children's oncology group,

NOTE Confidence: 0.84232676

 $00:07:42.630 \longrightarrow 00:07:45.174$  so the rare tumors that we see are

NOTE Confidence: 0.84232676

 $00:07:45.174 \longrightarrow 00:07:47.619$  things like nasopharyngeal carcinoma,

NOTE Confidence: 0.84232676

 $00:07:47.620 \longrightarrow 00:07:49.432$  adrenocortical carcinoma, thyroid cancer,

NOTE Confidence: 0.84232676

 $00:07:49.432 \longrightarrow 00:07:52.584$  which of course can occur in adults

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 $00{:}07{:}52.584 \dashrightarrow 00{:}07{:}55.512$  but also starts in young adolescence.

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 $00:07:55.520 \longrightarrow 00:07:58.425$  So we see several of those patients,

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 $00{:}07{:}58.430 \dashrightarrow 00{:}08{:}00.872$  and now we've started seeing some

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 $00:08:00.872 \longrightarrow 00:08:03.840$  of the tumors that are adult tumors

 $00:08:04.672 \longrightarrow 00:08:06.336$  earlier in Pediatrics,

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 $00:08:06.340 \longrightarrow 00:08:08.900$  such as even colorectal carcinoma.

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 $00:08:08.900 \longrightarrow 00:08:11.497$  So that's sort of the spectrum of

NOTE Confidence: 0.84232676

 $00:08:11.497 \longrightarrow 00:08:14.747$  tumors we see in pediatric solid tumors.

00:08:14.750 --> 00:08:17.198 I've not included brain tumors because

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 $00{:}08{:}17.198 \dashrightarrow 00{:}08{:}19.350$  we almost separate brain tumors,

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 $00:08:19.350 \longrightarrow 00:08:21.858$  just like we do leukemia and lymphomas.

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 $00:08:21.860 \longrightarrow 00:08:25.196$  And I don't treat brain tumors.

NOTE Confidence: 0.84232676

 $00:08:25.200 \longrightarrow 00:08:28.126$  I focus on the extracranial solid tumors,

NOTE Confidence: 0.84232676

 $00:08:28.130 \longrightarrow 00:08:31.218$  so those are the ones I've just mentioned

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 $00{:}08{:}31.218 \dashrightarrow 00{:}08{:}33.702$  with regards to the treatment and

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 $00{:}08{:}33.702 \dashrightarrow 00{:}08{:}36.150$  the role of personalized medicine or

NOTE Confidence: 0.84232676

 $00:08:36.225 \longrightarrow 00:08:39.090$  immunotherapy in treating these cancers.

00:08:41.650 --> 00:08:43.790 Again, the role of personalized medicine

 $00:08:44.570 \longrightarrow 00:08:47.300$  is very well known in the adult oncologic world.

 $00{:}08{:}48.910 \dashrightarrow 00{:}08{:}51.466$  In Pediatrics we still do profile

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00:08:51.470 --> 00:08:54.459 most of our patients with solid tumors,

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 $00:08:54.460 \longrightarrow 00:08:56.595$  and there have been tumors

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 $00{:}08{:}56.595 \mathrel{--}{>} 00{:}08{:}58.303$  which have happened recently and

NOTE Confidence: 0.84232676

 $00:08:58.310 \longrightarrow 00:09:00.596$  there's a lot of excitement on

NOTE Confidence: 0.84232676

 $00:09:00.596 \longrightarrow 00:09:02.683$  tumors where there's a specific

 $00:09:02.683 \longrightarrow 00:09:05.138$  targeted drug that is available,

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 $00{:}09{:}05.140 \dashrightarrow 00{:}09{:}09.109$  and one classic example of this is the

NOTE Confidence: 0.84232676

00:09:09.110 --> 00:09:09.996 TRK fusion cancers

NOTE Confidence: 0.84232676

 $00:09:09.996 \longrightarrow 00:09:12.654$  where there is a specific drug  $00:09:14.995 \longrightarrow 00:09:17.743$  that has been developed with

NOTE Confidence: 0.84232676

 $00:09:17.743 \longrightarrow 00:09:19.759$  excellent outstanding results.

NOTE Confidence: 0.84232676

00:09:19.760 --> 00:09:23.148 So TRK fusion cancers can occur

NOTE Confidence: 0.84232676

 $00:09:23.150 \longrightarrow 00:09:26.734$  from infants where you

NOTE Confidence: 0.84232676

 $00:09:26.734 \longrightarrow 00:09:29.439$  have infantile fibrosarcoma's that occur in

NOTE Confidence: 0.84232676

 $00:09:29.440 \longrightarrow 00:09:32.338$  the first year of life,

NOTE Confidence: 0.84232676

 $00:09:32.340 \longrightarrow 00:09:34.068$  and then TRK Fusion

NOTE Confidence: 0.84232676

00:09:34.068 --> 00:09:36.660 sarcomas are also seen in older

NOTE Confidence: 0.84232676

00:09:36.751 --> 00:09:39.119 adolescents and young adults,

NOTE Confidence: 0.84232676

 $00:09:39.120 \longrightarrow 00:09:40.832$  so in specific situations

NOTE Confidence: 0.84232676

 $00:09:40.832 \longrightarrow 00:09:44.044$  we do also use what the adults

NOTE Confidence: 0.84232676

00:09:44.044 --> 00:09:46.240 use much more frequently,

 $00:09:46.240 \longrightarrow 00:09:49.656$  which is a very targeted therapy based on

NOTE Confidence: 0.9806486

 $00:09:49.660 \longrightarrow 00:09:52.048$  tumor profiling.

 $00:09:55.040 \longrightarrow 00:09:57.150$  How does prognosis vary

NOTE Confidence: 0.9806486

00:09:57.150 --> 00:09:58.838 amongst the pediatric cancers?

NOTE Confidence: 0.9806486

00:09:58.840 --> 00:10:00.950 Because you've kind of mentioned

NOTE Confidence: 0.9806486

 $00:10:00.950 \longrightarrow 00:10:02.638$  this whole spectrum,

NOTE Confidence: 0.9806486

 $00:10:02.640 \longrightarrow 00:10:05.010$  we have the leukemia lymphoma

NOTE Confidence: 0.9806486

00:10:05.010 --> 00:10:07.562 as one separate group and brain

NOTE Confidence: 0.9806486

 $00{:}10{:}07.562 \dashrightarrow 00{:}10{:}09.807$  tumors as another separate group.

NOTE Confidence: 0.9806486

 $00{:}10{:}09.810 \dashrightarrow 00{:}10{:}12.799$  But even within the non cranial solid

NOTE Confidence: 0.9806486

 $00:10:12.799 \longrightarrow 00:10:16.049$  tumors in pediatric populations

NOTE Confidence: 0.9806486

 $00:10:16.050 \longrightarrow 00:10:19.326$  we're looking at everything from eye tumors,

NOTE Confidence: 0.9806486

00:10:19.330 --> 00:10:20.755 retinoblastoma's to kidney

NOTE Confidence: 0.9806486

00:10:20.755 --> 00:10:23.605 tumors like Wilms tumor

NOTE Confidence: 0.9806486

 $00:10:23.605 \longrightarrow 00:10:24.940$  to sarcomas.

NOTE Confidence: 0.9806486

 $00:10:24.940 \longrightarrow 00:10:29.143$  So how do these vary in terms of prognosis,

00:10:29.150 --> 00:10:33.362 and have we seen a shift in terms of

00:10:34.268 --> 00:10:36.962 moving towards being able to treat

NOTE Confidence: 0.9806486

 $00:10:36.962 \longrightarrow 00:10:39.920$  these children better with new therapies?

NOTE Confidence: 0.92642444

00:10:41.100 --> 00:10:44.439 Yeah, so it is a whole spectrum.

