

IN THE COURT OF COMMON PLEAS
PHILADELPHIA COUNTY

- - -

MICHAEL J. PULASKI,	:	August term, 2013
Individually and as	:	
Administrator of the Estate	:	
of SARAH PULASKI, Deceased,	:	
and RENE PARADIS,	:	
Plaintiffs,	:	
	:	
-vs.-	:	
	:	
CHILDREN'S HOSPITAL OF	:	
PHILADELPHIA, ET AL.,	:	
Defendants.	:	No. 002504

- - -

Wednesday, January 21, 2015

- - -

Videotaped deposition of MICHAEL PULASKI, taken pursuant to notice, was held at WHITE AND WILLIAMS LLP, 1650 Market Street, Suite 1800, Philadelphia, Pennsylvania 19103, commencing at 10:04 a.m., on the above date, before Jared Carey, a Professional Reporter and Notary Public in and for the Commonwealth of Pennsylvania.

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16 ALSO PRESENT:

17 Rosemary R. Schnall, Esquire
18 Jason W. Poore, Esquire
19 Phillip Roller - Videographer
20
21
22
23
24

1 I N D E X

2 WITNESS PAGE
3 MICHAEL J. PULASKI
4 BY: MR. CASSIDY 5
5 MR. SUSKO 7, 23
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7 E X H I B I T S

8 MARKED DESCRIPTION PAGE
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10 MP-2 Progress record 45
11 MP-3 4/22/10 email 71
12 MP-4 Clinician note 6/4/10 78
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1 DEPOSITION SUPPORT INDEX

2

3 Direction to Witness Not to Answer

4 Page Line Page Line Page Line

5 None

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8 Request for Production of Documents

9 Page Line Page Line Page Line

10 None

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12

13 Stipulations

14 Page Line Page Line Page Line

15 None

16

17

18 Question Marked

19 Page Line Page Line Page Line

20 None

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22

23

24

1 - - -

2 MICHAEL J. PULASKI, having been
3 duly sworn, was examined and testified as follows:

4 - - -

5 EXAMINATION

6 - - -

7 BY MR. CASSIDY:

8 Q Mr. Pulaski, we are here for your
9 deposition this morning. Did you bring some
10 documents and a computer disk with you to give
11 those documents and disk to counsel so that they
12 will have them as supplemental discovery?

13 A I did.

14 Q Could you tell the reporter and
15 counsel what documents you have here and what is
16 on the computer disk.

17 A I was asked to go through our
18 emails and my home computer and gather any of the
19 emails that were relevant to the case, you know,
20 emails between us and the doctors, emails between
21 us and friends regarding Sarah's treatment. So I
22 put that in two files. The first file was between
23 us and the doctors. The second file was between
24 us and friends. All of them relating generally to

1 Sarah's care.

2 So I printed them out. I will be
3 honest with you. My printer is not that fast. So
4 this isn't the greatest copy. You might want to
5 run a copy yourself. I did put them both on the
6 disk. And Bruce asked if I could bring my
7 daughter's journal, which I did. So there is not
8 a lot in it. But there is some.

9 Q And the last thing you mentioned
10 was that you brought two of Sarah's journals with
11 you to the deposition?

12 A Yes.

13 Q And then we had a Xerox copy of
14 those journals made for counsel.

15 A Okay.

16 MR. CASSIDY: Counsel, I'd ask
17 counsel to accept this as supplemental
18 discovery.

19 MR. SUSKO: Okay. So thank you.
20 And let me just ask a couple of questions --
21 off the record.

22 (Discussion held off the record.)

23 - - -

24 EXAMINATION

1 - - -

2 BY MR. SUSKO:

3 Q Let me ask a couple questions
4 before we get started. And with regard to the
5 testimony you just gave we had been provided
6 before today's deposition with some what I
7 understand to be emails between you and your wife
8 and medical doctors and care providers at CHOP as
9 well as emails to friends and family as well as
10 postings, I'll call them. But I will let you
11 identify them at some point.

12 A Okay.

13 Q Is what you produced today other
14 than Sarah's journals supplementary to that,
15 meaning you haven't produced it before? Or is
16 there some overlap or is it the same thing you
17 produced before?

18 A There is probably overlap. So what
19 I do is I went back and found old files that I
20 hadn't looked at and found some emails from my
21 wife that I wasn't aware were there. So I added
22 them to the files. So there is definitely more
23 here than you had in the past.

24 Q I was just trying to get that

1 clarified. And then as I also understand it with
2 regard to emails that you were looking for
3 relating to communications between you and your
4 wife and medical doctors and health care providers
5 at CHOP, those emails start at I believe September
6 I want to say 7th -- but sometime in September
7 of 2010 -- and then ran into 2011. But there were
8 no emails before September 2010. So I was
9 wondering do you know whether you were able to
10 locate any email communications between CHOP
11 doctors and you and your wife before September?

12 A Yes.

13 Q I certainly want to look at those
14 at a break. I guess we can stay off the videotape
15 record. So, Mr. Pulaski, did you receive a Notice
16 of Deposition from us --

17 MR. CASSIDY: I don't think --

18 MR. SUSKO: -- through your lawyer?

19 MR. CASSIDY: I don't think he
20 received it. I just told him his deposition
21 was today. I received the notice.

22 MR. SUSKO: Then I know that there
23 was a letter stating objections to the notice
24 itself. Let me just --

1 MR. CASSIDY: And there were
2 telephone conversations after the letter was
3 transmitted.

4 BY MR. SUSKO:

5 Q So, Mr. Pulaski, emails between
6 CHOP doctors and/or health care providers and you
7 and your wife or anyone else relating to Sarah
8 predating September 7th is what I have. But
9 predating -- let's pick a date -- September 30.
10 And I know you gave us some emails relating to
11 them before. But have you now searched for emails
12 predating September 30, 2010 between CHOP health
13 care providers and you and your wife and anyone
14 else relating to your daughter's care? Have you
15 made a search for those and produced everything
16 that you have found?

17 A I have made a search. I produced
18 everything I have found to date. And I will
19 continue to search.

20 MR. CASSIDY: The only thing -- and
21 he may not know this. But I wanted to put it
22 on the record. Andy, there were some emails
23 between him and my office and Dr. Sanders,
24 which I redacted. I just pulled them out. I

1 haven't read them all yet. But I would
2 believe they have to do with work product.
3 They exist separate from the emails which
4 have been provided so far.

5 BY MR. SUSKO:

6 Q Back to your last answer and the
7 question that I was asking was are you -- let me
8 ask it this way. Are you aware as you are sitting
9 here today of any additional emails between you,
10 your wife and anyone else and CHOP health care
11 providers -- when I'm saying anyone else, anyone
12 else on your behalf because there was some friends
13 you were communicating with too. I'll call them
14 people supporting you or advocating for you.

15 But are there any other emails in
16 that timeframe from the beginning of Sarah's care
17 to September 30, 2010 that you think exist that
18 you just haven't been able to locate?

19 A Yes.

20 Q So even though you've searched and
21 produced some of the emails you think there are
22 others that you have not been able to yet locate?

23 A I am 100 percent sure of that.

24 Q And are you able to give me an

1 approximation, your best approximation, of how
2 many emails that would be? We talking about a
3 half dozen, twenty, fifty? What are we talking
4 about?

5 A At a minimum forty to fifty.

6 Q That have not yet been located?

7 A I would hope that you could locate
8 them because they should be on CHOP servers.

9 Q We have made an effort to do that
10 and we've communicated to your counsel. And
11 apparently as I understand it they don't exist
12 prior to that -- to the time we are talking about.

13 MS. SCHNALL: Correct.

14 BY MR. SUSKO:

15 Q But in any event I just want to
16 focus on what you've searched for and what you
17 think exists that you don't have and have not yet
18 produced. So you think there are roughly, if you
19 had to estimate as best you could, understanding
20 there might be some margin of error, forty to
21 fifty emails that you have not yet been able to
22 locate?

23 A Probably.

24 Q And are you able to give testimony

1 about what you think the content of those emails
2 was back and forth?

3 A To a few of them absolutely.

4 Q Do you have specific emails in that
5 regard in mind as you are sitting here that you've
6 not been able to locate but you think are
7 important to the case that you would be able to
8 give detail about?

9 A One, yes.

10 Q And when was that email that you
11 are talking about approximately?

12 A Approximately July 10th, 2010.

13 Q And is that the time when you
14 contend you had a discussion where you requested
15 that your daughter be taken off study and given a
16 stem cell transplant?

17 A No.

18 Q I thought in the complaint you
19 allege that in July you made a request that your
20 daughter receive a stem cell transplant?

21 A That was late July, early August.
22 The email I'm referring to is earlier. I believe
23 it was around July 10th and it was regarding a
24 bone marrow aspirate that another doctor

1 requested.

2 Q Who was the other doctor that
3 requested the bone marrow aspirate?

4 A I apologize. I do not remember her
5 name completely.

6 Q A woman doctor?

7 A A woman doctor. Her first name is
8 Ann. Her last name is Leahy -- Laney -- Lane --

9 Q Is she at CHOP?

10 A She is a CHOP doctor. She is one
11 of the senior doctors in the clinic. She is also
12 a bone marrow transplant doctor.

13 MR. SUSKO: Why don't we -- I think
14 we are ready to go on the video. I didn't
15 realize we were going to get into such an
16 extended discussion. But I think we probably
17 ought to be on the record. Are you okay with
18 that?

19 MR. CASSIDY: I'm fine. I didn't
20 want to interrupt you while you were asking
21 questions. Any time you want to go on the
22 video is okay with me.

23 MR. SUSKO: Fair enough. Let me
24 just look because I think some of this -- let

1 me see if there's any other housekeeping. We
2 kind of went down that specific discussion.
3 But I wanted to see if there is anything
4 else.

5 BY MR. SUSKO:

6 Q Still off the video record. As
7 your attorney Mr. Cassidy referenced, there was a
8 request made that certain documents be produced in
9 conjunction with today's deposition. And one of
10 them is an email from Dr. Wood to the plaintiffs
11 dated 2/19/2011 referenced in answer to
12 interrogatory No. 31. Do you know if you brought
13 that here today with you?

14 A I'm not sure what email you are
15 referring to, sir.

16 Q I can't get any more specific than
17 that because we don't have the email other than
18 you referenced it in the Answers to
19 Interrogatories.

20 A What was the date?

21 Q The 2/19/2011.

22 A This is your copy. May I look at
23 this?

24 Q Sure. You are referencing now the

1 documents that you folks brought today to the
2 deposition?

3 A Yes. February 19, 2011?

4 Q Yes.

5 MR. CASSIDY: February 9th or 19th?

6 MR. SUSKO: 19th is what the letter
7 says. So I think that's -- meaning my
8 associate's letter.

9 BY MR. SUSKO:

10 Q Let's just -- suffice it to say you
11 don't know off the top of your head. And if it's
12 in there it's in there.

13 A I believe I know what email you are
14 referring to. And if I am correct in my
15 assumption then, yes, that email is in here.

16 Q And then any handwritten notes
17 memorializing conversations between the plaintiff
18 and the defendant that you referenced in answer to
19 interrogatory No. 32. And why don't we go off the
20 stenographic record.

21 (Discussion held off the record.)

22 BY MR. SUSKO:

23 Q While she is looking for that
24 document, I don't want to hold up the questioning,

1 but one of the other things we requested, I will
2 move on for now and we'll circle back to that, one
3 of the other things we asked for W-2s for
4 plaintiffs, meaning you and your wife, 2010
5 to 2013. Did you bring those today?

6 MR. CASSIDY: Andy, let me cut in
7 to save us some time.

8 MR. SUSKO: There is only one more
9 to cover and I'm going to cover so...

10 MR. CASSIDY: With regard to that
11 one I spoke the other day to Mr. Pulaski
12 about his wage loss situation. And based on
13 our conversation we're not going to put a
14 claim in that there was a wage or earning
15 loss by Mr. or Mrs. Pulaski as a result of
16 the care at CHOP.

17 MR. SUSKO: Okay.

18 MR. CASSIDY: So because we weren't
19 making the claim and because he didn't have
20 the tax documents available to bring and
21 would have to go get them from another
22 source, I told him not to go to any great
23 lengths to try to find those records
24 yesterday.

1 THE WITNESS: If you really need
2 them I can get them.

3 MR. SUSKO: I would say it would be
4 relevant on the daughter's, your deceased
5 daughter's, potential claim for loss of
6 future earnings, what the earning history of
7 the parents and educational attainment and
8 experience would be. And I do intend to get
9 into that.

10 MR. CASSIDY: We have no objection
11 to discussing all those things. I think that
12 Mike knows pretty much how much income he and
13 his wife make.

14 BY MR. SUSKO:

15 Q So the short answer is you did not
16 bring that today. There is reference to the notes
17 that the plaintiffs made regarding one of the
18 meetings where the consents, and I'm going to show
19 them to you shortly, were obtained. Did you bring
20 any notes from any meeting that you had with any
21 of the CHOP doctors relating to the consents to
22 enter this clinical trial and research study?

23 A I have those notes. I don't have
24 them with me.

1 MR. CASSIDY: Andy, with regard to
2 the February 19, 2011 email that you
3 referenced, I was looking through my file of
4 emails which have previously been exchanged.
5 And there is an email dated February 16,
6 2011. There is a few of them from Dr. Wood
7 to Mr. Pulaski and is also one of
8 February 18th. I don't have -- there is two
9 from February 18th. Sorry.

10 There are none from February 19th
11 in my file. But if I could show Mr. Pulaski
12 the February 16th and 18th emails that I have
13 and ask him if those are the emails he was
14 referencing when my office wrote down
15 February 19th, it might clear something up.

16 MR. SUSKO: You want to do that at
17 a break? Or you want to do that now? We can
18 do that now. It doesn't make a difference.

19 MR. CASSIDY: Take a look at those,
20 Mike, and tell me if those emails on those
21 two pages are the ones that you are
22 referencing when we've been talking about the
23 February 19, 2011.

24 THE WITNESS: The date was wrong.

1 It's February 16th.

2 BY MR. SUSKO:

3 Q So in the Answers to
4 Interrogatories, that's your signature which you
5 verified?

6 A Yes, sir.

7 Q You would say the answer to 31 A
8 through D No. 1, the date 2/19/2011 referencing an
9 email from Dr. Wood, of that date is an error and
10 you would amend to that to read to --

11 A May I read that?

12 Q Sure.

13 A May I read the email?

14 MR. CASSIDY: Sure. Here is
15 another copy of the February 16th email.
16 It's the same thing on a different page.

17 THE WITNESS: That is the email.
18 It's just the wrong date. It's three days
19 earlier.

20 BY MR. SUSKO:

21 Q You've had a chance look at the
22 emails that counsel was showing you, correct?

23 A Yes.

24 Q Just for the record: We were

1 referencing before when I asked you about your
2 signature Plaintiff's Answers to Defendant's
3 Interrogatories, correct?

4 A Okay.

5 Q And specifically I showed you the
6 answer to 31 A through D No. 1, referencing an
7 email from Dr. Wood dated 2/19/2011 to plaintiffs.
8 Do you see that?

9 A I do. I don't know what that is
10 referring to other than an email that is three
11 days within timeframe.

12 Q I'd like the question and I will
13 read him the question. Let's make sure we get --

14 MS. SCHNALL: Which number do you
15 want?

16 MR. SUSKO: 31.

17 BY MR. SUSKO:

18 Q So question 31, sir, is referring
19 back to question 30. Question 30 is, "Have you or
20 has anyone on your behalf obtained from any person
21 or persons including defendant or any employees of
22 defendant any oral or written statement or report
23 concerning the treatment, surgery or examination?"

24 And 31 is, "If so, state."

1 And A is, "When and where such
2 statement or report was obtained or made."

3 A Thank you. I understand. That
4 would be the correct email then.

5 Q What would be the correct email?

6 A The email dated the 16th.

7 MR. CASSIDY: 2/16/11.

8 THE WITNESS: I apologize. I just
9 want to make sure I understood the question.

10 BY MR. SUSKO:

11 Q No problem. I want to make sure
12 you understand the question too. When we go on
13 the video one of the things I will tell you is if
14 you don't understand a question, let me know.

15 A Okay.

16 Q This is -- we are just in
17 preliminaries here. Just for the record, and
18 we'll go on the video record once we are done with
19 this because some of this probably should be
20 captured. But just for the record answer 31A
21 through D question No. 1, asking when and where or
22 asking when and where each statement was made, the
23 answer of 2/19/2011 should be amended and read
24 2/16/2011.