NOTE Confidence: 0.92642444

00:10:44.440 --> 00:10:47.296 As you've already mentioned,

NOTE Confidence: 0.92642444

 $00{:}10{:}47.300 \dashrightarrow 00{:}10{:}50.639$  I think we've done really well in

NOTE Confidence: 0.92642444

 $00:10:50.640 \longrightarrow 00:10:53.496$  some of these tumors.

NOTE Confidence: 0.92642444

 $00:10:53.500 \longrightarrow 00:10:56.272$  For example, in patients with retinoblastoma

NOTE Confidence: 0.92642444

 $00:10:56.272 \longrightarrow 00:10:58.750$  you have an excellent outcome,

NOTE Confidence: 0.92642444

 $00{:}10{:}58.750 \dashrightarrow 00{:}11{:}01.195$  particularly now with intra arterial

NOTE Confidence: 0.92642444

 $00:11:01.195 \longrightarrow 00:11:03.640$  chemotherapy delivering very focused

NOTE Confidence: 0.92642444

 $00:11:03.705 \longrightarrow 00:11:05.900$  chemotherapy.

NOTE Confidence: 0.92642444

 $00:11:05.900 \longrightarrow 00:11:08.938$  We've also reduced the issue with long

NOTE Confidence: 0.92642444

 $00{:}11{:}08.938 \dashrightarrow 00{:}11{:}12.189$  term side effects giving systemic therapy.

NOTE Confidence: 0.92642444

00:11:14.790 --> 00:11:17.744 Treatment has evolved

NOTE Confidence: 0.92642444

 $00:11:17.744 \longrightarrow 00:11:20.266$  significantly over the last maybe 10-15

 $00:11:20.266 \longrightarrow 00:11:22.636$  years with the development of

NOTE Confidence: 0.92642444

 $00{:}11{:}22.636 \dashrightarrow 00{:}11{:}25.207$  an antibody called dinutux imab

NOTE Confidence: 0.92642444

 $00:11:25.210 \longrightarrow 00:11:27.978$  which focuses on the GD2

NOTE Confidence: 0.92642444

 $00:11:27.978 \longrightarrow 00:11:31.290$  which is expressed by neuroblastoma cells.

NOTE Confidence: 0.92642444

00:11:31.290 --> 00:11:34.466 So now we have this multi modality therapy

NOTE Confidence: 0.92642444

 $00:11:34.466 \longrightarrow 00:11:37.799$  that we do in addition to chemotherapy,

NOTE Confidence: 0.92642444

 $00:11:37.800 \longrightarrow 00:11:38.720$  surgery, and radiation.

NOTE Confidence: 0.92642444

 $00:11:38.720 \longrightarrow 00:11:42.400$  We also have this immunotherapy that is done

NOTE Confidence: 0.92642444

 $00:11:42.400 \longrightarrow 00:11:43.546$  in combination

NOTE Confidence: 0.92642444

00:11:43.546 --> 00:11:45.838 particularly for those who have high

NOTE Confidence: 0.92642444

 $00:11:45.838 \longrightarrow 00:11:48.138$  risk neuroblastoma in Wilms tumor,

NOTE Confidence: 0.92642444

 $00:11:48.140 \longrightarrow 00:11:50.600$  our outcomes have always been excellent,

NOTE Confidence: 0.92642444

00:11:50.600 --> 00:11:52.650 and we're continuing to improve

NOTE Confidence: 0.92642444

 $00:11:52.650 \longrightarrow 00:11:53.470$  those outcomes.

NOTE Confidence: 0.92642444

00:11:53.470 --> 00:11:55.520 And similarly I didn't

NOTE Confidence: 0.92642444

 $00:11:55.520 \longrightarrow 00:11:57.160$  mention germ cell tumors,

 $00:11:57.160 \longrightarrow 00:12:00.030$  which honestly, is

NOTE Confidence: 0.92642444

00:12:00.030 --> 00:12:02.490 a really strong interest of mine,

NOTE Confidence: 0.92642444

 $00:12:02.490 \longrightarrow 00:12:06.180$  so we do very well in germ cell tumors.

NOTE Confidence: 0.92642444

 $00:12:06.180 \longrightarrow 00:12:08.640$  And in all these four categories,

NOTE Confidence: 0.92642444

 $00:12:08.640 \longrightarrow 00:12:11.510$  I would say we have excellent outcomes.

NOTE Confidence: 0.92642444

00:12:11.510 --> 00:12:12.424 In sarcomas,

NOTE Confidence: 0.92642444

 $00:12:12.424 \longrightarrow 00:12:15.166$  I think we still have challenges.

NOTE Confidence: 0.92642444

 $00{:}12{:}15.170 \dashrightarrow 00{:}12{:}17.918$  And the challenge really depends on

NOTE Confidence: 0.92642444

 $00:12:17.918 \longrightarrow 00:12:21.280$  the time of presentation,

NOTE Confidence: 0.92642444

 $00:12:21.280 \longrightarrow 00:12:23.036$  what the staging is, and

NOTE Confidence: 0.92642444

 $00:12:23.036 \longrightarrow 00:12:25.231$  for patients who present

NOTE Confidence: 0.92642444

00:12:25.231 --> 00:12:27.389 with metastatic sarcomas,

NOTE Confidence: 0.92642444

 $00{:}12{:}27.390 \dashrightarrow 00{:}12{:}29.930$ be it Rhabdomyosarcoma or osteosarcoma,

NOTE Confidence: 0.92642444

 $00{:}12{:}29.930 \dashrightarrow 00{:}12{:}33.020$  we still are challenged in terms

NOTE Confidence: 0.92642444

 $00:12:33.020 \longrightarrow 00:12:36.039$  of long term outcomes at times,

 $00:12:36.040 \longrightarrow 00:12:39.940$  and we have numerous clinical trials

NOTE Confidence: 0.92642444

 $00{:}12{:}39.940 \dashrightarrow 00{:}12{:}43.090$  looking at different options which

 $00:12:46.240 \longrightarrow 00:12:48.856$  this is where we are

NOTE Confidence: 0.92642444

00:12:48.856 --> 00:12:50.721 looking to improve our outcomes

NOTE Confidence: 0.92642444

 $00:12:50.721 \longrightarrow 00:12:51.840$  by newer therapies.

NOTE Confidence: 0.92642444

 $00:12:51.840 \longrightarrow 00:12:54.690$  And as you mentioned, personalized therapies are

00:12:55.090 --> 00:12:57.575 so important to really try to get

NOTE Confidence: 0.98094404

 $00{:}12{:}57.575 \dashrightarrow 00{:}13{:}00.029$  people involved in clinical trials

NOTE Confidence: 0.98094404

 $00:13:00.029 \longrightarrow 00:13:02.669$  to really move those therapies forward,

NOTE Confidence: 0.98094404

 $00:13:02.670 \longrightarrow 00:13:05.726$  but it's really great to hear that

NOTE Confidence: 0.98094404

 $00:13:05.726 \longrightarrow 00:13:08.260$  we're moving in the right direction,

NOTE Confidence: 0.98094404

 $00{:}13{:}08.260 \dashrightarrow 00{:}13{:}11.444$  at least for the majority of solid tumors in kids.

NOTE Confidence: 0.98094404

 $00:13:11.450 \longrightarrow 00:13:14.154$  We're going to take a short

NOTE Confidence: 0.98094404

 $00:13:14.154 \longrightarrow 00:13:17.070$  break for medical minute and then learn

NOTE Confidence: 0.98094404

00:13:17.070 --> 00:13:19.830 more not only about pediatric cancer,

NOTE Confidence: 0.98094404

 $00:13:19.830 \longrightarrow 00:13:22.637$  but also delve into your interest in

NOTE Confidence: 0.98094404

 $00:13:22.637 \longrightarrow 00:13:25.130$  sickle cell disease right after this break.

 $00:13:25.130 \longrightarrow 00:13:27.674$  Please stay tuned for more

NOTE Confidence: 0.98094404

 $00{:}13{:}27.674 \dashrightarrow 00{:}13{:}29.370$  with my guest Doctor Farzana Pashankar.

NOTE Confidence: 0.90915823

 $00:13:29.370 \longrightarrow 00:13:32.338$  Funding for Yale Cancer

NOTE Confidence: 0.90915823

00:13:32.338 --> 00:13:34.883 Answers comes from AstraZeneca, working

NOTE Confidence: 0.90915823

 $00:13:34.883 \longrightarrow 00:13:38.267$  to eliminate cancer as a cause of death.

NOTE Confidence: 0.90915823

 $00:13:38.270 \longrightarrow 00:13:41.770$  Learn more at astrazeneca-us.com.

NOTE Confidence: 0.90915823

00:13:41.770 --> 00:13:44.194 Genetic testing can be useful for

NOTE Confidence: 0.90915823

00:13:44.194 --> 00:13:46.568 people with certain types of cancer

NOTE Confidence: 0.90915823

 $00:13:46.568 \longrightarrow 00:13:48.962$  that seem to run in their families.

NOTE Confidence: 0.90915823

 $00:13:48.970 \longrightarrow 00:13:51.268$  Genetic counseling is a process that

NOTE Confidence: 0.90915823

 $00:13:51.268 \longrightarrow 00:13:53.222$  includes collecting a detailed personal

NOTE Confidence: 0.90915823

 $00:13:53.222 \longrightarrow 00:13:55.742$  and family history or risk assessment and

NOTE Confidence: 0.90915823

 $00{:}13{:}55.742 \dashrightarrow 00{:}13{:}58.069$  a discussion of genetic testing options.

NOTE Confidence: 0.90915823

 $00:13:58.070 \longrightarrow 00:14:01.100$  Only about 5 to 10% of all cancers

NOTE Confidence: 0.90915823

 $00:14:01.100 \longrightarrow 00:14:02.994$  are inherited, and genetic testing

 $00:14:02.994 \longrightarrow 00:14:04.884$  is not recommended for everyone.

NOTE Confidence: 0.90915823

 $00{:}14{:}04.890 \dashrightarrow 00{:}14{:}07.020$  Individuals who have a personal and

NOTE Confidence: 0.90915823

 $00:14:07.020 \longrightarrow 00:14:08.910$  or family history that includes

NOTE Confidence: 0.90915823

00:14:08.910 --> 00:14:10.950 cancer at unusually early ages,

NOTE Confidence: 0.90915823

 $00:14:10.950 \longrightarrow 00:14:11.778$  multiple relatives

NOTE Confidence: 0.90915823

 $00:14:11.778 \longrightarrow 00:14:14.262$  on the same side of the

NOTE Confidence: 0.90915823

 $00:14:14.262 \longrightarrow 00:14:16.379$  family with the same cancer,

NOTE Confidence: 0.90915823

 $00:14:16.380 \longrightarrow 00:14:18.450$  more than one diagnosis of

NOTE Confidence: 0.90915823

 $00{:}14{:}18.450 \dashrightarrow 00{:}14{:}20.520$  cancer in the same individual,

NOTE Confidence: 0.90915823

 $00:14:20.520 \longrightarrow 00:14:23.061$  rare cancers or family history of a

NOTE Confidence: 0.90915823

00:14:23.061 --> 00:14:25.158 known altered cancer predisposing gene

NOTE Confidence: 0.90915823

 $00:14:25.158 \longrightarrow 00:14:27.978$  could be candidates for genetic testing.

NOTE Confidence: 0.90915823

 $00:14:27.980 \longrightarrow 00:14:30.075$  Resources for genetic counseling and

NOTE Confidence: 0.90915823

 $00{:}14{:}30.075 \dashrightarrow 00{:}14{:}32.170$  testing are available at federally

NOTE Confidence: 0.90915823

 $00:14:32.236 \longrightarrow 00:14:33.475$  designated comprehensive cancer

NOTE Confidence: 0.90915823

 $00{:}14{:}33.475 \dashrightarrow 00{:}14{:}35.953$  centers such as Yale Cancer Center

 $00:14:35.953 \longrightarrow 00:14:37.908$  and at Smilow Cancer Hospital.

NOTE Confidence: 0.90915823

 $00{:}14{:}37.910 \dashrightarrow 00{:}14{:}40.265$  More information is available at

NOTE Confidence: 0.90915823

00:14:40.265 --> 00:14:41.678 valecancercenter.org. You're listening

NOTE Confidence: 0.90915823

00:14:41.678 --> 00:14:43.399 to Connecticut Public Radio.

NOTE Confidence: 0.90915823

 $00:14:43.400 \longrightarrow 00:14:43.760$  Welcome

NOTE Confidence: 0.9770544

 $00:14:43.760 \longrightarrow 00:14:45.560$  back to Yale Cancer Answers.

NOTE Confidence: 0.9770544

00:14:45.560 --> 00:14:47.648 This is doctor Anees Chappar

NOTE Confidence: 0.9770544

 $00:14:47.648 \longrightarrow 00:14:49.846$  and I'm joined to night by my

NOTE Confidence: 0.9770544

 $00:14:49.846 \longrightarrow 00:14:51.676$  guest Doctor Farzana Pashankar.

NOTE Confidence: 0.9770544

 $00{:}14{:}51.680 \dashrightarrow 00{:}14{:}53.705$  We're talking about sickle cell

NOTE Confidence: 0.9770544

00:14:53.705 --> 00:14:55.730 disease and cancer in pediatric

NOTE Confidence: 0.9770544

00:14:55.801 --> 00:14:57.655 patients. Before the break for

NOTE Confidence: 0.9770544

 $00:14:57.655 \longrightarrow 00:14:59.925$  any of you who missed it,

NOTE Confidence: 0.9770544

 $00:14:59.925 \longrightarrow 00:15:01.875$  there is no connection between sickle

NOTE Confidence: 0.9770544

 $00{:}15{:}01.875 \dashrightarrow 00{:}15{:}03.920$  cell disease and pediatric cancers,

 $00:15:03.920 \longrightarrow 00:15:05.680$  except that our guest happens

NOTE Confidence: 0.9770544

 $00:15:05.680 \longrightarrow 00:15:07.880$  to be an expert in both.

NOTE Confidence: 0.9770544

 $00{:}15{:}07.880 \dashrightarrow 00{:}15{:}10.688$  Right before the break we were

NOTE Confidence: 0.9770544

 $00:15:10.688 \longrightarrow 00:15:13.400$  talking about pediatric cancers and the fact

NOTE Confidence: 0.9770544

 $00:15:13.400 \longrightarrow 00:15:17.285$  that some kids get solid tumors.

NOTE Confidence: 0.9770544

00:15:17.290 --> 00:15:20.677 This must not be very common, right?

NOTE Confidence: 0.9770544

 $00:15:20.677 \longrightarrow 00:15:24.646$  How common are pediatric cancers?

NOTE Confidence: 0.9770544

00:15:24.650 --> 00:15:26.760 Especially the non hematologic cancers?

 $00:15:28.450 \longrightarrow 00:15:31.187$  I think of course each one of those

NOTE Confidence: 0.8816699

 $00{:}15{:}31.187 \dashrightarrow 00{:}15{:}33.378$  cancers is overall pretty rare

NOTE Confidence: 0.8816699

00:15:33.378 --> 00:15:36.043 and even leukemias, which are the

NOTE Confidence: 0.8816699

 $00:15:36.043 \longrightarrow 00:15:38.148$  most common pediatric cancer we say

NOTE Confidence: 0.8816699

 $00:15:38.150 \longrightarrow 00:15:41.111$  happens one in a million.