1 A Correct.

2 MR. SUSKO: Let's go on the video.

3 (Discussion held off the record.)

4 THE VIDEOGRAPHER: We are now on
5 the video record. My name is Phillip Roller.
6 I'm a videographer obtained by Elite
7 Litigation Solutions. This is a video
8 deposition for the Court of Common Pleas,
9 Philadelphia County. Today's date is
10 January 21, 2015. The video time is 10:27
11 a.m.

12 This deposition is being held at
13 1650 Market Street, Suite 1800, Philadelphia,
14 Pennsylvania in the matter of Pulaski versus
15 Children's Hospital of Philadelphia, et al.
16 The deponent is Michael J. Pulaski. Will all
17 counsel please identify themselves.

18 MR. CASSIDY: I guess I'll go first
19 then. I'm Bruce Cassidy and I represent
20 Mr. and Mrs. Pulaski.

21 MR. SUSKO: Andrew Susko on behalf
22 of defendants in the case.

23 MS. SCHNALL: Rosemary Schnall on
24 behalf of the defendants.

1 THE VIDEOGRAPHER: The witness has
2 already been sworn in by court reporter Jared
3 Carey. You may now begin the questioning.

4 - - -

5 EXAMINATION

6 - - -

7 BY MR. SUSKO:

8 Q Mr. Pulaski, we were introduced
9 earlier and we've had some discussion off the
10 record. But, again, my name is Andrew Susko and
11 it's my privilege to represent the Children's
12 Hospital of Philadelphia and other defendants, the
13 other defendants that you've -- against whom you
14 brought this lawsuit. And I'm going to be asking
15 you some questions today. It's my hope to finish
16 today. There's a lot of material. And off the
17 record we were discussing some of the things that
18 you have that are not with us today. And you
19 produced -- you've been kind enough to produce
20 some things today.

21 So I will do everything I can to
22 complete the deposition today. But I want you to
23 know that there are some basic ground rules. One
24 of which is that we are not trying to hurry this

1 proceeding along. I want you to take your time.
2 Make sure importantly that you understand the
3 questions that I put to you. If for any reason
4 you are not understanding the question or unsure
5 for any reason, please let me know that. And I
6 will rephrase the question until you tell -- until
7 we know and have established you understand the
8 question. Do you understand that instruction?

9 A I do.

10 Q And do you understand that you are
11 under oath to tell the truth today?

12 A I do.

13 Q Is there any reason, impediment,
14 impairment, medication, anything, any reason why
15 you are unable to answer the questions that I put
16 to you today honestly and to the best of your
17 recollection?

18 A Any reason why I couldn't?

19 Q Yes. Could not.

20 A No, sir.

21 Q Okay. Couple more instructions:
22 If for any reason you want to take a short break,
23 all you have to do is say, I'd like to take a
24 short break. And we'll stop. Whether it's to use

1 the restroom or take a walk or whatever -- or look
2 at documents. I just want you to know that we can
3 interrupt the proceeding just by you telling me
4 you'd like to take a short break.

5 A Okay.

6 Q The other thing is is I, whether
7 it's vestige of academia, but I don't like to
8 continue questioning more than an hour or so at a
9 stretch. So we'll be stopping every hour for five
10 minutes or so, give you a chance to stand up,
11 stretch and walk around. So factor that in if you
12 feel like you are getting to a point where you
13 need a break. It's an easy thing.

14 We are going to take a short break
15 for lunch. And I think our plan is to be done by
16 5:00 today and hopefully we'll be concluded other
17 than potentially some questions on the documents
18 that you have produced. But if for some reason it
19 slows down and we don't get through, I just want
20 you to know that I want you to take the time you
21 need to say -- be responsive to the questions. Do
22 you understand that?

23 A I do.

24 Q Do you have any questions for me

1 before we get started?

2 A No, sir.

3 Q Can we agree, sir, that if you
4 answer a question you will have understood it and
5 answered it truthfully?

6 A I can assume so, yes. If I don't
7 understand something I will ask you to restate it.

8 Q All right. Fair enough. And just
9 to review in terms of just to make sure I fully
10 understand, and we did discuss this off the
11 record, as I understand it you believe there are
12 additional emails or communications between CHOP
13 health care providers and yourself, your wife or
14 others on your behalf that are in the timeframe
15 from January to September of 2010 that existed at
16 least at one point that you have not been able to
17 locate, correct? As of your sitting here today?

18 A Correct. I had a virus on my
19 laptop last year. And as I was attempting to
20 clean the virus I backed up the computer with a
21 product call Norton 360. I didn't realize that
22 that did not back up my email. So thankfully I
23 had another computer that had a lot of the emails.
24 But there are some that I have not been able to

1 locate. I don't know if I'll be able to locate
2 them. But I will continue to try.

3 Q Okay. Fair enough. And then in
4 addition, as I understand it, you have some notes
5 from a meeting with CHOP where consent, a consent
6 or more than one consent, was obtained for
7 treatment for your daughter. And you have those
8 notes, but you just did not bring them today,
9 correct?

10 A I was not aware that I was supposed
11 to --

12 Q Understood. I'm just saying you
13 have them, correct?

14 A And I'm happy to get them to you.

15 Q Fair enough. Then we also
16 referenced income tax returns. And we had a
17 discussion about that. So I will ask you some
18 questions about that and we can follow up with
19 your lawyer about those as well.

20 Okay. I want to ask you some
21 questions generally about your involvement in
22 interacting with health care providers at CHOP
23 with regard to your daughter's care as well as
24 your wife. I just want to ask some general

1 questions. So let me ask you this, were -- did
2 you make it a point as best you could to
3 understand the treatment that your daughter was
4 undergoing?

5 A Yes.

6 Q Did you use your similar best
7 efforts to understand what her condition was?

8 A Yes.

9 Q Did you do yourself personally any,
10 I'll call it, independent research, meaning get on
11 the internet and look up terms that were being
12 discussed, treatments that were available and
13 things like that?

14 MR. CASSIDY: At what time?

15 BY MR. SUSKO:

16 Q At any time while your daughter was
17 alive in connection with her care.

18 A As much as I could, yes.

19 Q Fair enough. And let me probe that
20 a bit. When you say as much as you could, would
21 that be something that you would do periodically?
22 You only did it once or twice? You did it dozens
23 of times? How would you characterize it?

24 A Often.

1 Q Once a week or more?

2 A Or more.

3 Q How about the same question for --
4 strike that.

5 Did you have any friends,
6 acquaintances that you reached out to during
7 Sarah's care that were not at CHOP or not
8 affiliated with CHOP?

9 A Yes.

10 Q Can you identify who those
11 individuals were.

12 A The -- at what point in time
13 because --

14 Q While she was still living and
15 under the care of CHOP.

16 A So when Sarah was first diagnosed
17 we have a very good friend who is a cancer
18 survivor who we communicated with. She works at
19 the FDA. After --

20 Q Who was that?

21 A Her name is Toni. I believe her
22 last name is Stefano. I could be wrong with the
23 pronunciation.

24 Q Fair enough. And there are some

1 emails with her identified. So we'll get to
2 those. So go ahead.

3 A And --

4 Q Was that your friend? Your wife's
5 friend?

6 A My wife's friend.

7 Q Fair enough.

8 A Then after Sarah relapsed Toni
9 asked a doctor friend of hers to look at Sarah's
10 case.

11 Q Is that Dr. Rehman?

12 A That is Dr. Rehman.

13 Q Anybody else that comes to mind in
14 terms of friends or acquaintances or anyone that
15 you reached out to while your daughter was living
16 in connection with getting information or any
17 purpose related to her care that you can remember?

18 A I believe there was a doctor at
19 another hospital that my wife spoke with once very
20 early on. But I don't even -- I couldn't even
21 tell you who he was.

22 Q Fair enough.

23 A I think it was more of a
24 conversation where he was just trying to calm her

1 down.

2 Q And there -- your recollection may
3 be jogged by some of the emails we look at. So
4 but nothing -- no one else comes to mind?

5 A They were the primaries.

6 Q Okay. Fair enough. How about, and
7 I'm talking pretty much at the 30,000-foot level
8 here, because we'll get more specific when we are
9 looking at emails. But how about your wife, was
10 she engaged in understanding your daughter's
11 condition and treatment she was undergoing?

12 A We tried our best, yes.

13 Q Would she also herself do
14 independent looking into treatment and the
15 condition on the computer or other ways of looking
16 at -- researching?

17 A I want to make sure I understand
18 the question.

19 Q It's relating to your wife and
20 whether she would do any, other than talking to
21 CHOP physicians, would she also get on the
22 computer and look up terms and --

23 A So you are saying other than
24 talking to CHOP physicians?

1 Q Yes.

2 A Okay. Because my answer to that
3 would be yes; however, understand -- I hope you
4 understand we talked to the CHOP physicians a lot.

5 Q Understood. I do know that. Okay.

6 Was one of the parents either by
7 virtue of circumstance or, in fact, more involved
8 in understanding the treatment and condition? Or
9 would you say you were essentially equally
10 involved in that?

11 A I would say that my wife had most
12 of the communications with Toni because they are
13 dear friends.

14 Q Okay. Fair enough.

15 A But I was involved in that I was
16 knowledgeable of that communication.

17 Q Fair enough. But and I'm talking
18 now about Sarah's condition and treatment
19 available for her condition. Would you say you
20 and your wife were essentially both knowledgeable
21 to a similar degree? Or was it primarily because
22 of any circumstance, work or anything else, that
23 one parent was more engaged and more involved in
24 the care than the other?

1 A I would -- Andy, I would say that
2 we were both as involved as we could be. But I do
3 hope you understand that in January of 2010 we
4 were lucky if we could spell leukemia.

5 Q Understood. Understood. In terms
6 of communicating with the doctors early on, and
7 I'm going to say January through May as a
8 timeframe 2010, were you both having
9 communications with the physicians at CHOP?

10 A Yes and no. But not for that
11 timeframe. We both were in the first few months.
12 But then what happened is my wife went back to
13 work. So I became the primary communication as
14 she went back to work.

15 Q Fair enough. That's sort of what I
16 was getting at. We're trying to get a general
17 understanding. I don't -- if you were the primary
18 contact though, would you then turn around and
19 communicate when you could to your wife what was
20 going on? Did you guys keep each other abreast I
21 guess is the question?

22 A Yes.

23 Q So if there was something important
24 going on you and your wife communicated about it

1 if one or the other happened to be the person
2 interfacing with the CHOP doctors?

3 A We would always talk, yes.

4 Q Okay. Fair enough.

5 A That's why I couldn't print out a
6 good copy for you.

7 MS. SCHNALL: A lot of paper.

8 (Exhibit MP-1 was marked for
9 identification.)

10 BY MR. SUSKO:

11 Q Let me show you what I'm marking as
12 MP-1. Do you recognize that document, sir?

13 A Yes, sir.

14 Q What is it?

15 A It is a consent form. I'm checking
16 the date, however. Okay.

17 Q Did you check the date?

18 A I did, yes.

19 Q What was the date?

20 A January 4, 2010.

21 Q Who diagnosed your daughter's
22 leukemia?

23 A Doctors at CHOP. But we were told
24 by three different doctors over the course of a

1 difficult evening so...

2 Q Fair enough. What evening was
3 that? Was that early in January?

4 A We went to the emergency room the
5 evening of the 2nd.

6 Q At CHOP or St. Mary's?

7 A At St. Mary's. We were transferred
8 late in the evening to CHOP. Our first full day
9 at CHOP was say midnight 12:00 a.m. in the morning
10 on the 3rd. We were living in ICU at the time.

11 Q Did you understand your daughter
12 was very sick?

13 A I did.

14 Q And what was your -- you referenced
15 this and alluded to this earlier about your level
16 of understanding of leukemia in January. But
17 before you had any communication with the CHOP
18 doctors, did you have any knowledge about what
19 leukemia was?

20 A Not really. I knew it was a
21 cancer.

22 Q And how about your -- the same
23 question with regard to your wife. Did she have
24 any special knowledge about what leukemia was?

1 A We had no firsthand experience with
2 it.

3 Q Fair enough. Any medical
4 background in either your family or your wife's
5 family?

6 A Not that I'm aware of.

7 Q No doctors in the family?

8 A No.

9 Q How about the more extended family,
10 either your brothers or sisters or your wife's
11 brothers or sisters? Any doctors in the family?

12 A No. We would -- there are no
13 family get-togethers where there is a doctor or a
14 nurse or anything.

15 Q Understood. I was just thinking in
16 terms of if you had a brother maybe you'd call --

17 A I'd reach out to him, sure. He'd
18 be at the hospital.

19 Q I'm just trying to be thorough.
20 Okay. All right. Fair enough. So you are at the
21 hospital and you are saying really within 24 hours
22 of being there the diagnosis was made?

23 A Yes.

24 Q Or did it take a little -- okay.

1 A It was earlier than that.

2 Q What exactly were you told?

3 A We were told that she had leukemia.

4 Q And what, if anything, was
5 explained to you about what leukemia was?

6 A In the first few hours?

7 Q Let's start with that.

8 A Explained that it was a type of
9 cancer. But the first few hours didn't focus on
10 the cancer. It focused on issues and concerns
11 that they had with regards to the amount of
12 leukemia in her blood. So the immediate concern
13 was, I guess, getting Sarah stable before we could
14 talk about cancer.

15 Q All right. Fair enough. Did you
16 understand irrespective, I'm not timing this to
17 that first night or even the first day, but did
18 you come to learn early on that her cancer was,
19 for lack of a better word, not a mild form of
20 cancer but a serious or a more severe form of
21 cancer?

22 MR. CASSIDY: Just have to object
23 to the form of the question.

24

1 BY MR. SUSKO:

2 Q Fair enough. Go ahead.

3 A Can I ask you to state that again?

4 Q Yeah. I'm just trying to get an
5 understanding of whether the severity of how it
6 was described to you of the type of cancer and her
7 specific cancer, because you alluded to that in
8 your answer, was, if they ever communicated at
9 CHOP. And at some point they are talking high
10 risk, moderate risk and low risk. But I'm saying
11 early on did they -- did anyone express to you the
12 severity, anything with regard to the severity of
13 your daughter's condition?

14 A So there is two answers to that
15 question, if I might.

16 Q Sure.

17 A The first answer would be: Did
18 anyone explain the severity of where Sarah was
19 when we came in? Because the amount of leukemia
20 cells in her blood were high. So --

21 Q Do you remember -- are you able to
22 quantify that or give any information?

23 A I believe it was 530,000 or
24 580,000.

1 Q White blood cells?

2 A Yes. I remember they were
3 extremely high. And that was a concern that they
4 wanted to address. Later it was explained to us
5 that Sarah had a translocation that was rare but
6 curable.

7 Q Was it a good thing that she had
8 the translocation as it was described to you? Or
9 did that make treatment more challenging?

10 A Well, again, two parts to that
11 answer. Early on we asked about the translocation
12 and were told that it didn't have any impact. And
13 I say that because the second part of that is that
14 later in Sarah's treatment when I questioned Andy
15 Wood about the translocation -- and I referenced
16 another translocation. I believe it's 922. I
17 could be wrong. It might be a different number.
18 That is known to be extremely bad. And Andy Wood
19 said, No, if she had that we'd have a lot more
20 options.

21 Q Okay. Back to my question, though.
22 Did you ever learn at any point while your
23 daughter was alive and treating at CHOP that the
24 translocation made and the specific type of

1 leukemia your daughter had made treatment more
2 challenging?

3 A That is I believe why many of the
4 doctors at CHOP were telling us that Sarah would
5 need a bone marrow transplant.

6 Q Fair enough. When was that first
7 discussed?

8 A Within --

9 Q Meaning bone marrow transplant.

10 A Within the first week of treatment.

11 Q So is it fair to say, sir, that you
12 understood that one of the treatment options or
13 alternatives for your daughter was a bone marrow
14 transplant?

15 A Yeah. Absolutely it was -- we knew
16 that it was a option that many doctors at CHOP
17 recommended and referenced. And we -- but we
18 never -- well, yes.

19 Q We're going to get into some of the
20 details of that. But as I understand it when you
21 first got there within short order one of the
22 things on the table was bone marrow transplant,
23 correct?