NOTE Confidence: 0.8816699

00:15:41.111 --> 00:15:43.637 So the solid tumors are much rarer

00:15:44.906 --> 00:15:47.860 and each one has a different frequency,

NOTE Confidence: 0.8816699

 $00:15:47.860 \longrightarrow 00:15:50.932$  so it's hard to give a

NOTE Confidence: 0.8816699

 $00:15:50.932 \longrightarrow 00:15:53.768$  number for all of them combined.

 $00:15:55.980 \longrightarrow 00:15:57.752$  This is very interesting

NOTE Confidence: 0.8816699

00:15:57.752 --> 00:15:59.967 because as you may know,

NOTE Confidence: 0.8816699

 $00:15:59.970 \longrightarrow 00:16:03.506$  there's a lot of interest in rare cancers,

NOTE Confidence: 0.8816699

 $00:16:03.510 \longrightarrow 00:16:06.862$  and the NIH was looking at developing a

NOTE Confidence: 0.8816699

 $00:16:06.862 \longrightarrow 00:16:10.393$  rare Cancer Institute in order to try and

NOTE Confidence: 0.8816699

 $00:16:10.393 \longrightarrow 00:16:13.700$  improve the outcomes in these rare cancers.

NOTE Confidence: 0.8816699

 $00:16:13.700 \longrightarrow 00:16:16.418$  And when we were looking at

NOTE Confidence: 0.8816699

00:16:16.418 --> 00:16:18.570 defining what rare cancers is,

NOTE Confidence: 0.8816699

 $00{:}16{:}18.570 \dashrightarrow 00{:}16{:}21.755$  it's very clear up front that every

NOTE Confidence: 0.8816699

00:16:21.755 --> 00:16:24.779 pediatric cancer is rare in that sense,

NOTE Confidence: 0.8816699

 $00:16:24.780 \longrightarrow 00:16:26.604$  but the solid tumors,

NOTE Confidence: 0.8816699

00:16:26.604 --> 00:16:27.060 particularly,

NOTE Confidence: 0.8816699

 $00:16:27.060 \longrightarrow 00:16:30.070$  many of the tumors we discussed are

 $00{:}16{:}33.510 \dashrightarrow 00{:}16{:}35.660$  even much rarer than leukemia,

NOTE Confidence: 0.8816699

 $00:16:35.660 \longrightarrow 00:16:38.279$  which is already

NOTE Confidence: 0.8816699

 $00:16:38.280 \longrightarrow 00:16:38.966$  pretty uncommon.

 $00:16:39.310 \longrightarrow 00:16:41.446$  And I'm sure that every parent

 $00:16:41.446 \longrightarrow 00:16:43.258$  out there thinks that their

NOTE Confidence: 0.98617375

 $00:16:43.258 \longrightarrow 00:16:45.136$  child is one in a million,

NOTE Confidence: 0.98617375

 $00:16:45.140 \longrightarrow 00:16:46.600$  but really wouldn't want their

NOTE Confidence: 0.98617375

 $00:16:46.600 \longrightarrow 00:16:49.375$  child to be one in a million in

NOTE Confidence: 0.98617375

 $00:16:49.375 \longrightarrow 00:16:50.626$  this particular circumstance.

NOTE Confidence: 0.98617375

 $00:16:50.630 \longrightarrow 00:16:53.087$  And one of the

NOTE Confidence: 0.98617375

 $00:16:53.087 \longrightarrow 00:16:54.739$  questions that comes up and

NOTE Confidence: 0.98617375

 $00{:}16{:}54.740 \dashrightarrow 00{:}16{:}56.868$  you mentioned that you had an

NOTE Confidence: 0.98617375

00:16:56.868 --> 00:16:58.860 interest in clinical trials,

NOTE Confidence: 0.98617375

 $00:16:58.860 \longrightarrow 00:17:00.380$  especially in rare tumors,

NOTE Confidence: 0.98617375

 $00:17:00.380 \longrightarrow 00:17:03.505$  is that so much of the data that

NOTE Confidence: 0.98617375

 $00:17:03.505 \longrightarrow 00:17:06.165$  we get that leads to best practice

NOTE Confidence: 0.98617375

 $00{:}17{:}06.165 \dashrightarrow 00{:}17{:}09.044$  that dictates how we treat cancer

NOTE Confidence: 0.98617375

 $00:17:09.044 \longrightarrow 00:17:10.976$  comes from clinical trials.

NOTE Confidence: 0.98617375

 $00:17:10.980 \longrightarrow 00:17:13.766$  And when you have these tumors that

00:17:13.766 --> 00:17:17.256 are so rare that are one in a million,

NOTE Confidence: 0.98617375

00:17:17.260 --> 00:17:19.900 how on Earth do we get the data

NOTE Confidence: 0.98617375

 $00{:}17{:}19.900 \dashrightarrow 00{:}17{:}22.029$  to actually know what's best

NOTE Confidence: 0.98617375

00:17:22.029 --> 00:17:24.334 practice to treat our children,

NOTE Confidence: 0.98617375

00:17:24.340 --> 00:17:27.084 and for every parent going through this,

NOTE Confidence: 0.98617375

 $00:17:27.090 \longrightarrow 00:17:29.834$  I mean that is their deepest anxiety.

NOTE Confidence: 0.9725143

 $00:17:31.160 \longrightarrow 00:17:34.088$  That's a very good point

NOTE Confidence: 0.9725143

00:17:34.088 --> 00:17:38.385 and I think what I must say is that in

NOTE Confidence: 0.9725143

 $00{:}17{:}38.385 \dashrightarrow 00{:}17{:}41.222$  pediatric oncology we have honestly and I

NOTE Confidence: 0.9725143

00:17:41.222 --> 00:17:44.596 am not taking all the any credit for this,

NOTE Confidence: 0.9725143

 $00{:}17{:}44.596 \dashrightarrow 00{:}17{:}47.734$  but we have done an amazing job at

NOTE Confidence: 0.9725143

 $00:17:47.734 \longrightarrow 00:17:50.164$  being able to conduct clinical trials

NOTE Confidence: 0.9725143

 $00:17:50.164 \longrightarrow 00:17:53.448$  and the way we've done this is through

NOTE Confidence: 0.9725143

00:17:53.448 --> 00:17:55.438 the development of a consortium

NOTE Confidence: 0.9725143

00:17:55.438 --> 00:17:57.428 called the Children's Oncology Group,

NOTE Confidence: 0.9725143

 $00:17:57.430 \longrightarrow 00:17:59.605$  which really has about 230

 $00:17:59.605 \longrightarrow 00:18:01.345$  institutions across the United States,

NOTE Confidence: 0.9725143

 $00{:}18{:}01.350 \dashrightarrow 00{:}18{:}04.255$  Australia, New Zealand and Canada

NOTE Confidence: 0.9725143

 $00:18:04.255 \longrightarrow 00:18:08.068$  and the beauty of this is that

NOTE Confidence: 0.9725143

 $00:18:08.068 \longrightarrow 00:18:10.480$  as a group then we can,

NOTE Confidence: 0.9725143

 $00:18:10.480 \longrightarrow 00:18:12.340$  because each individual

NOTE Confidence: 0.9725143

 $00:18:12.340 \longrightarrow 00:18:14.820$  institution will only have

NOTE Confidence: 0.9725143

00:18:14.820 --> 00:18:17.142 a patient very rarely with a

NOTE Confidence: 0.9725143

00:18:17.142 --> 00:18:18.690 particular type of cancer,

NOTE Confidence: 0.9725143

 $00:18:18.690 \longrightarrow 00:18:21.786$  we can bring all of us together,

NOTE Confidence: 0.9725143

 $00{:}18{:}21.790 \dashrightarrow 00{:}18{:}23.932$  and we can then get the numbers to

NOTE Confidence: 0.9725143

 $00:18:23.932 \longrightarrow 00:18:26.403$  be able to conduct a clinical

NOTE Confidence: 0.9725143

00:18:26.403 --> 00:18:28.367 trial and more importantly,

NOTE Confidence: 0.9725143

 $00{:}18{:}28.370 \dashrightarrow 00{:}18{:}30.315$  conduct some randomized clinical trials

NOTE Confidence: 0.9725143

 $00:18:30.315 \longrightarrow 00:18:33.340$  to be able to answer the question of

NOTE Confidence: 0.9725143

 $00:18:33.340 \longrightarrow 00:18:35.699$  which treatment is the best and most

 $00:18:35.769 \longrightarrow 00:18:38.039$  appropriate for these rare cancers.