24 A Well, when you say on the table --

1 Q Meaning they are discussing it with
2 you. Giving you information about it.

3 A No.

4 Q Oh, okay. I thought you said it
5 was discussed in that first --

6 A We were told that Sarah would
7 likely require a bone marrow transplant. But
8 there were no discussions around what steps needed
9 to occur with that. There were no conversations
10 with the team that actually do bone marrow
11 transplants. It was simply doctors at CHOP
12 alerting us to the fact that it was probably a way
13 Sarah had to go.

14 Q Okay. Fair enough. So you
15 understood at least very early on that one of the
16 treatment options would be bone marrow transplant,
17 correct?

18 A I understood that a form of
19 treatment -- that a form of treatment that was
20 probably recommended by several doctors was a bone
21 marrow transplant. I worry that you think that I
22 had control over those discussions.

23 Q Well, I'm a little bit concerned,
24 let me just say, that you are worried about

1 anything about what's in my head. My job is to
2 ask questions. Your job is to answer them
3 truthfully. So that's the ground rules. If you
4 need to confer with counsel or you are getting
5 concerned about what I'm thinking, feel free to do
6 that. But --

7 A Sir, I'm just trying to answer your
8 questions in a fair way so that I'm giving you an
9 accurate answer.

10 Q And that's what I want too. And I
11 think your testimony has been fairly clear on the
12 point. Okay. So and can I just direct your
13 attention to MP-1.

14 A Mm-hmm.

15 Q And the date that you identified is
16 1/4/2010. Did you become -- were you -- strike
17 that.

18 Were you present when your wife
19 signed this?

20 A I was.

21 Q Did you review it?

22 A A very high level, yes.

23 Q Was someone explaining it to you?

24 A Yes.

1 Q Why don't you tell me what you
2 recall, and I realize it's now nearly five years
3 ago, what do you recall about what was explained
4 to you about MP-1?

5 A So there were two doctors in the
6 room with us. One was a Dr. Carly Varela. She
7 was the lead doctor. And I apologize. I don't
8 remember the second doctor's name. She must have
9 been a fellow that was working with her. And
10 during this meeting it was a conversation about
11 this new clinical trial drug that could
12 potentially be available to Sarah. It was
13 explained to us that --

14 Q Do you know the name of the drug?

15 A Nelarabine.

16 Q Okay. Go ahead.

17 A That's the name I know it by unless
18 you have a different name.

19 Q That's the name I know it by too.
20 But I'm just probing that. But I'm sorry to
21 interrupt. Go ahead. You were explaining what
22 they told you at this meeting.

23 A So in this meeting this doctor made
24 us aware of a clinical trial that was available to

1 Sarah. And --

2 Q This is Dr. Varela?

3 A This is Dr. Varela.

4 Q First name Carly?

5 A Yes. Yes. And she spoke about
6 this drug nelarabine that could be available to
7 Sarah and the fact that if we wanted it to
8 potentially be available to Sarah we would need to
9 enroll her in the clinical trial that day. We
10 were a little concerned about that not knowing
11 anything about it. And Dr. Varela said that it
12 was -- because there was no difference in the
13 first thirty days of treatment between standard of
14 care versus the clinical trial. What was on the
15 table was if we agree to the clinical trial in
16 thirty days Sarah may be able to get nelarabine.
17 If we don't agree to the clinical trial, then
18 there is no way she can get nelarabine.

19 Q Okay. So if --

20 A There was no conversation of bone
21 marrow transplant at that time.

22 Q Okay. If I understand what you
23 just said: There was a meeting. Two docs were
24 there. You and your wife were there. There was a

1 question about your agreeing to be part of a
2 clinical trial but what was also said was that
3 your treatment during the first part of this would
4 be the same whether you were part of the trial or
5 not?

6 A Correct.

7 (Exhibit MP-2 was marked for
8 identification.)

9 BY MR. SUSKO:

10 Q Let me show you what I'm marking as
11 MP-2. Do you have MP-2 in front of you, sir?

12 A I do.

13 Q And I'm referencing -- these are
14 stamped in the lower right-hand corner. I am
15 going to represent to you this is the oncology
16 progress record that reflects in part your
17 discussion with Dr. Varela. And I'm looking at
18 page 5706 which is the second page. Have you seen
19 this document before?

20 A I may have, sir. I'm not sure.

21 Q Can you stay on 5706.

22 A Sure.

23 Q And I'm going to reference, I'm
24 pointing to it right now, but I'm going to

1 reference a part of that record. It's about --
2 it's No. 1. It says T-A-L-L. And about four
3 lines down it says, and this is what I want to
4 focus my question on, Discussed risk of death from
5 leukemia treatment and infection. Discussed side
6 effects in detail. Consent obtained for ALL0434.
7 Do you see that?

8 A Yes.

9 Q I want to ask you whether in this
10 meeting with Dr. Varela that the risk of death was
11 discussed with you and your wife?

12 A The exact way that Dr. Varela
13 phrased it was, We cure three out of four
14 children.

15 Q And was the risk of death from the
16 leukemia discussed?

17 A Only as it relates to that comment.

18 Q So that was the only thing she said
19 to you in terms of risk?

20 A It's the only thing I recall.

21 Q Do you think she discussed more
22 things and you just aren't recalling it? Or do
23 you think that's essentially all she said about
24 the risk from leukemia, the treatment and

1 infection?

2 A I believe that was about it.

3 Q And how long was this discussion?

4 A Thirty to forty-five minutes, I
5 believe.

6 Q Did you have an understanding that
7 there was a risk to your daughter's ability to
8 survive that was present from the leukemia itself?

9 A I'm sorry. Are you asking --

10 Q Let me rephrase that. That was not
11 answered -- or asked as cleanly as it could. Did
12 you understand that from the leukemia your
13 daughter had a risk of death?

14 A Yes.

15 Q Did you understand that there was
16 also a risk of death from any treatment she might
17 receive?

18 A On January 4th? Not really.

19 Q Did you later come to understand
20 that?

21 A After my daughter relapsed.

22 Q Well, just from the chemotherapy,
23 your daughter underwent chemotherapy?

24 A Yes.

1 Q And she was taking some pretty
2 powerful drugs?

3 A Yes.

4 Q You and your wife or at least one
5 of you or both looked at what information was
6 publicly available relating to nelarabine?

7 A I'm sorry. Are you asking if --

8 Q Not in the context of this meeting.
9 At any point?

10 A No. I understand that. Are you
11 asking if we knew that some of the drugs could
12 have adverse side effects?

13 Q Yes.

14 A Oh, yes.

15 Q I mean that's -- she writes here,
16 and I'm just using my own lay interpretation.
17 Your lawyer will have a chance to depose her.
18 Discussed risk of death from leukemia treatment
19 and infection. So my question was, was there a
20 discussion in this initial meeting that the
21 leukemia could kill your daughter? The treatment
22 itself? The strong drugs they were going to give
23 her? The chemotherapy could kill your daughter?
24 And infection also was a risk of death for your

1 daughter?

2 A So I would answer that in saying,
3 yes, there was a discussion. I do not recall ever
4 discussing infections and the risk of infections,
5 nor do I recall any conversation about a specific
6 drug in this meeting. This was a pretty high
7 level, and as I remember it, it was really kind of
8 just talking about treatment in general.

9 Q Within the first month -- by the
10 way, was there a second consent that was presented
11 to you and that you signed?

12 A Yes.

13 Q At some point in the first month of
14 your treatment at CHOP, your daughter's treatment
15 at CHOP, did you have an understanding that the
16 chemotherapy presented a risk of death to your
17 daughter as well as infection?

18 A Chemotherapy, yes. The infection,
19 no.

20 Q So part of the discussion wasn't
21 that your daughter's immunity system would be
22 compromised by the chemotherapy. She's be at risk
23 for infection. And that that is something you had
24 to be very careful about?

1 A Yes. Those conversations did
2 occur.

3 Q All right.

4 A They were more focused on if there
5 was an infection you had to come back and be
6 inpatient.

7 Q Understood. I want to ask you some
8 questions specifically about MP-1 now. So if you
9 can get that in front of you.

10 A Okay.

11 Q I'm directing your attention to the
12 identified number that related to the study
13 AALL0434. It's right in the upper left-hand
14 corner.

15 A Yes, sir.

16 Q Did you -- does that number or did
17 that number have any significance to you as it was
18 being explained? Or was it just one way to
19 describe this study?

20 A The number meant nothing to me at
21 that point.

22 Q Did you understand that there
23 were -- that there were other clinical trials
24 going on with regard to leukemia?

1 A No.

2 Q Did you understand that CHOP was
3 offering to you, as a parent, treatment for your
4 daughter through a clinical trial?

5 A I understood, as I explained
6 earlier, that this was a clinical trial that Sarah
7 qualified for that had the potential for her to
8 get a drug that may help her with the further
9 understanding that if you didn't sign that day
10 there was no chance of her getting into the
11 clinical trial at a later date. But if we did
12 sign that day, there would be no difference in her
13 treatment over the next thirty days and that we
14 would make determinations at the end of that first
15 treatment.

16 Q Fair enough. And you said all of
17 that. Did you understand I'm referencing now in
18 Part 1 Induction Therapy, it says, This study is
19 called a clinical trial. A clinical trial is a
20 research study involving treatment of a disease in
21 human patients.

22 Did you have that basic
23 understanding as a result of this meeting?

24 A Basic understanding, yes.

1 Q Had you ever heard of the
2 Children's Oncology group before?

3 A No, sir.

4 Q Did you come to learn that the
5 study was organized by an entity called the
6 Children's Oncology Group?

7 A I came to understand that, yes.

8 Q And that the study involved many
9 hospitals? One of which was CHOP?

10 A Yes.

11 Q And did you at some point shortly
12 into your daughter's treatment understand that one
13 of the things that your daughter might receive as
14 a part of this study is that drug nelarabine?

15 A Correct.

16 Q Would I be correct that at some
17 point you also understood before you actually --
18 strike that. Let me ask it this way.

19 Did you understand at the time of
20 the consent that is marked MP-1 that there was no
21 guarantee that you would receive nelarabine?

22 A I did.

23 Q Was it explained -- was the process
24 of randomization explained to you at that time?

1 A I don't know about in this meeting.
2 It may have but I don't remember.

3 Q How about at some later point
4 before you signed the second -- before the second
5 content was signed, was that explained?

6 A About getting randomized?

7 Q Yes.

8 A Yes.

9 Q Your daughter had T-cell acute
10 lymphoblastic leukemia?

11 A Correct.

12 Q Did you have any understanding or
13 develop any understanding at any time while your
14 daughter was treating about the significance of it
15 being T-cell as opposed to B-cell?

16 A Not early on. But eventually as
17 you live this life you do learn more.

18 Q What did you learn in that regard,
19 if anything?

20 A I learned that there are
21 differences in treatments, that there are
22 different drugs that work on one versus another.

23 Q Did you learn anything about
24 patient outcomes, t-cell versus B-cell acute

1 lymphoblastic leukemia?

2 A No.

3 Q At any point?

4 A No. Most of the focus was on ALL
5 versus AML.

6 Q And then if you look at the consent
7 it says, Why is this study being done? It's on
8 the first page, sir, at the bottom. It says ALL
9 is a type of cancer that occurs in the bone
10 marrow. Was that explained to you that the cancer
11 your daughter had was in the bone marrow?

12 A Yes, sir.

13 Q And then in bold at the bottom of
14 the page it says, The overall goal of this study,
15 referring to the clinical trial and research study
16 that you were signing up for, is to see if we can
17 get rid of the cancer for as long as possible with
18 acceptable side effects of therapy. Do you see
19 that?

20 A I do.

21 Q Was that your understanding going
22 into participation in this trial?

23 A Well, as Dr. Varela said to me my
24 understanding was my daughter will either survive

1 or she will die, that there is no -- because I was
2 questioning her about the 85 percent, 75 percent
3 likely survival. And Dr. Varela said it's either
4 100 or 0.

5 Q How about duration of survival or
6 the length of time, was there ever any discussion
7 about remission, lengths of period of remission,
8 that would be expected with effective treatment?

9 A No.

10 Q Or anything like that?

11 A Not that I recall.

12 Q Did anybody guarantee you that
13 going into this clinical trial would cure your
14 child?

15 A Guarantee?

16 Q Yes.

17 A No, sir.

18 Q Can you look at page 870 or turn to
19 that on Exhibit MP-1. Do you have 870 in front of
20 you?

21 A Yes.

22 Q I'm referencing the bottom of the
23 page. What happens if you decide not to take part
24 in this study? Do you see that?

1 A Yes.

2 Q I'm going to just read that first
3 sentence. Participation in this study is
4 voluntary. You do not have to take part in order
5 to receive care at CHOP. You may choose to leave
6 the study at any time. Do you see that?

7 A Yes.

8 Q Did you understand at the time that
9 you and your wife agreed to participate in the
10 clinical trial that you did not have to do that to
11 be treated at CHOP, meaning you did not have to
12 participate in the trial and that you could in
13 addition to that leave the study at any time?

14 A I don't recall if there was a
15 conversation on January 4th about that. Again,
16 the conversation on the 4th was primarily about
17 the fact that if you signed today there is a
18 chance that you could get access to this drug. If
19 you don't, there is no chance.

20 Q Do you know the why of that? And
21 I'm not even asking then. I'm just saying if you
22 learned or developed an understanding of why that
23 was true at that time.

24 A The clinical trial says that.

1 Q Well, did you understand that --

2 A I know that now. I didn't know
3 that then.

4 Q Yeah. Okay. Do you understand
5 that the -- that the clinical trial -- the ARM of
6 the clinical trial Sarah was put in was utilizing
7 the drug you mentioned nelarabine as a frontline
8 drug to be used before the patient was in
9 remission and then had a relapse?

10 A On the 4th? No.

11 Q No. I'm not asking -- I'm saying
12 at any time.

13 A Oh, yes.

14 Q You came to learn that, right?

15 A Yes, I came to learn that.

16 Q So the reason -- wasn't that the
17 whole purpose at least -- strike that.

18 Wasn't that the purpose at least in
19 part of the clinical trial was they were testing
20 the use of nelarabine, this drug, for patients who
21 had not yet had a relapse?

22 MR. CASSIDY: Are you saying did he
23 know about it on January --

24

1 BY MR. SUSKO:

2 Q No. I'm not asking that. I'm
3 asking at any point did you learn what the fact
4 was you couldn't get that drug as a frontline use
5 in care without this trial because the drug was
6 only being used at that point for patients that
7 had had a relapse in leukemia? Did you come to
8 understand that?

9 A We came to understand that it was
10 something that was not normally available.

11 Q Okay.

12 A And that they -- the doctors felt
13 that Sarah needed it to get into remission. And
14 we couldn't go to transplant unless she was in
15 remission.

16 Q Okay. Fair enough. Did the -- and
17 I'm jumping ahead a little bit here. But when you
18 consented to be randomized in one of four options
19 that included nelarabine as one of the options,
20 did you understand that stem cell transplant was
21 not a part of that trial?

22 A On the 28th?

23 Q At any time.

24 A Or whatever date that was in

1 February.

2 Q In February. Yeah.

3 A Can you restate the question?

4 Q Well, and we are going to get to
5 the consent. So if you don't know this off the
6 top of your head -- I thought you might. But
7 that's why --

8 A I might. I want to understand the
9 question.

10 Q I'm asking you the second consent
11 identified ARM D which is what you were randomized
12 to and the treatment you get in that ARM as well
13 as the other ARMs of the clinical trial, correct?

14 A Correct.

15 Q And stem cell was not one of those
16 treatment alternatives, was it, that was
17 identified in the study?

18 A So I believe --

19 Q Can you answer that question?

20 A I'm -- please give me an
21 opportunity.

22 Q Well, I am. I am.

23 A On that date for the second consent
24 the paperwork says that and --

1 Q Says what? I'm sorry.

2 A The paperwork is clearly about the
3 clinical trial and potential to get randomized
4 into nelarabine. And I remember that day very
5 clearly because we were on pins and needles by
6 that time praying that we got nelarabine.

7 Q I understand all that.

8 A Because the doctors felt that Sarah
9 needed nelarabine in order to eventually come out
10 of trial, of clinical trial, and proceed to a bone
11 marrow transplant.

12 Q But my question is different. My
13 question was, while you were on the trial, and
14 trial just so we are clear, you understood it was
15 two years or more long --

16 A I understood --

17 Q -- participation in that trial?

18 A -- that Sarah's treatment was going
19 to be a few years, yes.

20 Q And didn't the clinical trial that
21 you consented to, the second consent, identify the
22 treatment that you were going to receive during
23 that trial?

24 A I do wish I had my notes, sir.

1 Q I'll get the -- we'll get the
2 consent out in front of you. That's why I was
3 saying -- that was the question I was asking. Did
4 you understand the treatment solicited, which it
5 is, and that stem cell is not identified in the
6 list of treatment?

7 A I do. But I have my notes from
8 that meeting.

9 Q Fair enough.

10 A And clearly point to transplant.

11 Q Okay. Well, understand you got a
12 lot emails in there about transplant was an
13 option. You were going to choose a path. We are
14 going to get to all of that. I'm just asking you
15 in terms of when you selected to go into the
16 clinical trial, the second consent, you understood
17 you were making the primary therapy nelarabine,
18 did you not?

19 A I understood that our goal was to
20 get nelarabine.

21 Q Fair enough. All right. By the
22 way, was there -- was there -- let me ask it this
23 way. Did the doctors at CHOP make time for you
24 and your wife to talk?

1 A In the first thirty days? Yeah.

2 Q At any time.

3 A Well, not at any time. In the very
4 beginning, yes. After Sarah relapsed, no.

5 Q When you are saying after she
6 relapsed you are talking about March of 2011?

7 A Correct.

8 Q Before March of 2011 did the
9 doctors -- were they available to you to talk?

10 A Dr. Wood was. Dr. Rheingold was in
11 the very early -- in the very beginning and then
12 on and off.

13 Q Okay. Did you -- were you able to
14 ask questions if you had them before the relapse
15 in March of 2011?

16 A Yes.

17 Q Did you ask questions?

18 A Yes.

19 Q Were your questions answered?

20 A Not always.

21 Q Did you make records of when
22 questions weren't answered? Make notes of them?

23 A Sure. They are in the care pages.

24 Q Do the care pages give us the best

1 look at what was going on five years ago?

2 A They give us an accurate look, yes.

3 Q Okay. Fair enough. Back to the
4 consent we were reading --

5 MR. CASSIDY: Still on the first
6 consent?

7 BY MR. SUSKO:

8 Q Yeah, we're on the first consent.
9 And we're on page 870. And I'll turn now to the
10 top of 871 and it says, You can decide to stop
11 being on study at any time.

12 Did you understand that at any time
13 you could stop being on the study?

14 A That was my understanding. It
15 wasn't accurate. But it was my understanding.

16 Q Okay. That's what I was asking.

17 A It was also my understanding that
18 Sarah would be pulled off trial.

19 Q Where did you develop that -- when
20 did you have that understanding?

21 A Through conversations with the
22 doctors.

23 Q The question was when, not how.

24 A Prior to the second consent.

1 Q So between January 5th and
2 February 5th or January 4th and February 5th you
3 thought your daughter was being pulled off the
4 trial? Is that what you just said?

5 A We thought there was a likelihood
6 she was going be pulled off on several occasions.

7 Q So there were discussions in the
8 interim while your daughter was under care about
9 taking her off the trial, right?

10 A Prior to the second.

11 Q At any time. At any time. There
12 were discussions you had with CHOP doctors about
13 taking your daughter off the trial?

14 A Not at any time. Prior to the
15 second consent there were numerous because of
16 Sarah's response or lack of response to
17 traditional chemo. However there was another
18 conversation in late July early August where I
19 specifically requested and was denied.

20 Q Who did you -- let's -- you keep
21 coming back to that so why don't we talk about
22 that. When -- do you have an exact date of that
23 conversation?

24 A I do not.

1 Q Did you post anything on a blog
2 about it?

3 A I probably --

4 Q It's a specific question.

5 MR. CASSIDY: You are being
6 argumentative.

7 MR. SUSKO: Well, he is starting
8 out at probably.

9 MR. CASSIDY: He is trying to
10 answer the question.

11 MR. SUSKO: The question is, did he
12 post it on the blog? It's either I don't
13 remember. Yes. No.

14 THE WITNESS: I don't remember.

15 MR. CASSIDY: Let him answer.

16 BY MR. SUSKO:

17 Q You probably -- what were you going
18 to say?

19 A I don't remember.

20 Q We have the blog postings from that
21 time.

22 A Yes.

23 Q Okay. Have you reviewed that?
24 Specifically have you searched those postings to

1 see if you referenced that you -- any thought
2 process about pulling your daughter off the study
3 that is reflected in those blogs or any of the
4 emails that you produced?

5 A I have not looked for that
6 specifically, no.

7 Q Because it's confusing to me based
8 on what I'm reading in those blogs, the content of
9 them, when you are describing how happy you and
10 the family are about your daughter's progress that
11 you also had a conversation with CHOP where you
12 were asking your daughter, who was in remission,
13 to be pulled off that study. I'm not
14 understanding why you wouldn't have written such
15 an event in your materials.

16 MR. CASSIDY: Objecting to the form
17 of the question.

18 BY MR. SUSKO:

19 Q Okay. Go ahead. You can answer.

20 A A lot of my communication at that
21 point with my wife was through text messages and
22 phone calls. And it was a conversation that I was
23 a little upset about. So it was probably -- it
24 probably occurred over the phone.

1 Q Well, was there any lead up to it?
2 Was this just a sort of off-the-top-of-your-head
3 conversation -- idea that came into your head and
4 then a conversation with somebody at CHOP? Or was
5 this something you had been giving thought to for
6 a while?

7 A It was something that we always
8 thought about.

9 Q That's not my question.

10 MR. CASSIDY: It sounded like your
11 question from where I sit.

12 BY MR. SUSKO:

13 Q My question wasn't whether you'd
14 always thought about it. My question is very
15 specific. You are referencing you requested to be
16 taken off study. And my question was, was that
17 something that just occurred on the day you
18 thought it? Or was that something you'd given
19 some thought to before approaching the CHOP
20 doctors to ask them to take you off the study?

21 MR. GELB: Object to the form of
22 the question.

23 BY MR. SUSKO:

24 Q Go ahead. You can answer.

1 A I had a conversation with Dr. Wood
2 in the presence of my daughter. And I was upset
3 about the fact that another patient that Dr. Wood
4 and Dr. Rheingold cared for of a family that I was
5 very close to was in a situation where they had a
6 sibling who was a perfect match. And they could
7 no longer get that child into remission. And I
8 was sitting there knowing that this child was
9 going to die. And in this meeting with Dr. Wood I
10 forced him to talk to me about the results of my
11 son's testing. Because it had never been reviewed
12 with us.

13 Q Your daughter's testing or your
14 son?

15 A I'm sorry. My son's testing for
16 the match.

17 Q Okay. Go ahead.

18 A I forced him to have that
19 conversation. And in that conversation I wanted
20 to know why we were not proceeding towards a bone
21 marrow transplant. And that was when Dr. Wood
22 told me that CHOP had taken that off the table.
23 And when I told him I didn't agree with that,
24 because I did not want to be in the same situation

1 as Ricky McAvate's (ph) family, Dr. Wood would
2 spend several minutes explaining to Sarah and I
3 why we can't compare ourselves to them and made
4 all of the assurances in the world that I was
5 overly reacting to the fact that if Sarah relapsed
6 that they wouldn't be able to get her back into
7 remission. And in that meeting I said to him,
8 well, my preference is that we come off the
9 clinical trial and we proceed down that road. And
10 Dr. Wood told me it was not an option, that CHOP
11 was no longer offering Sarah a bone marrow
12 transplant.

13 Q My question, sir, I appreciate all
14 that information, relates to: Is that something
15 that you came up with at the time of the meeting?
16 Or had you given thought to that in the days
17 running up? Had you discussed with your wife that
18 you were going to have this conversation with
19 Dr. Wood?

20 A I had discussed with my wife that I
21 was going to find out what the test results were
22 because we had been waiting.

23 Q Did you have a conversation with
24 your wife to let her know at any point before you

1 spoke to Dr. Wood the conversation you just
2 recounted -- recanted -- recounted? Did you have
3 a conversation with your wife about the fact that
4 you were going to request that Sarah be taken off
5 the trial?

6 A I probably did.

7 Q So you don't know for sure?

8 A I'm not 100 percent sure of every
9 conversation that we had. You are asking me if I
10 ever spoke to her and the answer is yes.

11 Q I didn't ask you if you ever spoke
12 to her. I asked you, did you speak to her about
13 whether that you were going to approach CHOP about
14 taking your daughter off the trial?

15 A I spoke to her about the
16 conversation.

17 Q In advance of the conversation?

18 A Most likely in advance, but
19 definitely shortly after.

20 Q Would that be the kind of thing
21 given your relationship with your wife that you
22 would decide on your own that you were going to
23 request that she be taken off the trial without
24 conferring with her?

1 A Yes. Because we always -- we were
2 always waiting to have that conversation. We were
3 promised that we were going to have that
4 conversation. And I just told her that I was
5 going to force Andy to talk to me about it.

6 (Exhibit MP-3 was marked for
7 identification.)

8 BY MR. SUSKO:

9 Q Let me show you, since we went down
10 this road, I am going to mark it. I'll have the
11 court reporter date it later. But I'm going to
12 mark it MP-3. An email I think it says posted by
13 Mike. Does that mean that this is your email,
14 sir?

15 A It would be a blog posting.

16 Q Just for the record standpoint --

17 MR. CASSIDY: Do you have copies?

18 MR. SUSKO: I do. I do. Hang on.

19 You'll get them.

20 BY MR. SUSKO:

21 Q Can you give me the number in the
22 lower right-hand corner of exhibit MP-3?

23 A No. 198.

24 MR. SUSKO: Thank you. I'll just

1 give you the whole set.

2 MR. CASSIDY: Thank you.

3 BY MR. SUSKO:

4 Q Do you have MP-3 in front of you?

5 A I do.

6 Q And MP-3 is -- you are calling that
7 or that is a blog posting, sir?

8 A Yes.

9 Q And it says, Posted by Mike. That
10 meaning yourself?

11 A Yes.

12 Q So let's look at that posting. And
13 I'm in the middle. It says, Once Sarah's counts
14 recover -- do you see that paragraph?

15 A Yes.

16 Q She will have another bone marrow
17 test to determine if she is in remission and if
18 there is any residual disease. Once this is
19 completed we expect the docs to make their
20 recommendation for treatment, i.e., continue the
21 course with chemo or choose the transplant path.
22 Do you see that?

23 A Yes.

24 Q Now, and you posted this when, sir?

1 A April 22, 2010.

2 Q So let me ask you about this
3 posting. You understood certainly in April
4 of 2010 that depending on whether your daughter
5 got in remission at that moment there was going to
6 be a path to choose either chemo or continue on
7 the chemo and you were on chemo at the time,
8 right? Correct?

9 A Correct.

10 Q Or do a transplant; is that right?
11 That's what you wrote anyway.

12 A Yes. I expected us to have
13 follow-up meetings to discuss where we were going.

14 Q But my question is you wrote that
15 once you determined that there was no residual
16 disease, the patient was -- your daughter was in
17 remission. You are -- there would be a choice
18 being made: Chemo or transplant, correct? That's
19 what you wrote?

20 A Yes. I wrote that we will meet
21 with the doctors --

22 MR. CASSIDY: Wait a second. I
23 want to object to the form of the question.

24 MR. SUSKO: Your objection is

1 noted. Go ahead.

2 THE WITNESS: When we met, when I
3 wrote this, I said we expect the docs to make
4 their recommendations for treatment, meaning
5 continued treatment.

6 BY MR. SUSKO:

7 Q It says, Continue the course with
8 chemo or choose the transplant path?

9 A Correct.

10 Q Those are your words, right?

11 A Yes.

12 Q So you understood in April of 2010
13 that if your daughter got completely in remission
14 there would be a choice being made. You would
15 either use the frontline therapy of this clinical
16 trial nelarabine, continue to use it. Or you
17 would choose the transplant path; is that
18 accurate?

19 A Yes.

20 Q And isn't it true that when she
21 went in remission you made a choice, you and your
22 wife, to keep receiving the chemo?

23 A Absolutely, positively 100 percent
24 false.

1 Q Okay. So if there was a meeting
2 between you and the hospital staff in which you
3 reaffirmed that you wanted to continue with the
4 chemo you'd think that's not correct?

5 MR. CASSIDY: Too many negatives.

6 Object to the form of the question.

7 BY MR. SUSKO:

8 Q Didn't you have a meeting in June
9 with the hospital staff and reaffirm that you
10 wanted to stay with the chemo?

11 A A meeting? I'm not aware of a
12 meeting that ever occurred in June.

13 Q Well, meaning you don't remember
14 that as you are sitting here?

15 A I don't remember.

16 Q While I'm searching for that record
17 your daughter did get in remission, right?

18 A We were told she was in remission.
19 However, the MRD is questionable.

20 Q Where did you get that from?

21 A In reading it.

22 Q So did you post on your blog that
23 the MRD was zero?

24 A Yes.

1 Q Were you told the MRD was zero?

2 A Yes.

3 Q You are saying, what, after the
4 fact today you are questioning whether she was
5 actually zero?

6 A I am saying after my daughter
7 passed away and I obtained her medical records and
8 saw the MRD test results for the first time, I had
9 a doctor look at them and said that they were
10 questionable.

11 Q Who was that?

12 A The medical expert.

13 Q Who was that?

14 MR. CASSIDY: Doctor --

15 THE WITNESS: Dr. Sanders.

16 BY MR. SUSKO:

17 Q When was that?

18 A Sometime in the past year.

19 Q So well after the fact?

20 A I had never seen it prior to that.

21 Q No. Well after the fact did you
22 have some question in your mind about after your
23 daughter's death, did you have some question about
24 whether she had zero Minimal Residual Disease?

1 MR. CASSIDY: Just for the record
2 after the fact of what?

3 BY MR. SUSKO:

4 Q After her death. You didn't
5 question before she died that she had zero Minimal
6 Residual Disease as of --

7 A No. I trusted the doctors.

8 Q -- May 2010, right?

9 A I trusted the doctors.

10 Q I understand that. That's not the
11 question.

12 MR. CASSIDY: It sure sounds like
13 it.

14 MR. SUSKO: That I asked him
15 whether he trusted the doctors?

16 MR. CASSIDY: No. You asked --

17 MR. SUSKO: Let's go back and read
18 the question and see if it sounds like that.
19 Can we have the question back?

20 (The reporter read back the
21 record as requested.)

22 BY MR. SUSKO:

23 Q So my question is, before your
24 daughter passed away did you ever question in your

1 own mind whether she actually had zero Minimal
2 Residual Disease as of May 2010?

3 A No.

4 Q I wouldn't think you did. So we'll
5 do better if when I ask a question if you just try
6 to answer it. If you want to give an explanation
7 you are free to do that. But try to answer the
8 question, if you can.

9 A I'm trying, sir.

10 MR. SUSKO: Why don't we take a
11 short break here. We are at a pretty good
12 breaking point. I'll get this record to put
13 in front of you.

14 THE VIDEOGRAPHER: 11:32, off the
15 record.

16 (Discussion held off the record.)

17 THE VIDEOGRAPHER: The time is
18 11:53. We are back on the record.

19 (Exhibit MP-4 was marked for
20 identification.)

21 BY MR. SUSKO:

22 Q Mr. Pulaski, when we took a break I
23 was getting the record in June of 2010. We had
24 looked at your blog posting that occurred in April

1 of 2010 referencing that if Sarah went in
2 remission you would have a choice between
3 continuing the course of chemo or going down the
4 transplant path. Do you remember that's where we
5 left off?

6 A Yes, sir.

7 Q Okay. So and I had represented to
8 you that there was a further discussion and I put
9 in front of you MP-4. Do you have that in front
10 of you, sir?

11 A I do.

12 Q Do you recall having a family
13 meeting on June 4th with Dr. Rheingold?

14 A I do not.

15 Q In that it says, Father present.
16 Correct?

17 A That's what this document says,
18 correct.

19 Q And it said, Reviewed with father
20 the new risk information as outlined in CTEP 5/27
21 action letter, clarified some risks, described new
22 risks, and reviewed risks associated with
23 nelarabine. But already associated with other
24 meds. Family -- father fully understanding and

1 cognizant of the new/modified risks. Desires to
2 remain on study. Did I read that correctly?