NOTE Confidence: 0.9725143

 $00:18:38.040 \longrightarrow 00:18:40.332$  So the children's Oncology Group has

NOTE Confidence: 0.9725143

 $00:18:40.332 \longrightarrow 00:18:43.140$  existed for a while and we

NOTE Confidence: 0.9725143

00:18:43.140 --> 00:18:45.145 have designed clinical trials

NOTE Confidence: 0.9725143

 $00:18:45.150 \longrightarrow 00:18:47.436$  on each type of pediatric cancer,

NOTE Confidence: 0.9725143

00:18:47.440 --> 00:18:49.305 but more recently what is happening

NOTE Confidence: 0.9725143

 $00:18:49.305 \longrightarrow 00:18:51.630$  that I am very

 $00:18:52.218 \longrightarrow 00:18:55.667$  happy to be involved with is that we are now

NOTE Confidence: 0.9725143

 $00{:}18{:}55.667 \dashrightarrow 00{:}18{:}57.715$  looking at international collaborations.

NOTE Confidence: 0.9725143

 $00{:}18{:}57.720 \dashrightarrow 00{:}19{:}00.331$  So for example in germ cell tumors

NOTE Confidence: 0.9725143

 $00:19:00.331 \dashrightarrow 00:19:02.766$  because germ cell tumors are again so

NOTE Confidence: 0.9725143

00:19:02.766 --> 00:19:05.583 rare even in the US and Canada and

NOTE Confidence: 0.9725143

 $00:19:05.583 \longrightarrow 00:19:08.253$  Australia we cannot have the appropriate

NOTE Confidence: 0.9725143

 $00:19:08.253 \longrightarrow 00:19:10.622$  numbers to do a randomized trial.

NOTE Confidence: 0.9725143

 $00:19:10.622 \longrightarrow 00:19:13.340$  So currently we are conducting two trials,

NOTE Confidence: 0.9725143

 $00:19:13.340 \longrightarrow 00:19:15.520$  one for low risk and

 $00:19:15.520 \longrightarrow 00:19:16.645$  intermediate risk,

NOTE Confidence: 0.9725143

 $00:19:16.645 \longrightarrow 00:19:18.895$  and one for high risk.

 $00:19:20.380 \longrightarrow 00:19:22.230$  So we've collaborated with the

NOTE Confidence: 0.9725143

00:19:22.230 --> 00:19:24.150 UK with India with Australia,

NOTE Confidence: 0.9725143

 $00:19:24.150 \longrightarrow 00:19:26.400$  New Zealand and we are all

NOTE Confidence: 0.9725143

 $00:19:26.400 \longrightarrow 00:19:27.900$  running the same trials,

NOTE Confidence: 0.9725143

 $00:19:27.900 \longrightarrow 00:19:30.908$  so that again we can bring all this

NOTE Confidence: 0.9725143

00:19:30.908 --> 00:19:33.189 information together and be able to

NOTE Confidence: 0.9725143

 $00:19:33.189 \longrightarrow 00:19:35.014$  make advances for future patients.

 $00:19:35.396 \longrightarrow 00:19:36.148$  I think that's so critical.

NOTE Confidence: 0.95737374

 $00:19:38.020 \longrightarrow 00:19:40.716$  You know one of the issues that we

NOTE Confidence: 0.95737374

00:19:40.716 --> 00:19:43.296 face in a dult tumors, however, is,

NOTE Confidence: 0.95737374

 $00:19:43.296 \longrightarrow 00:19:46.400$  although all of us know that clinical trials

NOTE Confidence: 0.95737374

 $00:19:46.400 \longrightarrow 00:19:48.724$  are the drivers of improved care

NOTE Confidence: 0.95737374

 $00:19:48.730 \longrightarrow 00:19:50.728$  it's how we make practice

NOTE Confidence: 0.95737374

 $00:19:50.730 \longrightarrow 00:19:52.977$  changing discovery, is that still there is

NOTE Confidence: 0.95737374

 $00:19:52.977 \longrightarrow 00:19:55.694$  a reluctance on the part of some patients

 $00:19:55.694 \longrightarrow 00:19:57.384$  to participate in clinical trials.

NOTE Confidence: 0.95737374

 $00{:}19{:}57.390 \dashrightarrow 00{:}20{:}00.575$  So if you look across the board,

NOTE Confidence: 0.95737374

 $00:20:00.580 \longrightarrow 00:20:02.770$  our rate of clinical trial

NOTE Confidence: 0.95737374

 $00:20:02.770 \longrightarrow 00:20:05.280$  accrual is somewhere South of 5\%,

NOTE Confidence: 0.95737374

 $00:20:05.280 \longrightarrow 00:20:08.376$  and with children I mean I can imagine

NOTE Confidence: 0.95737374

00:20:08.376 --> 00:20:10.988 that parents have obvious anxiety when

NOTE Confidence: 0.95737374

00:20:10.988 --> 00:20:14.240 you talk about clinical trials,

NOTE Confidence: 0.95737374

 $00{:}20{:}14.240 \dashrightarrow 00{:}20{:}17.228$  but I understand that the rate

NOTE Confidence: 0.95737374

 $00:20:17.228 \longrightarrow 00:20:18.722$  is much higher for accrual

NOTE Confidence: 0.95737374

 $00:20:18.730 \longrightarrow 00:20:20.640$  to these clinical trials.

NOTE Confidence: 0.95510423

00:20:20.640 --> 00:20:22.920 Honestly in Pediatrics,

NOTE Confidence: 0.95510423

00:20:22.920 --> 00:20:24.830 the rate is significantly higher,

NOTE Confidence: 0.95510423

 $00{:}20{:}24.830 \dashrightarrow 00{:}20{:}27.493$  and I think part of the reason

NOTE Confidence: 0.95510423

 $00:20:27.493 \longrightarrow 00:20:30.920$  at least at Yale,

NOTE Confidence: 0.95510423

00:20:30.920 --> 00:20:33.968 of all the patients eligible for a trial,

 $00:20:33.970 \longrightarrow 00:20:34.724$  because sometimes,

NOTE Confidence: 0.95510423

 $00{:}20{:}34.724 \dashrightarrow 00{:}20{:}37.740$  of course a trial may not be available

NOTE Confidence: 0.95510423

 $00:20:37.816 \longrightarrow 00:20:40.066$  for that particular type of tumor.

NOTE Confidence: 0.95510423

00:20:40.070 --> 00:20:41.970 But for any eligible patient,

NOTE Confidence: 0.95510423

 $00:20:41.970 \longrightarrow 00:20:45.023$  we enroll up to 80% of the children

NOTE Confidence: 0.95510423

00:20:45.023 --> 00:20:47.309 who are eligible for a trial.