3 A You read that correctly.

4 Q Is it your testimony, sir, that you
5 don't believe that there was a further discussion
6 in June of 2010 where you were presented with some
7 additional information about the drug and were
8 asked again whether you wanted to stay on study
9 and you said you did?

10 A I do not recall any family meeting
11 or conversation that included all of these items.
12 Is it possible that there was a meeting regarding
13 something called CTEP? It's possible. I'd like
14 to see what CTEP is. Because I don't recall. But
15 I certainly can tell you that there was no formal
16 family meeting on June 4th where we discussed
17 continuing on clinical trial versus going another
18 direction.

19 Q Did you reaffirm that you wanted
20 stay on clinical trial in June of 2010?

21 A I don't recall that.

22 Q Okay. You are not saying it's
23 not -- it didn't happen, are you?

24 MR. CASSIDY: I think he was in the

1 middle of his answer.

2 MR. SUSKO: I though he said I
3 don't recall that.

4 MR. CASSIDY: And then he started
5 saying something else. So if you just let
6 him finish.

7 THE WITNESS: I don't recall -- I
8 apologize. I lost my train of thought now.
9 Is it possible that there was a meeting where
10 we discussed something new that was going to
11 occur, meaning there was a new drug or a new
12 test? And every time one of those would
13 occur you would have to sign something
14 saying, okay, we discussed that? Yes, there
15 probably was one of those. I don't know
16 whether it was June 4th or not. Was there a
17 formal family meeting on June 4th where we
18 discussed continuing on treatment?
19 Absolutely not.

20 BY MR. SUSKO:

21 Q Okay. So if Dr. Rheingold would
22 come in and say what is written here in her note
23 happened, you would think that's incorrect?

24 A I would say this as it's written is

1 incorrect, yes.

2 Q And you are not recalling a
3 discussion that there were some new information
4 out about nelarabine. They needed to update you
5 on that information and they reaffirmed at this
6 time on June 4 that you wanted to stay on study.
7 You would say that's not correct?

8 A I remember conversations about
9 nelarabine where Dr. Rheingold was telling me that
10 she was excited because it was now approved for
11 kids on intermediate risk. I don't remember
12 conversations beyond much more than that.

13 Q Okay. Are you saying this
14 conversation on June 4 she has documented it did
15 not happen?

16 A There was no family meeting where
17 we discussed continuing on trial, no.

18 Q Was there a meeting with you where
19 you discussed -- alone -- where you discussed
20 continuing on trial?

21 A No.

22 Q So if Dr. Rheingold wrote that you
23 desired to remain on study and documented that on
24 June 4 and signed it, you think that is

1 inaccurate?

2 A I do believe it's inaccurate. And
3 I would -- could I see what I supposedly signed?

4 MR. CASSIDY: No. He didn't say
5 you signed --

6 BY MR. SUSKO:

7 Q I didn't say you signed anything.

8 A I apologize. I thought you did.

9 MR. CASSIDY: He is saying that she
10 signed the note. I think that's what you
11 mean.

12 MR. SUSKO: Yeah.

13 THE WITNESS: Okay.

14 BY MR. SUSKO:

15 Q She is a medical doctor. She is
16 referencing a meeting with you and advising you of
17 new risks and new information associated with
18 nelarabine and concludes, Father fully understands
19 and cognizant of new modified risk. Desires to
20 remain on study. And my question is, are you
21 saying when Dr. Rheingold signed that, despite the
22 fact she signed it, this did not happen the way
23 she wrote it?

24 A I don't recall the meeting that

1 happened as it is written. No, I do not.

2 Q Are you saying you believe it never
3 happened that way? Or are you saying you don't
4 remember?

5 A As it's written I said it didn't
6 happen.

7 Q Fair enough.

8 A I am telling you that is there a
9 possibility there was a meeting where we discussed
10 something related to nelarabine? Yes. There is
11 probably a chance there was a meeting like that.
12 Was there an actual family meeting where we
13 discussed staying on study? Absolutely not.

14 Q Well, I'm trying to give you the
15 benefit. And I'm modifying my question that when
16 she wrote, Family meeting, father present, that
17 maybe it was just you and her. And maybe CHOP
18 calls that a family meeting. So let's start with
19 that. A meeting with you and Dr. Rheingold where
20 Dr. Rheingold is expressing some new information
21 about nelarabine and the purpose of that is to
22 make sure you want to stay with that drug and stay
23 on study. And you said you understood it and you
24 wanted to stay on study. Are you saying that

1 conversation never happened?

2 MR. CASSIDY: Objection to the form
3 of the question.

4 THE WITNESS: I am not saying a
5 conversation never happened. But I am
6 saying --

7 MR. SUSKO: I'm saying my question
8 is, are you saying that conversation as I
9 paraphrased it never happened?

10 MR. CASSIDY: And I objected to the
11 form of the question.

12 MR. SUSKO: You have your
13 objection.

14 THE WITNESS: As you paraphrased it
15 because you say that I desired to stay on
16 study, then I'm saying, no, that never
17 happened.

18 MR. SUSKO: Okay. Fair enough.

19 THE WITNESS: May I finish my
20 answer? If you want to discuss whether we
21 discussed nelarabine --

22 BY MR. SUSKO:

23 Q I don't. I don't. I want to know
24 -- look. The way this works is I ask the

1 questions I feel like as the attorney for CHOP
2 should be asked. And you answer them. It's
3 not -- our dialogue isn't you want to tell me how
4 to ask another question.

5 A I'm not trying to do that, sir.
6 I'm trying to make sure that I give you the
7 appropriate answer.

8 Q Well, that's not -- you are here to
9 just tell the truth in response to my questions,
10 not give me the appropriate answer.

11 A Okay. The honest answer. Is that
12 a better word?

13 Q Well, when you say appropriate I'm
14 concerned that you are talking about meaning that
15 what you mean by that is consistent with what
16 you've alleged in your complaint.

17 A No, sir.

18 Q And that's not the purpose of this
19 deposition.

20 A Not at all.

21 Q It's my opportunity to ask you
22 questions and have you answer them truthfully.

23 A Sir, when you laid the groundwork
24 you told me that if I didn't thoroughly understand

1 a question that I should stop and you would
2 rephrase it. We've done that a number of times.
3 And when I say I want to make sure I give the
4 appropriate answer maybe honest is a better word.
5 But I'm trying to make sure I'm answering the
6 actual questions you are asking.

7 Q Okay. So let's move to the second
8 consent, if we can. Because we were touching on
9 that. That was done in February of --

10 A May I get some more water?

11 Q Sure. We'll get it for you.

12 A Thank you.

13 Q That way you don't have to undo the
14 mic.

15 A Thanks.

16 (Exhibit MP-5 was marked for
17 identification.)

18 BY MR. SUSKO:

19 Q I'm going to mark MP-5 the second
20 consent for this clinical trial. Did you
21 understand there was a second consent, I think you
22 referenced it earlier, associated with the
23 clinical trial?

24 A Absolutely.

1 Q And just to review the testimony
2 you also understood that in the first or induction
3 phase of the clinical trial, that was essentially
4 the standard therapy you would get even if you
5 weren't in the clinical trial, correct?

6 A For the first twenty-eight days or
7 thirty days, whatever it might have been, yes.

8 Q And then when this consent was
9 signed this was actually the time when there was
10 going to be the randomized assignment by a
11 computer of your child's case to a particular ARM
12 of this research study, correct?

13 A Correct.

14 Q And did the consent that we marked
15 MP-5 identify the ARMs of the study and the
16 treatment associated with those ARMs?

17 MR. CASSIDY: I'm sorry. Can you
18 repeat that, please?

19 BY MR. SUSKO:

20 Q Did the consent that your wife
21 signed, the second consent, identify the ARMs of
22 the study and the treatment associated with those
23 ARMs?

24 A Yes.

1 Q I want to ask you some questions
2 about that. You were interested, am I correct,
3 both you and your wife, in -- and you posted this
4 on your blogs -- in being or having Sarah receive
5 the drug nelarabine, correct?

6 A Correct.

7 Q And you were happy that she was
8 randomized to receive the nelarabine, correct?

9 A Happy is a understatement.

10 Q How would you state it?

11 A Ecstatic.

12 Q That's what you wanted, right?

13 A Correct.

14 Q And that was in February of 2010,
15 correct?

16 A Correct.

17 Q Now, I will direct your attention,
18 sir, to page 94 of this document. You have 94 in
19 front of you?

20 A I do.

21 Q And is this referencing the
22 treatment for ARM D?

23 A Yes, it is.

24 Q And there were three other ARMs of

1 the study. But your daughter was randomized to
2 ARM D as I understand it, correct?

3 A Correct.

4 Q And just so I understand the full
5 picture: As parents of a daughter who you had
6 agreed to participate in this clinical research
7 study, you didn't know before you signed onto the
8 research study this particular time in February
9 of 2010 which ARM she was going to be assigned to,
10 correct?

11 A Correct.

12 Q And you understood that going in?

13 MR. CASSIDY: Going in to what?

14 MR. SUSKO: To signing the consent.

15 THE WITNESS: When we signed the
16 consent, yes, we knew that. But understand
17 we were very clear that we wanted nelarabine.

18 MR. SUSKO: I understand that.

19 THE WITNESS: And the doctors were
20 very clear that they wanted nelarabine.

21 BY MR. SUSKO:

22 Q That wasn't the question. All of
23 that information you are giving me is not
24 responsive and I would move to strike it. I don't

1 want to start moving to strike parts of your
2 answer. But the question was, did you understand
3 when you signed it that it was going to be
4 randomized? You didn't know which ARM you were
5 going to be put to?

6 A Correct.

7 Q I understand. Look, there is a lot
8 of information in the case. I don't mean to be
9 harsh. I just -- if every answer is going to have
10 a speaking monologue following it about all the
11 things that relate to what I'm asking, this would
12 be a three-week deposition. We don't -- I'm just
13 trying to move things along. So I'm not trying to
14 be heavy-handed. I'm just trying to ask the
15 questions that I think are appropriate -- again,
16 doing my job.

17 A And I'm only trying to answer them,
18 sir.

19 Q Okay. So if you could try to just
20 answer what I'm asking, I think -- if you feel
21 like you need to explain I don't want to tell you
22 you can't. If you can focus on my question and
23 try to answer my question I think that's what we
24 are trying to do. Okay.

1 So did you know going in that you
2 wanted ARM D as opposed to any other ARM of the
3 study?

4 A No. We were looking -- I believe
5 there were two ARMs that includes nelarabine. And
6 Dr. Rheingold just wanted one of those two.

7 Q Fair enough. And if we look at
8 that, are we able to tell from the consent which
9 ARMs included nelarabine?

10 A I'm sure you can.

11 Q And that's because the treatment
12 that was going to be for participants who were in
13 a particular ARM is all spelled out, correct?

14 A Yes.

15 Q And did Sarah go through the
16 treatment in ARM D? That's A-R-M and then capital
17 "D."

18 A Yes. Well, yes, but not as
19 defined.

20 Q Okay. When you say not as defined,
21 what do you mean by that?

22 A The treatment has specific days and
23 spans that she was supposed to receive nelarabine
24 on days 1 through 5 and days 43 through 47 she's

1 supposed to receive --

2 Q Intrathecal methotrexate?

3 A A number different drugs and spinal
4 taps and so forth. And as an example if a phase
5 is supposed to take thirty days, it says on day 1
6 you get this. On day 2 you --

7 Q Understood. Keep going.

8 A So you asked if she did the ARM and
9 the answer is yes; however, not as identified
10 here.

11 Q Pretty close, right?

12 A No. No, sir.

13 Q Okay. Well, there are bunch of
14 asterisks to this and they talk about if you
15 develop an allergy you may have this. If you have
16 this we'll skip this part of it. What I'm saying
17 is she received the drugs identified pretty
18 closely -- forget the days she received them --
19 but she received the drugs identified here pretty
20 closely during the consolidation, interim
21 maintenance, delayed intensification, and
22 maintenance cycles, did she not?

23 MR. CASSIDY: I have to object to
24 the form of the question. When you say very

1 closely he's indicated the days are
2 different.

3 MR. SUSKO: Well, that's why I
4 said -- that's why I changed my question,
5 Counsel. I'm talking now -- I'm not talking
6 about the days. I'm talking about the drugs
7 that are identified in those phases of the
8 ARM. And I use pretty closely because I
9 don't want to get into an argumentative
10 discussion about, well, she didn't receive
11 this drug on that day but she may have not
12 received it at all. I mean, we can go
13 through the record about the administration
14 record of all of these drugs if you want.
15 I'm trying to cut through that. But let me
16 ask it differently. I'll withdraw the
17 question and rephrase it.

18 BY MR. SUSKO:

19 Q As you are sitting here today, are
20 you able to point to specific drugs identified in
21 this treatment ARM that she did not receive?

22 A She received the drugs but not in
23 the dosages and the timeframes that were outlined
24 for the trial.

1 Q Okay. And the reason -- and did
2 you understand from looking at the document that
3 there are times when if the counts aren't
4 sufficient they might skip a dose or they might
5 modify it?

6 A Within reason, yes.

7 Q Do you think that there was
8 unreasonable modification of the treatment plan?

9 A Yes, I do.

10 Q And did you think that while the
11 treatment was being rendered?

12 A It was raised to the doctors on
13 several occasions.

14 Q And who raised it?

15 A Generally myself or my wife on
16 numerous occasions. We would raise concerns
17 regarding delays to both Andy and Sue.

18 Q Well, I saw some information where
19 you were concerned about your daughter's counts
20 and the timeliness of starting things up again.
21 But were you actually -- are you giving testimony
22 that you questioned their medical judgment, that
23 if your daughter hadn't recovered from a prior
24 chemo that it might be dangerous to her to keep to

1 a set schedule?

2 A We questioned the fact that they
3 had told us on a number of occasions that due to
4 the delays in Sarah's treatment that they were
5 going to meet and modify her dosages. And there
6 are a few blog entries where I talk about the fact
7 that they are going to address it. And they never
8 would meet and modify anything with the exception
9 of one drug called mercaptopurine which if you
10 look at the clinical trial it says that's the one
11 that you are not supposed to modify.

12 Q Well, I'm confused by your
13 testimony now. So you are saying they did modify
14 you and you were concerned about that or modify
15 the drugs she was receiving and the timing of it.
16 But then you said you are raising issues with them
17 and they weren't modifying it. I'm confused by
18 what you just said.

19 A So the primary drugs nelarabine,
20 the non --

21 Q Methotrexate?

22 A Methotrexate. It's called 6-MP.
23 That's the one that's an oral drug that's taken as
24 a pill.

1 Q And the PEGs?

2 A PEGs are extremely painful shots.

3 Q Understood. Did she have those
4 three?

5 A She did. However we were told on
6 numerous occasions that they were going to meet to
7 discuss primarily modifying the nelarabine dosage.
8 Because there was concern about Sarah's delays in
9 her treatment. And on numerous occasions we'd
10 question them. On --

11 Q Are those documented in your notes?

12 A The blog entries have probably a
13 few comments about the fact that the doctors are
14 going to meet to modify the dosages.

15 Q I just didn't see criticism of the
16 doctors in any of those notes.

17 A See, you have to understand the
18 blog entries are something that my daughter read.
19 So as I was writing them, you know, you weren't
20 typically critical. You were informative and in
21 many cases praise them. I mean, I loved these
22 doctors.

23 Q You also were -- okay. But I'm not
24 detecting that. I'm detecting that you think that

1 they mismanaged her drug administration. And you
2 also -- I think you gave testimony that they
3 didn't meet. How would you know whether they had
4 met or not?

5 A I believe I said I'm not sure if
6 they met.

7 Q I thought you said they didn't
8 meet.

9 A I don't recall what I said.

10 Q Do you know whether they met --

11 A I --

12 Q -- to discuss medication and timing
13 of medication for your daughter?

14 A I know that they promised they were
15 going to meet.

16 Q That wasn't the question.

17 A I don't know if they met.

18 Q Because I think you gave
19 testimony -- if you gave testimony that they did
20 not meet, are you withdrawing that? Because I
21 think the truth is you wouldn't know whether they
22 met. But I'm giving you an opportunity now.

23 A On numerous occasions we raised
24 concerns regarding Sarah's delays. We were told

1 that they were going to meet to discuss changing
2 her dosages. What I am saying to you is I don't
3 know if they met. But I can tell you they never
4 changed her dosages.