NOTE Confidence: 0.95510423

 $00:20:47.310 \longrightarrow 00:20:50.054$  When you're taking care of

NOTE Confidence: 0.95510423

 $00:20:50.060 \longrightarrow 00:20:51.950$  your child, who has cancer

NOTE Confidence: 0.95510423

 $00:20:51.950 \longrightarrow 00:20:54.484$  I think the motivation from the parents

NOTE Confidence: 0.95510423

 $00:20:54.484 \longrightarrow 00:20:56.803$  is very different than maybe

NOTE Confidence: 0.95510423

 $00:20:56.803 \longrightarrow 00:20:58.748$  the motivation for yourself.

NOTE Confidence: 0.95510423

 $00:20:58.750 \longrightarrow 00:20:59.833$  I'm not sure,

NOTE Confidence: 0.95510423

 $00:20:59.833 \longrightarrow 00:21:01.999$  but clearly we all do go

NOTE Confidence: 0.95510423

 $00:21:01.999 \longrightarrow 00:21:04.418$  above and beyond for our kids.

NOTE Confidence: 0.95510423

 $00:21:04.420 \longrightarrow 00:21:06.310$  Then we probably even do

NOTE Confidence: 0.9755941

 $00:21:06.310 \longrightarrow 00:21:07.066$  for ourselves.

 $00:21:07.066 \longrightarrow 00:21:09.712$  And I think that that desire

NOTE Confidence: 0.9755941

 $00:21:09.720 \longrightarrow 00:21:12.736$  to figure out the best treatment,

NOTE Confidence: 0.9755941

 $00:21:12.740 \longrightarrow 00:21:14.954$  especially when we're talking

NOTE Confidence: 0.9755941

 $00:21:14.954 \longrightarrow 00:21:17.279$  about rare diseases is so important.

NOTE Confidence: 0.9755941

 $00{:}21{:}17.280 \dashrightarrow 00{:}21{:}20.808$  And I think the other piece is that

NOTE Confidence: 0.9755941

 $00:21:20.810 \longrightarrow 00:21:22.562$  parents sometimes have trepidation

NOTE Confidence: 0.9755941

 $00:21:22.562 \longrightarrow 00:21:25.190$  about what is the

NOTE Confidence: 0.9755941

 $00:21:25.270 \longrightarrow 00:21:27.496$  right answer to treat my child,

NOTE Confidence: 0.9755941

00:21:27.500 --> 00:21:29.846 especially when all of these cancers

NOTE Confidence: 0.9755941

 $00{:}21{:}29.846 \dashrightarrow 00{:}21{:}32.368$  are so rare and clinical trials

NOTE Confidence: 0.9755941

00:21:32.368 --> 00:21:35.014 gives you some modicum of this

NOTE Confidence: 0.9755941

 $00:21:35.020 \longrightarrow 00:21:37.528$  actually might be best practice because,

NOTE Confidence: 0.9755941

 $00:21:37.530 \longrightarrow 00:21:38.655$  as you say,

NOTE Confidence: 0.9755941

 $00{:}21{:}38.655 \dashrightarrow 00{:}21{:}40.530$  all of these professionals get

NOTE Confidence: 0.9755941

 $00:21:40.530 \longrightarrow 00:21:42.958$  together in designing these trials,

00:21:42.960 --> 00:21:46.304 so they've put in that brain trust of,

NOTE Confidence: 0.9755941

 $00:21:46.310 \longrightarrow 00:21:49.052$  you know this is potentially best

NOTE Confidence: 0.9755941

 $00:21:49.052 \longrightarrow 00:21:51.660$  practice or best practice versus

NOTE Confidence: 0.9755941

 $00:21:51.660 \longrightarrow 00:21:54.316$  what best practice will be and we want to see

NOTE Confidence: 0.9755941

00:21:54.316 --> 00:21:57.136 which is best for patients who are

NOTE Confidence: 0.9755941

00:21:57.136 --> 00:21:59.708 not candidates for a clinical trial

NOTE Confidence: 0.9755941

 $00:21:59.708 \longrightarrow 00:22:02.613$  where there still may be

NOTE Confidence: 0.9755941

 $00:22:02.613 \longrightarrow 00:22:05.422$  questions about what is best practice.

NOTE Confidence: 0.9755941

 $00{:}22{:}05.422 \dashrightarrow 00{:}22{:}08.380$  How do you reassure patients and parents

NOTE Confidence: 0.9755941

 $00:22:08.468 \longrightarrow 00:22:11.359$  that this really is

NOTE Confidence: 0.9755941

 $00:22:11.360 \longrightarrow 00:22:13.500$  the way to go?

 $00{:}22{:}14.330 \to 00{:}22{:}16.820$  Are there still collaborations where you

NOTE Confidence: 0.9755941

 $00:22:16.820 \longrightarrow 00:22:19.916$  get together with a consensus,

NOTE Confidence: 0.9755941

 $00{:}22{:}19.920 \dashrightarrow 00{:}22{:}21.604$  either nationally or internationally,

NOTE Confidence: 0.9755941

 $00:22:21.604 \longrightarrow 00:22:24.628$  to figure out what might be best

NOTE Confidence: 0.9755941

 $00:22:24.628 \longrightarrow 00:22:26.340$  practice for these patients?

 $00:22:26.770 \longrightarrow 00:22:29.584$  Absolutely. I think one thing

 $00:22:29.584 \longrightarrow 00:22:32.641$  is that the best practice is obviously

NOTE Confidence: 0.92648417

 $00:22:32.641 \longrightarrow 00:22:35.860$  the standard of care in many cases.

NOTE Confidence: 0.92648417

 $00:22:35.860 \longrightarrow 00:22:38.242$  But in many cases there is

NOTE Confidence: 0.92648417

00:22:38.242 --> 00:22:40.330 no proper standard of care,

NOTE Confidence: 0.92648417

00:22:40.330 --> 00:22:43.501 but the beauty again of having these

NOTE Confidence: 0.92648417

 $00:22:43.501 \longrightarrow 00:22:45.560$  close collaborations working together

NOTE Confidence: 0.92648417

 $00:22:45.560 \longrightarrow 00:22:48.150$  on trials means that we have a

NOTE Confidence: 0.92648417

 $00:22:48.150 \longrightarrow 00:22:50.099$  really great phenomenal community of

NOTE Confidence: 0.92648417

 $00:22:50.099 \longrightarrow 00:22:52.780$  oncologists that you can call upon to

NOTE Confidence: 0.92648417

00:22:52.780 --> 00:22:54.988 discuss and get guidance on in

NOTE Confidence: 0.92648417

 $00:22:54.988 \longrightarrow 00:22:56.960$  really rare cases.

NOTE Confidence: 0.92648417

 $00:22:56.960 \longrightarrow 00:22:59.730$  So I think that is a really

NOTE Confidence: 0.92648417

 $00{:}22{:}59.810 \dashrightarrow 00{:}23{:}02.690$  fulfilling part of being able to

NOTE Confidence: 0.92648417

 $00{:}23{:}02.690 \dashrightarrow 00{:}23{:}05.052$  connect with friends and colleagues across

NOTE Confidence: 0.92648417

 $00:23:05.052 \longrightarrow 00:23:07.621$  the country, across the world to be

00:23:07.621 --> 00:23:09.880 able to discuss some difficult cases.

NOTE Confidence: 0.92648417

 $00{:}23{:}09.880 \to 00{:}23{:}12.880$  What is really fun is

NOTE Confidence: 0.92648417

 $00:23:12.880 \longrightarrow 00:23:15.660$  we've now developed these virtual

NOTE Confidence: 0.92648417

00:23:15.660 --> 00:23:16.707 International tumor boards

NOTE Confidence: 0.92648417

00:23:16.707 --> 00:23:19.150 for some of these really rare cancers,

NOTE Confidence: 0.92648417

 $00{:}23{:}19.150 \dashrightarrow 00{:}23{:}21.243$  so we have an international tumor board

NOTE Confidence: 0.92648417

 $00:23:21.243 \longrightarrow 00:23:22.990$  for patients with hepatoblastoma,

NOTE Confidence: 0.92648417

 $00:23:22.990 \longrightarrow 00:23:24.845$  where experts from across the

NOTE Confidence: 0.92648417

 $00{:}23{:}24.845 \dashrightarrow 00{:}23{:}27.301$  country meet once a month and you

NOTE Confidence: 0.92648417

 $00:23:27.301 \longrightarrow 00:23:29.405$  can put in a case and they will

NOTE Confidence: 0.92648417

 $00{:}23{:}29.479 \dashrightarrow 00{:}23{:}31.709$  review everything and discuss it,

NOTE Confidence: 0.92648417

 $00:23:31.710 \longrightarrow 00:23:34.860$  just like we do at a local tumor board.

NOTE Confidence: 0.92648417

00:23:34.860 --> 00:23:35.187 Similarly,

NOTE Confidence: 0.92648417

 $00:23:35.187 \longrightarrow 00:23:37.476$  we have a rare tumor board

NOTE Confidence: 0.92648417

 $00:23:37.476 \longrightarrow 00:23:39.389$  which is across the country,

NOTE Confidence: 0.92648417

 $00:23:39.390 \longrightarrow 00:23:40.110$  so again,

 $00:23:40.110 \longrightarrow 00:23:43.461$  people do go above and beyond to try and

NOTE Confidence: 0.92648417

 $00{:}23{:}43.461 \dashrightarrow 00{:}23{:}46.525$  put in their time and effort to bring their

NOTE Confidence: 0.92648417

 $00:23:46.530 \longrightarrow 00:23:48.720$  thoughts and their experience to help

NOTE Confidence: 0.92648417

00:23:48.720 --> 00:23:50.839 kids across the country and across

NOTE Confidence: 0.98801035

 $00:23:50.840 \longrightarrow 00:23:53.790$  the world.

NOTE Confidence: 0.98801035

00:23:53.869 --> 00:23:56.575 I love the fact that there is such humility

NOTE Confidence: 0.98801035

00:23:56.580 --> 00:23:59.022 among pediatric oncologists to

NOTE Confidence: 0.98801035

 $00:23:59.022 \longrightarrow 00:24:01.609$  really collaborate with each other and to

NOTE Confidence: 0.98801035

 $00{:}24{:}01.609 \dashrightarrow 00{:}24{:}04.120$  figure out what's the best for this child.

NOTE Confidence: 0.98801035

 $00:24:04.120 \longrightarrow 00:24:06.850$  Which is so important and so

NOTE Confidence: 0.98801035

 $00{:}24{:}06.850 \to 00{:}24{:}09.450$  hear tening for parents going through this.

NOTE Confidence: 0.98801035

 $00:24:09.450 \longrightarrow 00:24:12.114$  Now I did promise that we'd

NOTE Confidence: 0.98801035

 $00{:}24{:}12.114 \dashrightarrow 00{:}24{:}14.783$  spend at least a few minutes

NOTE Confidence: 0.98801035

00:24:14.783 --> 00:24:17.178 talking about your other passion,

NOTE Confidence: 0.98801035

 $00:24:17.180 \longrightarrow 00:24:19.586$  which is sickle cell disease and

00:24:19.586 --> 00:24:22.069 sickle cell disease is still rare,

NOTE Confidence: 0.98801035

00:24:22.070 --> 00:24:23.698 but presumably less rare

NOTE Confidence: 0.98801035

 $00:24:23.698 \longrightarrow 00:24:24.919$  than pediatric cancers.

NOTE Confidence: 0.98801035

 $00:24:24.920 \longrightarrow 00:24:27.440$  Is that right?

NOTE Confidence: 0.9396146

 $00:24:27.440 \longrightarrow 00:24:30.840$  I think it is rarer than pediatric cancers,

NOTE Confidence: 0.9396146

 $00:24:30.840 \longrightarrow 00:24:33.416$  and in the US now with

NOTE Confidence: 0.9396146

00:24:33.416 --> 00:24:35.959 also a changing demographic,

NOTE Confidence: 0.9396146

 $00:24:35.960 \longrightarrow 00:24:38.655$  we have patients of many

NOTE Confidence: 0.9396146

00:24:38.655 --> 00:24:40.811 different ethnicities who can

NOTE Confidence: 0.9396146

 $00:24:40.811 \longrightarrow 00:24:44.009$  also have sickle cell disease so

NOTE Confidence: 0.9396146

 $00{:}24{:}44.010 \dashrightarrow 00{:}24{:}47.405$  it's definitely something that we

NOTE Confidence: 0.9396146

 $00:24:47.410 \longrightarrow 00:24:50.874$  in Connecticut see 24 to 26 new

NOTE Confidence: 0.9396146

 $00{:}24{:}50.874 \dashrightarrow 00{:}24{:}53.387$  diagnoses of sickle cell disease

NOTE Confidence: 0.9396146

 $00:24:53.387 \longrightarrow 00:24:56.999$  each year and about 600 new patients

NOTE Confidence: 0.9396146

 $00:24:57.098 \longrightarrow 00:25:00.050$  with sickle cell trait per year.

 $00:25:07.210 \longrightarrow 00:25:09.554$  Talk a little

 $00:25:09.554 \longrightarrow 00:25:11.998$  bit about sickle cell disease and

NOTE Confidence: 0.98500466

 $00{:}25{:}11.998 \dashrightarrow 00{:}25{:}14.429$  the problems that people can run into.

NOTE Confidence: 0.98500466

 $00:25:14.430 \longrightarrow 00:25:16.719$  I mean, when people think about cancer,

NOTE Confidence: 0.98500466

 $00:25:16.720 \longrightarrow 00:25:19.107$  you really don't need to say anything

NOTE Confidence: 0.98500466

00:25:19.107 --> 00:25:21.639 more than cancer for it to strike

NOTE Confidence: 0.98500466

 $00:25:21.639 \longrightarrow 00:25:23.940$  the fear of God into some people.

NOTE Confidence: 0.98500466

00:25:23.940 --> 00:25:26.190 But what problems do people with

NOTE Confidence: 0.98500466

 $00:25:26.190 \longrightarrow 00:25:28.442$  sickle cell disease run into that

NOTE Confidence: 0.98500466

 $00{:}25{:}28.442 \dashrightarrow 00{:}25{:}30.488$  are problematic and talk a

NOTE Confidence: 0.98500466

 $00:25:30.488 \longrightarrow 00:25:32.886$  little bit about some of the new

NOTE Confidence: 0.98500466

 $00:25:32.886 \longrightarrow 00:25:34.526$  therapies that are out now?

NOTE Confidence: 0.9453884

 $00:25:37.170 \longrightarrow 00:25:39.810$  So sickle cell disease

NOTE Confidence: 0.9453884

 $00:25:39.810 \longrightarrow 00:25:42.010$  interestingly, is the first single

NOTE Confidence: 0.9453884

 $00:25:42.010 \longrightarrow 00:25:44.210$  gene disorder that was described

NOTE Confidence: 0.9453884

 $00:25:44.210 \longrightarrow 00:25:48.170$  over 120 years ago.

 $00:25:49.334 \longrightarrow 00:25:52.050$  It is a lifelong chronic disease that

00:25:52.127 --> 00:25:54.863 obviously you inherit from your parents

NOTE Confidence: 0.9453884

 $00{:}25{:}54.863 \dashrightarrow 00{:}25{:}58.289$  and the hallmarks of sickle cell disease

NOTE Confidence: 0.9453884

 $00:25:58.290 \longrightarrow 00:26:01.810$  are these painful crises,

NOTE Confidence: 0.9453884

 $00:26:01.810 \longrightarrow 00:26:04.065$  which really mean that patients

NOTE Confidence: 0.9453884

 $00:26:04.065 \longrightarrow 00:26:05.869$  with sickle cell disease

NOTE Confidence: 0.9453884

00:26:05.870 --> 00:26:09.134 can come into the hospital or have pain

NOTE Confidence: 0.9453884

 $00{:}26{:}09.134 \dashrightarrow 00{:}26{:}12.560$  at home several times a year.