5 Q That's different testimony. They
6 may have met, discussed it thoroughly and decided
7 that they weren't going to make any change that
8 you might have been suggesting or that you might
9 have thought was appropriate. But I believe you
10 said earlier they never met. So are you
11 retracting that you said that?

12 A They never met with us. If I said
13 that they never met, then obviously I will retract
14 that because I don't know every meeting that they
15 had and every conversation they had.

16 Q Right. Did you know what their
17 process of meeting on the various patients were?
18 Did they describe that to you?

19 A I do know that they have a Thursday
20 meeting where we were -- they told us on numerous
21 occasions beginning in Sarah's very first or
22 second week at the hospital that Sarah was often a
23 topic during the Thursday meetings because --

24 Q All the kids were, weren't they?

1 A I don't know.

2 Q All right. Fair enough.

3 A I don't know.

4 Q Okay. Fair enough.

5 A So --

6 Q That's all -- that's the only point
7 I was making. It sounds like the testimony is
8 that whether there were meetings or not you didn't
9 feel like some things you were raising were
10 addressed? Is that the fair essence of it?

11 A Correct. I mean, because I want to
12 come back to your question. Your question is did
13 my daughter follow ARM D as laid out? And did she
14 receive those specific drugs? Yes. However, what
15 I am saying to you is that there were numerous
16 delays that took her off of the schedule;
17 therefore, if she was supposed to receive -- I
18 don't know -- I'm just going to use a number and
19 say a hundred. Let's say that's a dosage of
20 something. In Sarah's treatment she probably
21 received 60 percent of that dosage because of
22 delays that were never addressed.

23 Q And do you know whether that was
24 within the margins of what the team thought

1 therapeutically was appropriate for her given her
2 condition or not?

3 A I can tell you --

4 Q Can you answer that question?

5 A Yes.

6 MR. CASSIDY: Nobody can know what
7 somebody -- come on.

8 THE WITNESS: I can tell you if --

9 MR. SUSKO: You just said yes.

10 THE WITNESS: If I can tell you
11 that Dr. Wood himself on numerous occasions
12 told me that other doctors would freak out if
13 they saw how often Sarah was off treatment.
14 And he said, however, he and Sue know it's
15 just Sarah being Sarah.

16 BY MR. SUSKO:

17 Q Okay. And can you be more specific
18 than that with regard to what he was referring to
19 in particular?

20 A The delays in her treatment.

21 Q Well, you are talking about delays.
22 You took her to the hospital all the time, didn't
23 you?

24 A Yes. But that didn't mean that

1 every time you went to the hospital you received
2 treatment.

3 Q And when you are saying delays in
4 treatment are you talking about their getting
5 blood work, getting her counts, making a
6 determination, a judgment, whether she can endure
7 the chemo without a significant adverse side
8 effect? Or are you just saying you are waiting in
9 line and they can't get to her? What are you
10 saying?

11 A No. You're -- I'm saying you go in
12 and based upon the recovery from the treatment
13 that they previously gave her they will either
14 restart treatment or you go home.

15 Q It might be medically unsafe to
16 administer treatment. Did you have this
17 understanding that it might be medically unsafe to
18 administer treatment if she hadn't recovered from
19 the prior time?

20 A I had the understanding of that in
21 addition to the understanding that it may be
22 medically unsafe not to restart treatment.

23 Q Understood. It's a difficult
24 position. They are trying to do what they can do

1 to keep her disease in check. But that is back to
2 my original question: Did they discuss with you
3 at any point, and I was referring to the first
4 note we looked at today at today's deposition,
5 that there was risk to the chemotherapy itself?

6 MR. CASSIDY: Just object to the
7 first half of that question.

8 BY MR. SUSKO:

9 Q Okay. Go ahead.

10 A You are asking if I understood
11 there was risk to having chemotherapy? Yes.

12 Q Yes. And there certainly was
13 risk -- did you understand there was certainly
14 risk if you administered chemotherapy if she
15 hadn't fully recovered from the prior chemo?

16 A Yes. And I apologize. But I need
17 to explain this answer. There were doctors --

18 Q I'm not trying to make you the
19 expert by the way. My question -- this case has a
20 lot to do about what you understood.

21 A Sure.

22 Q Not necessarily the why of it. You
23 maybe -- that may or may not be relevant. But if
24 you had an understanding that what expressed to

1 you my client may have fully discharged their
2 obligation under the lay. So all I'm asking you
3 is whether you understood that there was a risk of
4 administering chemo to your daughter's safety if
5 she hadn't fully recovered from the prior session?

6 A I understand that there was a risk
7 to administering it. I understand there was a
8 risk to not administering it.

9 Q Okay. Now, did you understand,
10 sir, that stem cell transplant was not an
11 identified treatment option in this clinical
12 trial?

13 A Yes. However, I understood that we
14 were moving towards transplant, that we were
15 testing my son for to see if he would be a match
16 for transplant. And I understood that we were
17 going to meet to discuss transplant and moving in
18 that direction.

19 Q Because if your daughter didn't
20 respond appropriately CHOP might recommend to you
21 to take her off study to do a transplant, right?
22 That would be one option, right?

23 A No. You had to get into remission
24 before transplant was an option. Which is why --

1 Q Wasn't -- go ahead.

2 A Which was why they needed -- why
3 they felt they needed nelarabine.

4 Q Wasn't your daughter -- well, we
5 are talking across each other. As of May 20, 2010
6 wasn't your daughter identified to have zero
7 disease and didn't you post that in your blog?

8 A Yes.

9 Q It's May 28th?

10 A Yes.

11 Q So you understood at that point,
12 and this is my question, that if you're part of
13 clinical trial she is not going to have a stem
14 cell at that point because she is going to have
15 two years of this therapy. Didn't you understand
16 that?

17 A If you remain in the clinical
18 trial, yes.

19 Q Okay. And, in fact, after you had
20 signed, your wife had signed this consent in
21 February of 2010, because of the way she was
22 responding to the chemo initially CHOP actually
23 had your son go to Johns Hopkins to get matched in
24 case there was a need to take your daughter off

1 the study, right?

2 A No.

3 Q When did your son go to Johns
4 Hopkins?

5 A He didn't.

6 Q I thought you alleged that in the
7 complaint?

8 MR. CASSIDY: He was tested but he
9 wasn't tested at Johns Hopkins.

10 MR. SUSKO: I think the complaint
11 says he was.

12 THE WITNESS: The testing -- they
13 conducted the test at CHOP. The test results
14 were sent to Johns Hopkins.

15 BY MR. SUSKO:

16 Q Fair enough. That's not
17 necessarily material. I thought your complaint
18 said something to the contrary. But let me just
19 look real quick.

20 A They drew his blood at CHOP. The
21 test was done at Johns Hopkins.

22 Q I got it. Fair enough. Whatever
23 those facts are, they are. I just seem to recall
24 that you alleged in your complaint something

1 different. Just give me a second to locate that.
2 Hold on. So -- and I'm not sure that I was
3 looking for the match.

4 So in or about May 2010 plaintiff's
5 decedent -- plaintiff's decedent underwent a flow
6 cytology study at Johns Hopkins. You are saying
7 that was sending blood work there?

8 A Yes.

9 Q Okay. And the timing of the match
10 identification of your son as a bone marrow
11 transplant donor was when, sir?

12 A The only time we ever were told
13 anything about it was within a few weeks after the
14 test was conducted.

15 Q Which was when?

16 A That was I want to say April --

17 Q April 2010?

18 A Yeah, late April.

19 Q Now, are you saying that it wasn't
20 discussed with you at the time by Dr. Rheingold
21 and/or Wood or anybody else at CHOP, that the
22 reason why this testing was done was if Sarah
23 didn't get the response on this clinical trial
24 that everyone was hopeful for with nelarabine,

1 meaning achieve remission, that if she didn't get
2 that response one option would be to take her out
3 of the trial and then do a bone marrow transplant?
4 And they wanted to be ready for that. That's why
5 they sent the blood down to Hopkins?

6 A Sir, I'm sorry. But the question
7 doesn't make sense. If she --

8 Q So the answer to that is no.

9 A The answer to that is no. May I
10 explain?

11 Q I don't know -- I'm just trying to
12 understand if you had that understanding. And if
13 you didn't, if --

14 A Not as you just questioned it.
15 You're making the assumption that if Sarah doesn't
16 respond to the treatment and get into remission
17 that she can go transplant. But I'm telling --

18 Q I'm not making any such assumption.

19 A That's what your question just
20 said. The reality --

21 Q But I wasn't.

22 A -- is if you don't get into
23 remission you cannot get a transplant.

24 Q Well, we can have a medical debate.

1 But that's not going to be particularly helpful --

2 A That's how it was explained to me.

3 Q Okay. Let's step back from this
4 and the fray of the deposition. Let me ask you
5 this. The object of this treatment was to get
6 your daughter in remission, right?

7 A The object of the treatment was to
8 cure my daughter. Getting her in remission was a
9 piece of that.

10 Q Oh. Did they tell you that they
11 could completely cure leukemia?

12 A They said that they cured three out
13 of four kids.

14 Q Was that -- did you confirm that in
15 your internet research that patients who have
16 leukemia and are under therapy are cured
17 completely?

18 MR. CASSIDY: He never said they
19 were cured completely.

20 BY MR. SUSKO:

21 Q I'm asking him. Wait. I'm asking
22 him whether in his research he ever found research
23 that said patients were cured completely?

24 A As I understand it in my research

1 they consider someone cured after five years.

2 Q Okay. So and that was another
3 question that I had asked you earlier about remain
4 disease-free for a period of time. And I asked
5 you and you said you didn't really have that data.
6 But back to my question which is that when you
7 were advised that your son was a match --

8 MR. CASSIDY: Daughter. I'm sorry.
9 My mistake.

10 BY MR. SUSKO:

11 Q Okay. Let me rephrase. Let me
12 start back up. When you were advised your son was
13 a match at or around that time, weren't you having
14 discussions with CHOP that if your daughter did
15 not continue to progress, meaning her numbers did
16 not pan -- prove out to be in remission, that one
17 of the things that would have to be considered is
18 taking her off study?

19 A It was always the plan was to have
20 those meetings and discuss that. But they never
21 formally --

22 Q But why -- why was your -- the blog
23 posting where you said we are going to choose a
24 path: Either continue chemo or go down the

1 transplant path. Why was CHOP matching your son
2 if you had chosen to do the chemo?

3 A Because we were always supposed to
4 have that meeting and have that discussion about
5 moving down that road.

6 Q Are you saying that after you
7 participated in this two-year chemo treatment that
8 after that there was going to be some
9 consideration of stem cell?

10 A No. I'm saying long before that.

11 Q Okay. I understand that's your
12 position in the case. But what I'm asking you is
13 your understanding at the time. You are in this
14 ARM. I showed you a note saying in June you
15 reaffirmed your desire to stay on study. You did
16 stay on study, right?

17 A Mm-hmm.

18 Q Correct? You have to answer
19 verbally.

20 A Yes.

21 Q You stayed on study despite the
22 conversation you had with Dr. Wood, right?

23 A Which the --

24 Q The June, July, August --

1 A The July/August conversation. Yes,
2 I did.

3 Q You stay on study. Okay. And you
4 understood that staying on study meant nelarabine
5 was the principal therapy and you understood this
6 clinical trial study was going to last two to two
7 and a half years, correct?

8 A But I need to stop you with the way
9 you just phrased that. It sounds to me that you
10 just said I stayed on study after that
11 conversation with Andy Wood.

12 Q Well, not you, your daughter. You
13 didn't pull her off of the study.

14 A I was essentially told that I
15 didn't have an option.

16 Q I know you felt that way and you
17 trusted the doctors, right?

18 A Absolutely, I trusted the doctors.

19 Q But you had an absolute right in
20 the consent, let's turn to it, to remove your
21 daughter at any time, did you not?

22 A That was my understanding.

23 Q And you have this discussion with
24 Dr. Wood in which at the end of it you did not

1 take your daughter off the study, right?

2 A In the end of it I was told that
3 CHOP would no longer offer Sarah a bone marrow
4 transplant.

5 Q Okay. Well, look, that's
6 different, sir, respectfully than what you said
7 about 25 minutes ago.

8 A I don't think it is.

9 Q The fact that CHOP -- if you are in
10 this ARM, the fact that CHOP is not going to offer
11 a bone marrow transplant doesn't keep you from
12 taking her off the study, does it?

13 A During -- I guess not. I mean, I
14 made it clear to Dr. Wood that I would prefer to
15 come off the clinical trial and go to transplant.
16 And he told me that wasn't an option.

17 Q Well, because she was in remission,
18 right? It wasn't in their view -- hold on. It
19 wasn't in their view the appropriate way to
20 proceed for your daughter, right? She was in
21 remission according to them on nelarabine.

22 A And that's when you take a child to
23 transplant.

24 Q Well, that's your opinion. But

1 they didn't have that view, right?

2 A That's what they've told me.

3 Q Then why did you sign on to the
4 clinical trial in the first place?

5 A To get my daughter into remission.

6 Q Did she get into remission?

7 A I assume so, yes.

8 Q They told you that, right?

9 A Yes.

10 Q And you did not take her off the
11 trial at that point, right? You didn't take her
12 off the trial when she was in remission?

13 A I eventually requested to Dr. Wood,
14 When are we going to have the meeting about
15 transplant? Because that was the direction I
16 wanted to go because I saw another child dying.

17 Q And there was -- why didn't you
18 just take her off the study and go treat somewhere
19 else?

20 A Because I had a meeting with this
21 doctor in front of my daughter where he made every
22 effort to tell me that my concerns were not
23 founded and that I couldn't compare Sarah's
24 treatment to another child's treatment and where

1 he said we can always get these kids back into
2 remission.

3 Q That's what you heard?

4 A No. That's what he said.

5 Q So he guaranteed you that if there
6 was relapse that he could a hundred percent
7 achieve remission?

8 A He did not give me a hundred
9 percent. He didn't talk about percentages.

10 Q You just said he said always.

11 A I'd have to go back to my notes. I
12 actually think he did say "almost always." He
13 made it very clear that I couldn't compare Sarah's
14 case to Ricky's.

15 Q Okay. Is that because Ricky was a
16 relapse patient?

17 A Well, Ricky was a relapse patient.

18 Q Yeah. Right.

19 A Who had a fully matched sibling
20 who --

21 Q Correct. But Ricky was a relapse
22 patient, right?

23 MR. CASSIDY: He just said he was.

24 THE WITNESS: Correct.

1 BY MR. SUSKO:

2 Q Okay. I'm trying to ask the next
3 question and he wants to explain that too. But so
4 Ricky is a relapse patient. And do you know if
5 the CHOP doctors' opinion was that's the
6 appropriate time to then put the patient in
7 remission and consider stem cell?

8 A What I was learning at the time was
9 if you wait until a child relapses before you take
10 them to a bone marrow transplant there is the risk
11 that you will never get to bone marrow transplant.

12 Q Of course.

13 A That was never explained to us.

14 Q I think that's -- look --

15 A That was never explained to us.

16 Q You never got there with her?

17 A We tried.

18 Q You -- when you say it was never
19 explained to you, you had a note that said once
20 she is in remission I've got to make a decision
21 whether to continue chemo or go down the
22 transplant path. You certainly knew that was the
23 option, right?

24 A Mm-hmm.

1 Q Correct? You have to answer
2 verbally.

3 A Mm-hmm.

4 Q That's what you wrote.

5 A I also wrote --

6 Q Did you write that? That's what
7 you wrote. That was your option. She is in
8 remission. I can either take her to transplant or
9 I can stay with the chemo, right?

10 A I wrote on numerous occasions that
11 we will meet with the doctors to have that
12 discussion.

13 Q Right. But so your fault is in
14 terms of the care you did have the discussion
15 because you were pursuing that avenue you are
16 saying, right?

17 A I had a discussion with a fellow.

18 Q Okay. And that fellow was
19 Dr. Wood. Did you ever say, hey, you are a
20 fellow. I have no demeaning intended. You are
21 still a student. You are still in study. Can I
22 talk Dr. Rheingold about this?

23 A No, I did not.

24 Q Did you ever go to the

1 institutional review board at the hospital and
2 raise that issue with them?