NOTE Confidence: 0.9453884

 $00:26:12.560 \longrightarrow 00:26:15.038$  These chronic VS occlusive crises can

NOTE Confidence: 0.9453884

 $00{:}26{:}15.038 \dashrightarrow 00{:}26{:}17.750$  also lead to multiple complications,

NOTE Confidence: 0.9453884

 $00:26:17.750 \longrightarrow 00:26:20.576$  including stroke

NOTE Confidence: 0.9453884

 $00:26:20.580 \longrightarrow 00:26:23.884$  and acute chest syndrome.

NOTE Confidence: 0.9453884

 $00:26:28.810 \longrightarrow 00:26:32.430$  You can also have a lot of long term chronic

NOTE Confidence: 0.9453884

00:26:32.514 --> 00:26:35.556 morbidity because of this ongoing

NOTE Confidence: 0.9453884

 $00:26:35.560 \longrightarrow 00:26:37.248$  microvascular occlusion that happens in

NOTE Confidence: 0.9453884

 $00:26:37.248 \longrightarrow 00:26:38.936$  all your organ systems.

NOTE Confidence: 0.9453884

 $00:26:38.940 \longrightarrow 00:26:41.649$  So patients with sickle cell disease can

00:26:41.649 --> 00:26:44.848 have long term problems with their kidneys,

NOTE Confidence: 0.9453884

 $00:26:44.850 \longrightarrow 00:26:46.454$  leading to sickle nephropathy.

NOTE Confidence: 0.9453884

00:26:46.454 --> 00:26:48.860 They can have problems with their

NOTE Confidence: 0.9453884

00:26:48.924 --> 00:26:51.179 liver leading to sickle hepatopathy.

NOTE Confidence: 0.9453884

00:26:51.180 --> 00:26:53.290 They can have sickle retinopathy,

NOTE Confidence: 0.9453884

 $00:26:53.290 \longrightarrow 00:26:55.996$  so it's a disease which has

NOTE Confidence: 0.9453884

 $00:26:55.996 \longrightarrow 00:26:57.800$  acute complications which brings

NOTE Confidence: 0.9453884

 $00:26:57.876 \longrightarrow 00:26:59.680$  someone to the hospital.

NOTE Confidence: 0.9453884

 $00:26:59.680 \longrightarrow 00:27:02.865$  But also has ongoing long term chronic

NOTE Confidence: 0.9453884

 $00:27:02.865 \longrightarrow 00:27:05.672$  disease burden which continues to affect

NOTE Confidence: 0.9453884

 $00{:}27{:}05.672 \dashrightarrow 00{:}27{:}09.320$  pretty much every organ system in their body.

NOTE Confidence: 0.9453884

 $00:27:09.320 \longrightarrow 00:27:13.543$  So it is a disease

NOTE Confidence: 0.9453884

 $00:27:13.543 \longrightarrow 00:27:17.575$  where you have to pay attention to

NOTE Confidence: 0.9453884

00:27:17.580 --> 00:27:20.340 obviously the acute management during pain,

NOTE Confidence: 0.9453884

 $00:27:20.340 \longrightarrow 00:27:21.256$  crisis, stroke,

00:27:21.256 --> 00:27:23.015 acute chest syndrome, etc.

NOTE Confidence: 0.9453884

 $00{:}27{:}23.015 \dashrightarrow 00{:}27{:}26.480$  but you also have to take care of these

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 $00:27:26.571 \longrightarrow 00:27:30.249$  adults and children for preventative care.

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00:27:30.250 --> 00:27:32.861 To make sure that you are monitoring

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 $00:27:32.861 \longrightarrow 00:27:35.620$  for these long term complications and

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 $00:27:35.620 \longrightarrow 00:27:38.225$  you are intervening when feasible.

 $00:27:38.622 \longrightarrow 00:27:41.758$  But the good part about sickle

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00:27:41.758 --> 00:27:44.619 cell disease or the exciting part

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 $00:27:44.619 \longrightarrow 00:27:48.141$  currently is that we have a lot of new

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 $00{:}27{:}48.141 \dashrightarrow 00{:}27{:}50.382$  the rapies which have come about in

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 $00:27:50.382 \longrightarrow 00:27:53.518$  order to improve not only the pain crises,

 $00:27:54.489 \longrightarrow 00:27:56.427$  the FDA has now approved several

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00:27:56.427 --> 00:27:58.610 new drugs besides hydroxyurea,

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00:27:58.610 --> 00:28:00.969 which was the only drug available for

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 $00:28:00.969 \longrightarrow 00:28:03.709$  a long time to

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 $00:28:03.710 \longrightarrow 00:28:06.314$  modify sickle cell disease and the

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 $00:28:06.314 \longrightarrow 00:28:08.620$  most exciting thing really is the

00:28:08.620 --> 00:28:10.360 advent of bone marrow transplant,

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 $00{:}28{:}10.360 \dashrightarrow 00{:}28{:}12.622$  which is currently the only curative

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00:28:12.622 --> 00:28:14.834 option for sickle cell disease but

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00:28:14.834 --> 00:28:17.074 also gene therapy and many of you

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00:28:17.074 --> 00:28:19.406 might have seen data on gene therapy,

 $00{:}28{:}20.349 \dashrightarrow 00{:}28{:}22.540$  some case reports of gene the rapy for

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 $00{:}28{:}22.606 \dashrightarrow 00{:}28{:}24.712$  sickle cell disease which is exciting

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 $00:28:24.712 \longrightarrow 00:28:27.285$  and we are looking forward to that

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 $00{:}28{:}27.285 \dashrightarrow 00{:}28{:}29.499$  becoming more streamlined in the next

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 $00:28:29.500 \longrightarrow 00:28:31.366$  few years.

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 $00:28:31.366 \longrightarrow 00:28:33.416$  Dr. Pashankar is an associate professor of

NOTE Confidence: 0.9662784

00:28:33.416 --> 00:28:34.912 Pediatrics in hematology oncology

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00:28:34.912 --> 00:28:37.159 at the Yale School of Medicine.

NOTE Confidence: 0.9662784

 $00:28:37.160 \longrightarrow 00:28:38.692$  If you have questions

NOTE Confidence: 0.9662784

 $00:28:38.692 \longrightarrow 00:28:40.224$  the address is canceranswers@yale.edu

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 $00:28:40.224 \longrightarrow 00:28:42.342$  and past editions of the program

 $00:28:42.342 \longrightarrow 00:28:44.274$  are available in audio and written

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 $00{:}28{:}44.337 \dashrightarrow 00{:}28{:}45.948$  form at yale cancercenter.org.

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00:28:45.950 --> 00:28:48.422 We hope you'll join us next week to

NOTE Confidence: 0.9662784

 $00{:}28{:}48.422 \dashrightarrow 00{:}28{:}50.800$  learn more about the fight against

NOTE Confidence: 0.9662784

 $00:28:50.800 \longrightarrow 00:28:52.915$  cancer here on Connecticut Public

NOTE Confidence: 0.9662784

 $00{:}28{:}52.915 \dashrightarrow 00{:}28{:}55.020$  radio. Funding for Yale Cancer

NOTE Confidence: 0.9662784

00:28:55.020 --> 00:28:57.035 Answers is provided by Smilow

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 $00{:}28{:}57.035 \dashrightarrow 00{:}29{:}00.072$  Cancer Hospital and Astra Zeneca.