3 A I didn't know that was an option.

4 Q It's right in the consent. Did you
5 read the consent?

6 A I did, sir.

7 Q Let's take a look at that just to
8 refresh you. If you would turn to page 101 and
9 102. Are you on that?

10 A Mm-hmm.

11 Q We did cover in the other consent,
12 and this is consistent with that, participation in
13 the study is voluntary. You do not have to take
14 part of it -- part in it in order to receive care
15 at CHOP. Your participation -- you may choose to
16 leave the study at any time, correct?

17 A Mm-hmm.

18 Q That's what is written here, right?

19 A Mm-hmm.

20 Q You have to answer verbally?

21 A Yes.

22 Q And you can decide to stop being on
23 the study at any time, correct?

24 A Yes.

1 Q So the truth is you raised it with
2 Dr. Wood, as you say, and you trusted him and
3 therefore you chose to stay on the study?

4 A I was told I had no option. It's
5 different. It is different.

6 Q Your option was to leave the study
7 and seek care elsewhere if you wanted it. You
8 certainly knew it was an option because you were
9 investigating -- you were requesting it yourself,
10 right?

11 A I was requesting to meet with the
12 bone marrow transplant team.

13 Q Okay. Let's look at 102. Whom do
14 I call if I have questions or problems? Do you
15 see that?

16 A Mm-hmm.

17 Q You have to answer all those
18 questions verbally.

19 A Yes.

20 Q If you have questions about the
21 study call the study doctor, Dr. Rheingold. It
22 gives her phone number. Do you see that?

23 A I do.

24 Q Then it says, The study has been

1 approved by a special group at CHOP called the
2 institutional review board. The institutional
3 review board looks at research studies like these
4 and makes sure rights and welfare are protected.
5 You can talk to a person in this group if you have
6 questions about your rights as someone taking part
7 in the research study.

8 Did you have questions after you
9 talked to the fellow about whether you had a right
10 to get either another treatment either at CHOP or
11 somewhere or any question about whether you had to
12 leave the study?

13 A I did not.

14 Q Was there a reason why you didn't
15 talk to the attending physician who was
16 responsible for your daughter's care at CHOP about
17 this?

18 A There is. Because the conversation
19 that occurred with Andy, with my daughter present,
20 he spent an least seven, eight, ten minutes
21 telling me why I was wrong to have the concerns
22 that I have where he said he could almost -- they
23 can almost always get these kids back into
24 remission, and that I shouldn't worry about

1 relapse. And he spent -- and I was very clear to
2 him that I did not want to be like the McAvate
3 family where you relapse and then find out that
4 you can't get a child back into remission. And he
5 told me that I couldn't look at that, that every
6 cancer was different.

7 Q And so you then took that
8 information and decided to stay on study?

9 A There was no decision. It was --

10 Q Well, you had one doctor giving you
11 an opinion.

12 MR. CASSIDY: Hold on. Let him
13 answer the question.

14 THE WITNESS: There was no
15 decision. Andy told me we were on the path
16 that they wanted us on. So I dropped it.

17 BY MR. SUSKO:

18 Q Okay. That's my point. When you
19 dropped it that was your way of staying on study.
20 You didn't raise it again. Did you raise this
21 conversation with your wife?

22 A Mm-hmm.

23 Q And what did she say?

24 MR. CASSIDY: Just for the record

1 when he asked you that question you were
2 making a noise while you were drinking.

3 MR. SUSKO: I think he said yes.
4 But go ahead.

5 MR. CASSIDY: I just want to get it
6 on the record.

7 THE WITNESS: Yeah. My wife and I
8 discussed it. We were dumbfounded.

9 BY MR. SUSKO:

10 Q And now that you've given that some
11 reflection, had you discussed with her in advance
12 that you were going to request to pull her off
13 study?

14 A I don't recall.

15 Q When you learned that your daughter
16 was zero --

17 A May I?

18 Q Do you need to take a break?

19 A No. No.

20 Q I think your answer stands. I
21 don't -- you want to just start talking? Go
22 ahead. The floor is yours. The way this works is
23 I ask questions and you answer. Bruce, you want
24 to make an objection, make an objection.

1 MR. CASSIDY: The only comment I'd
2 make is if you -- were you trying to answer
3 his last question?

4 THE WITNESS: I was. Because the
5 way that it was phrased, it didn't --

6 MR. CASSIDY: Go ahead and make
7 whatever answer you were going to make.

8 THE WITNESS: You asked about the
9 conversation with my wife and whether I
10 discussed whether we were going to come off
11 transplant -- or come off study --

12 MR. SUSKO: In advance of talking
13 to Dr. Wood.

14 THE WITNESS: -- in advance. And
15 my response to you was we had numerous
16 conversations. And if you go transplant,
17 which was always the plan to have those
18 conversations and go that direction, the fact
19 that you come off study is -- it's a given.
20 You have to come off study to go transplant.

21 BY MR. SUSKO:

22 Q Right. And that's -- you captured
23 that in your April email, right? So you
24 understood that, right?

1 A I understood that going to
2 transplant meant that you would come off study.

3 Q Okay. Right.

4 A That was the request.

5 Q Right. And that is why -- that is
6 why I asked you all the questions about whether
7 transplant is in treatment ARM D. And it's not,
8 correct?

9 A Correct.

10 Q Okay. So and the clinical trial
11 that you had your daughter participate in to get
12 the nelarabine, trusting the CHOP physicians that
13 this was a good option for your daughter, all of
14 that required you to say, yes, I want to do it.
15 And there were other options. And one of those
16 other options was the stem cell transplant, right?
17 In fact, that is -- you just said you were
18 pursuing -- you had always discussed with your
19 wife whether we were going to take her off study
20 to get her a stem cell, right?

21 A We always knew or we always
22 expected to have the meeting with the stem cell
23 transplant team to discuss that option.

24 Q Did you request that meeting?

1 A We requested on numerous occasions
2 with Andy and Sue when are we going to have that
3 meeting.

4 Q That's not what I asked you. I
5 said did you request --

6 A I just said yes.

7 Q Did you request from Dr. Rheingold
8 a meeting with the stem cell transplant team?

9 A Yes.

10 Q When did you do that?

11 A On numerous occasions.

12 Q Did you allege that in your
13 complaint?

14 A I don't know.

15 Q So when you -- you say on numerous
16 occasions. When is the first time you requested
17 from Dr. Rheingold -- hold on. Don't shake your
18 head if -- you got to let me get my question out.
19 Fair?

20 MR. CASSIDY: I'm with you. Go
21 ahead and ask again.

22 BY MR. SUSKO:

23 Q When is it that you first say you
24 made a request to Dr. Rheingold to meet with the

1 transplant team?

2 A As you just --

3 Q When?

4 A -- phrased that the answer is there
5 was never a specific request that said, We want
6 to. The request was, When will we, which is
7 different from your question. On numerous
8 occasions we asked, When are we going to meet?

9 Q Well, if you elected to go into a
10 treatment protocol for two and a half years using
11 nelarabine where transplant was not part of the
12 therapy you wouldn't be making a request, would
13 you, to meet with the transplant team at that
14 point?

15 A Sure you would.

16 Q Okay. So did anything prevent you
17 from meeting with any other -- going to any other
18 hospital, getting a second opinion, talking to the
19 IRB, exploring transplant on your own?

20 A No. We were at what we thought was
21 a great hospital.

22 Q Understood. And their view of it
23 was if she was in remission and had not relapsed
24 that wasn't standard of care to do a stem cell

1 transplant?

2 MR. CASSIDY: That's a statement.

3 That's not a question.

4 BY MR. SUSKO:

5 Q Right. Did you understand that?

6 A Can you restate that?

7 Q Did you understand that CHOP's view
8 of it in your daughter's care was that she was in
9 remission, she had not relapsed, and that they
10 were not going to do a stem cell transplant if
11 those were the circumstances?

12 A No. That's not my understanding.
13 My understanding transplant --

14 Q I thought that's what Dr. Wood told
15 you?

16 A And, again, I was dumbfounded after
17 that conversation with Dr. Wood that they'd go and
18 make that decision without us.

19 Q Did Dr. Wood communicate to you
20 that CHOP's view of appropriate care was if the
21 patient achieved remission and had not relapsed
22 that a stem cell transplant on this clinical trial
23 was not the appropriate thing for your daughter?

24 A No.

1 Q Now, you know, you are putting me
2 in a position of recounting your conversation
3 which I wasn't at. But so you didn't understand
4 and have a come to understand that CHOP's view is
5 if you are in first time remission and had no
6 recurrence that they don't think stem cell
7 transplant is the appropriate care?

8 A Sir, there were numerous
9 families that we --

10 Q I'm just asking you that question.

11 A May I please explain? Every time I
12 attempt to --

13 Q I don't get an answer.

14 MR. CASSIDY: Andy, let him try to
15 answer. See what he says.

16 MR. SUSKO: Telling me about
17 numerous families isn't answering the
18 question, I don't think. Maybe we need to
19 take a break.

20 THE WITNESS: You asked me if I was
21 aware that performing a stem cell transplant
22 in first remission was not the standard.

23 MR. SUSKO: That CHOP employed.

24 THE WITNESS: No. I'm not aware of

1 that because I saw many families that did go
2 the transplant first remission.

3 BY MR. SUSKO:

4 Q At CHOP?

5 A At CHOP.

6 Q And was who was their -- who was
7 their treating doctor?

8 A Numerous.

9 Q Identify one.

10 A I would have to go back and see.

11 MR. CASSIDY: Identify the patient.

12 That way you can find out.

13 THE WITNESS: Oh, Macy, Joey were
14 both transplants in first remission. Sue
15 Rheingold told me of a young girl named
16 Sophie who was a T-cell patient that was
17 going to transplant.

18 BY MR. SUSKO:

19 Q High risk patients?

20 A Probably.

21 Q Do you know one way -- don't just
22 make it up. You said probably. Do you think they
23 were or you don't know?

24 MR. CASSIDY: You just asked him to

1 identify the doctors and he's trying to get
2 you patient names.

3 BY MR. SUSKO:

4 Q No. No. No. I'm on a different
5 question now. I asked him high risk and he said
6 probably. And I'm following up. So don't go back
7 to my other question. He is making statements on
8 the record under oath. I'm just asking. Do you
9 know that for a fact that they were high risk or
10 not? Or is it just a guess?

11 A I don't know what the risk was.

12 Q I didn't think you would. Did you
13 have -- did you have medical information about
14 whether they were relapse? Where did you get that
15 information that they weren't relapse?

16 A From the families.

17 Q So you talked to them and their
18 understanding was it was first remission and they
19 were getting stem cell?

20 A The conversation wasn't about their
21 understanding. The conversation was about their
22 children who were going through transplant in
23 first remission. In addition --

24 Q So who -- let's talk about who the

1 families were. I want their names because I want
2 an opportunity to talk to them to see if it's
3 accurate.

4 A Sure. Macy Tilsner.

5 Q Okay. And where did they live?

6 A They are down the Jersey shore.

7 Q Where in New Jersey? That's pretty
8 broad.

9 A I don't know, sir.

10 MR. CASSIDY: I think he said the
11 Jersey shore.

12 BY MR. SUSKO:

13 Q That's pretty broad. That's why I
14 said what I said. You don't have a specific
15 location?

16 A Rio Grande down near Wildwood
17 Crest, I believe.

18 Q And is that the patient's name or
19 the parent?

20 A Macy is the patient.

21 Q Do you know the parents' names?

22 A The mother's name is Marti.

23 Q Marti?

24 A M-A-R-T-I.

1 Q And so you had a discussion with
2 Marti or the father or both? Or how did that go
3 down?

4 A Numerous. We got to be close to
5 them.

6 Q Did you discuss it with both of the
7 parents?

8 A No. Just Marti. I never really
9 met the father. I think they are divorced.

10 Q Okay. And she told you -- so the
11 discussion about first remission, relapse, were
12 you -- did this just come up out of the blue? Or
13 you were raising with her whether you can get a
14 transplant for your daughter in first remission?

15 A No. The conversations --

16 Q How did it come up?

17 A -- were just about the fact that
18 they were going to transplant.

19 Q So did you tell them about Sarah's
20 situation? Did you tell Marti about --

21 A Probably. I don't remember.

22 Q I'm just trying get how you got the
23 information. Like one way it could go down is you
24 were very concerned about whether you should

1 choose the path of stem cell or stay with the
2 chemo?

3 A So you are trying to get at how we
4 would have those conversations?

5 Q Yeah. What I'm just trying to get
6 a sense of is it you are both just comparing
7 notes? Or were you trying to make that decision
8 which path to go or what? How did that --

9 A No. At 2 o'clock in the morning
10 when you can't sleep you go out in the hall and
11 you talk to the parents who are also unable to
12 sleep. And you have conversations about your
13 kids. And you learn that your daughter has T-cell
14 and their daughter has B-cell or whatever it might
15 be. And you learn that they are going through
16 transplant. And you say, oh, well, we are
17 probably going through transplant too. We are
18 still in the early stages. Sarah is not in
19 remission yet. That's how you learn those things.
20 You don't have specific meetings and say, well, we
21 are getting this drug tomorrow. We're --

22 Q And I wouldn't expect that. So in
23 a hall conversation you are saying we haven't
24 achieved remission. And so it's early yet. But

1 you learn from Marti that their child who is in
2 first remission is receiving a transplant?

3 A Yep. Same thing with Joey.

4 Q Okay. Let's get the other name.
5 Who is it?

6 A I don't remember Joey's last name.
7 I can get that for you. They live in Deptford,
8 New Jersey.

9 Q And you mentioned T-cell, B-cell.
10 I mentioned high risk. Dr. Wood, when you were
11 raising this issue is saying -- and you were
12 talking about Ricky -- was saying all these
13 patients are different, right?

14 A Yes.

15 Q So you are basing your
16 understanding that there were first remission
17 patients going to transplant at CHOP. Would you
18 concede or would you agree with me you don't know
19 the exact circumstances? T-cell? B-cell? What
20 they were?

21 A For those two I don't. There is
22 another young girl named Sophie.

23 Q I'm focused on these two right now
24 and we'll add Sophie in a minute.

1 A Okay. For those two, no, I don't
2 know.

3 Q And so did you raise these two kids
4 with Dr. Wood?

5 A No. Because they were doing well.
6 They had been post transplant and were doing well
7 when I had my --

8 Q I'm confused. You are going to
9 Wood and you are saying, hey, I'd like to go to
10 transplant. And he is saying, no, I don't. Did
11 you know at the time you were having that
12 discussion with him that these two patients were
13 going to transplant?

14 A I did. But, again, my focus on
15 that -- in that meeting was I didn't want to be
16 like Ricky's family.

17 Q And Ricky was a relapse patient?

18 A Ricky was a patient that they
19 couldn't get back into remission, correct. He was
20 a relapse.

21 Q Right. So -- and by the way, those
22 terms of art "relapse," "second remission," "first
23 remission," that's something that you became
24 familiar with?

1 A I did.

2 MR. SUSKO: I think we are at a
3 good place for lunch.

4 THE VIDEOGRAPHER: The time is
5 12:49, off the record.

6 (A recess was taken from 12:51 p.m.
7 to 1:39 p.m.)

8 THE VIDEOGRAPHER: The time is
9 1:37. We are back on the record.

10 BY MR. SUSKO:

11 Q I just want to backtrack a minute,
12 Mr. Pulaski, and follow up on a couple of things
13 quickly. And then I want to move to a different
14 area. But you mentioned that you took notes or
15 had notes of a conversation that you would need to
16 check your notes about whether Dr. Wood used the
17 word "always," "almost always." And do you think
18 you have notes of that June or July, early August
19 meeting?

20 A Yeah. What I'm referring to is I
21 have an email where I described the meeting. And
22 I'm pretty sure it was almost always.

23 Q Okay. So it's not notes?

24 A It's an email.

1 Q It's an email. Okay. All right.
2 You also gave testimony earlier that, and you
3 clarified, that you -- the question you were
4 asking about the transplant and meeting with the
5 team was saying -- correct me if I'm not saying
6 this correctly -- was when will we meet with the
7 team?

8 A Correct.

9 Q The transplant team. What answer
10 did you get?

11 A Soon.

12 Q And do you remember whether this
13 was before -- strike that. Do you remember
14 whether the question, When can we meet with the
15 transplant team, was asked, the first time it was
16 asked, before or after your son was matched?

17 A It was more than likely both. I
18 don't remember specific dates. Because it was --
19 there were a few things that you would talk about
20 the same thing over and over again. And so I
21 don't have specific dates.

22 Q Okay. So --

23 A But it was something that was
24 raised several times.

1 Q So I saw, and this will probably be
2 for next time and hopefully we'll be more
3 efficient in terms of just plowing through
4 material, but I saw, and I'm going from the top of
5 my head, in your notes or the blogs and/or emails
6 there was reference, She will probably need a stem
7 cell transplant. There is a high probability of a
8 stem cell transplant. She may need a stem cell
9 transplant, but we're not going to know until a
10 month. To the point of while she may need one but
11 there is a possibility she may need one, but she
12 may not need one. And it appeared to evolve over
13 time in the notes as time went on. Is that
14 consistent with your recollection?

15 A That's very accurate.

16 Q And in fact -- well, let me ask
17 this. Were you being told that in the early time
18 when you thought there was a probability that you
19 would proceed to stem cell transplant, were you
20 being told early on that part of the thinking
21 there related to the response of your daughter to
22 the early phase of the nelarabine treatment?

23 A No. There -- difference is that in
24 the very early stage it was not going to be an

1 option for us. It was going to be, You are going
2 transplant. As early as I want to say
3 January 16th, I could be a couple days off, but
4 very early in the treatment we were told we may
5 need to make a decision the following day to
6 proceed right to transplant.

7 Q Who told you that?

8 A I believe that was Dr. Rheingold.
9 I'm pretty sure that was right after we met
10 Rheingold. And then as you go on then it did
11 change a little bit to, well, it may not be
12 required. So we always knew we would have a
13 meeting and discuss. And a large part of that was
14 because we understood that you didn't just go to
15 transplant because you wanted to. You had to see
16 if you had a potential match. And in those early
17 days we had no idea if we had a match. It wasn't
18 until April that we got a preliminary discussion
19 with Dr. Wood that said he thinks Ryan is a match.

20 (Exhibit MP-6 was marked for
21 identification.)

22 MR. SUSKO: Are we on 6?

23 MR. CASSIDY: I think so. 6.

24

1 BY MR. SUSKO:

2 Q Let me hand you what I'm marking as
3 MP-6, Dr. Rheingold's note dated 1/28/2010. There
4 is an assessment A and then a P for plan. And I'm
5 focused on one and the third dash. And I'm
6 reading now. "Will type Sarah and her brother due
7 to high risk of induction failure or early relapse
8 if obtains remission." Do you see that?

9 A Mm-hmm.

10 Q You have to answer verbally.

11 A I'm sorry. Yes.

12 Q And at that point you were day 21
13 of the chemo. It was January 28th roughly?

14 A I can't confirm day 21. But I do
15 see this --

16 Q When I'm saying 21 I'm just saying
17 ballpark it is the 28th. You signed the second
18 consent on the 4th.

19 A Yeah.

20 Q And I think it was 31 days. But in
21 any event -- that's not -- I'll withdraw the
22 question. So wasn't it true that CHOP was looking
23 at transplant as an option and that part of that
24 calculus was if induction fails we need to look at

1 that as an option? Or if you obtain remission and
2 there is an early relapse you may look at it as an
3 option?

4 MR. CASSIDY: I have to object to
5 the form of the question only insofar as it
6 asks what CHOP believes.

7 MR. SUSKO: Well, I'm asking if he
8 had that understanding.

9 MR. CASSIDY: Meaning did you
10 understand that relapse -- that transplant
11 would only be used if there was an early
12 relapse after remission.

13 BY MR. SUSKO:

14 Q Yeah. Let me rephrase it. But
15 that is where I'm headed. There was a discussion
16 and Sarah and her brother were typed or checked
17 for matching for possible stem cell bone marrow
18 transplant, right? Did that happen?

19 A Yes. We did -- they did type.

20 Q Did they discuss with you why they
21 wanted to do that?

22 A Because we were being told that
23 Sarah would likely need a bone marrow transplant.

24 Q So my question is, did

1 Dr. Rheingold and you and/or your wife to your
2 knowledge ever have a conversation where
3 Dr. Rheingold was explaining her thinking, We may
4 need to move to transplant, and you just said it
5 might be as quick as the next day, if there is
6 induction failure or if there is an early relapse?
7 Was that ever communicated to you by
8 Dr. Rheingold?

9 A There were -- I apologize. I went
10 to get some care pages out to give you the exact
11 date. There were conversations in that first
12 month where we were told by numerous doctors that
13 Sarah was mostly likely going transplant. The
14 question --

15 Q That's not my question but I
16 appreciate that.

17 A I'm sorry. Can you restate it?

18 Q My question is the why of the
19 transplant. That one of the -- that there were
20 two things that were in their mind as to why they
21 may need to do a transplant. One, she has
22 induction failure, meaning she goes into induction
23 and she doesn't really get control of her disease.
24 You got to be thinking much more strongly about

1 the potential of a transplant promptly. And,
2 secondly, if she does go into remission but then
3 has a very quick relapse, that would be another
4 circumstance where the whole team would be saying,
5 Let's go to -- let's further be ready for a
6 transplant. Let's -- that's on the table.

7 A Now the reason --

8 Q My question is, did she give you
9 those as reasons why they were matching --

10 A No.

11 Q -- your brother?

12 A No.

13 Q What were the reasons, if any, that
14 they gave you why they wanted to match your
15 brother and -- I mean Sarah's brother and Sarah.

16 A Because at the time they were
17 thinking Sarah had to go transplant. There were
18 not --

19 Q Do you know why they thought that I
20 guess is my question?

21 A Because she wasn't responding to
22 therapy.

23 Q So that would be risk of induction
24 failure?

1 A Yes.

2 Q And did they also discuss with you
3 if there was early relapse after remission that
4 would be another circumstance where they would
5 consider going quickly to stem cell?

6 A I don't recall that that early.

7 Q All right. Fair enough. We talked
8 briefly about looking up information online or
9 doing research or investigation. Did you maintain
10 any, either location on your computer or hard
11 copy, any articles that you read, any papers you
12 read, any blog postings by others that you read
13 that maybe necessarily weren't created by you but
14 were resource materials for your understanding of
15 Sarah's treatment care or anything related to
16 Sarah?

17 A I'm sure I did.

18 Q Do you have any of those materials?

19 A I don't have -- I have no clue
20 where they would even be. I can look but...

21 Q How about the same question with
22 regard to your wife, did she maintain either a
23 file or a folder or a computer location where she
24 kept information about either Sarah's condition,

1 generally, individually to Sarah, anything like
2 that?

3 A Yeah. I think there -- I think
4 there was some stuff that -- some of our notes and
5 things that we looked at, yes. I'm sure there
6 were.

7 Q Do you retain those?

8 A Oh, just as I was rooting through
9 my daughter's room last night looking for the
10 journal I would have to do the same search to see
11 if we have any. We've moved since Sarah was first
12 diagnosed. And could something be in a box
13 downstairs that I'm not aware of? I'm sure it's
14 possible. I'm happy to look. But I have not
15 looked to date -- not for stuff like that. But I
16 mean I'm happy to.

17 Q Well, it just might inform what
18 your level of knowledge was.

19 A Okay.

20 Q That's all I'm thinking. You are
21 receiving information from doctors at the
22 hospital. If you've read certain things I think
23 it might be probative to have it.

24 A Yeah. I mean, you are looking for

1 my level of knowledge. And the reality is I place
2 a lot of my faith in what I was told by the
3 doctors. I mean --

4 Q Understood.

5 A -- they loved nelarabine. They
6 loved nelarabine and they wanted Sarah on
7 nelarabine. And by the time we signed that second
8 consent, my goodness, we were -- that carrot was
9 out there. We were praying that we got
10 nelarabine.

11 Q Do you know, by the way, patient in
12 remission with recurrence what the survival rate
13 is in a high risk situation?

14 A No.

15 Q Did you know that Dr. Rheingold,
16 one of the doctors you sued here, actually
17 published a paper on the efficacy of nelarabine
18 putting patients who had relapsed back in
19 remission?

20 A I know of that today.

21 Q And did you see that all of those
22 patients in remission, all but one, underwent a
23 stem cell transplant?

24 A I don't remember that detail. But

1 again I was never made aware of that research. I
2 found it after my daughter passed away.

3 Q It's completely unrelated to your
4 daughter. Do you realize that? Because they were
5 all relapse patients.

6 A No. That's not true. They were
7 relapse and refractory. Refractory are high risk
8 kids that don't respond to initial treatment as I
9 understand it.

10 Q We'll have to ask Dr. Rheingold
11 that one, I guess.

12 A Okay.

13 Q And did you have any understanding
14 from speaking with the doctors that taking a
15 patient who had relapsed into remission a second
16 time, did you have any understanding that if that
17 patient could be in remission a second time and go
18 onto transplant that that established the efficacy
19 of the drug being used?

20 A I'm not sure I understand your
21 question.

22 Q You and your wife certainly
23 understood that nelarabine had been effective in
24 treating relapse patients, correct, and approved

1 by the FDA for that purpose?

2 A No. We were told by Dr. Rheingold
3 that she had cured seven children by using
4 nelarabine.

5 Q That's an additional piece of
6 information. But you didn't answer my question.
7 I think it's in your blogs. Did you or did you
8 not know that nelarabine was historically, as you
9 put it, used as treatment only in the setting
10 recurrence of leukemia?

11 A No. We knew that it was used
12 historically for relapse and refractory. There is
13 a difference.

14 Q I'm using relapse and recurrence
15 interchangeably. I apologize. Let me --

16 A No.

17 Q -- re-ask the question.

18 A Recurrence is relapse. Refractory
19 is not a relapse.

20 Q Okay. Were you -- let me ask the
21 question again. Were you aware that nelarabine
22 was being used before the clinical trial involving
23 your daughter only in the circumstance when the
24 patient had relapsed?

1 A No. Because that's not accurate.

2 Q So if your blog says that it's not
3 correct?

4 A It's relapse and refractory.

5 Q And what do you mean by refractory?

6 A Refractory are children like Sarah
7 who are not responding to standard treatment.

8 Q Sarah went into remission, did she
9 not?

10 A It took five month where it
11 normally takes most kids five weeks. So yes.

12 Q So Sarah went into remission,
13 right?

14 A Yes.

15 Q My question is separate. I think
16 your blog says this drug historically has been
17 used for relapse patients. Wasn't that your
18 understanding?

19 A My blog may say that. But -- no.
20 That's fine. My blog may say that. But my
21 understanding was relapse and refractory.

22 Q Okay.

23 A But we were told that Sarah
24 couldn't get it unless she was on the trial.

1 Q Of course. Of course. And also
2 affirming that understanding, am I correct, is
3 that's why it was a clinical trial. It wasn't
4 approved for use as a frontline or primary
5 treatment. That's what the trial was all about to
6 see if it would be effective in doing that, right?

7 A I can't confirm or deny that. I
8 can tell you that we were told the only way to get
9 nelarabine, which the doctors wanted for Sarah,
10 was to remain on the clinical trial. And we
11 were --

12 Q Because she wasn't a relapse
13 patient. She was a first-time diagnosis. She had
14 never been in remission, right?

15 MR. CASSIDY: Yeah. But I think
16 what he is saying is that part of the
17 conversation --

18 MR. SUSKO: I don't need -- I don't
19 need -- I don't need your -- sorry. He is
20 being deposed. Go ahead. If you don't know
21 I will rephrase it.

22 THE WITNESS: No. I can't agree
23 with the statement as you lay it out. So if
24 I can't explain --

1 BY MR. SUSKO:

2 Q If you can't agree you just say I
3 don't agree with you and we'll move one.

4 A Okay. I don't agree with that.

5 Q So -- and let me probe that. I'm
6 going to test that just a little bit. So
7 didn't -- wasn't it explained to you and didn't
8 you post in your blog that the -- your daughter
9 was part of study that was going to test whether
10 it's effective to use nelarabine on patients who
11 had never had a relapse as the frontline or
12 primary care?

13 A We may have.

14 Q Are you thinking today as you are
15 sitting here that that's just not accurate as a
16 statement? Or you don't know?

17 A No. I -- you are --

18 Q Go ahead.

19 A You are asking me things about
20 stuff that I wrote four years ago, many of them at
21 2 o'clock in the morning as I sat by my daughter's
22 bed. And I don't recall everything that I typed
23 and whether I said it was used primarily with kids
24 that were relapsed and whether I included

1 refractory in there or not.

2 Q Well, look, and all of that I
3 understand. And this isn't a memory test to see
4 if you can recite it. I thought you knew it. And
5 it's corroborated by everything I understand to be
6 true, which is the FDA hadn't approved it for
7 frontline treatment. That's why they were having
8 a clinical trial. That's why the Children's
9 Oncology Group put the study together. And your
10 daughter was one of the first in the nation to get
11 it in this fashion. Did you understand that?

12 A Absolutely I understood that.

13 Q Okay. Fair enough. Let's move to
14 that article. Because I think you also allege in
15 your complaint misrepresentation both intentional
16 misrepresentation by Dr. Rheingold, meaning she
17 told you something that she knew was a falsehood
18 as well as negligent misrepresentation. So I want
19 to go back to that or touch on that now in the
20 remaining time we have.

21 So first of all, when was the
22 conversation that you believe Dr. Rheingold
23 misrepresented to you the results of that study?

24 MR. CASSIDY: Just object to the

1 form of the question. I don't think the
2 conversation referenced the study.

3 THE WITNESS: It didn't. And
4 that's what I was going to say.

5 BY MR. SUSKO:

6 Q Okay. Let me rephrase it then.
7 Fair enough. When was it that you believe you had
8 communication with Dr. Rheingold where you believe
9 she made any misrepresentation?

10 A There were numerous times in that
11 first month when we first met Dr. Rheingold.

12 Q Numerous intentional
13 misrepresentations by Dr. Rheingold? That's the
14 allegation?

15 A That's your words.

16 Q No. No. I mean, that's what's in
17 your complaint it's a misrepresentation. I'm
18 asking you when and you are saying numerous times,
19 right?

20 A Okay. There were numerous times.

21 Q Okay. Go ahead.

22 A Where she would tell us about this
23 wonderful drug called nelarabine that she thought
24 would do wonders for Sarah.

1 Q Stop. The question is, when did
2 she make the misrepresentations? Not when she was
3 extolling the virtues of the drug. The question
4 is you say she misrepresented it.

5 A Numerous times.

6 Q And I'm saying when. Okay? And
7 then how many times would you estimate she
8 misrepresented the drug to you?

9 A At least -- at least four or five
10 conversations.

11 Q Okay. And when did the first
12 conversation where she misrepresented that to you?
13 When was that?

14 A Shortly after we met.

15 Q And what did she say specifically?

16 A She told us about this drug called
17 nelarabine that she thought would work wonders
18 with Sarah. And that she had used it successfully
19 over the last several years with seven patients.

20 Q And if she were sitting here under
21 oath and saying, I believe it was successful.
22 They went into remission after relapse, they went
23 onto stem cell transplant and had whatever period
24 of time that was, you think that's an intentional

1 misstatement to you?

2 A I absolutely do.

3 Q And even though the medical
4 community might think that is an FDA-approved drug
5 that is working?

6 MR. CASSIDY: Well, that's
7 argumentative.

8 MR. SUSKO: I'm asking.

9 MR. CASSIDY: It calls for a
10 conclusion of what some federal government --

11 MR. SUSKO: Well, he is the one
12 making the allegation that she
13 misrepresented.

14 MR. CASSIDY: Yes. That doesn't --

15 MR. SUSKO: I'm entitled to
16 challenge that.

17 MR. CASSIDY: Yeah. But you can't
18 challenge what the FDA thinks. Who knows
19 what the FDA thinks?

20 MR. SUSKO: It's approved for use
21 in the market. It wasn't approved for
22 Sarah's use. That's why they had the trial.

23 MR. CASSIDY: Yeah.

24

1 BY MR. SUSKO:

2 Q So your testimony is that --

3 A Dr. Rheingold told us that she had
4 used it successfully with seven children. And I
5 said, okay, successfully, what does that mean? I
6 said, Are they alive? And she said, They are all
7 doing well. And at that point in time six of them
8 had passed.

9 Q And how do you know that?

10 A Her own documentation.

11 Q So an article -- do you know when
12 the article was published?

13 A One month after she had us sign to
14 allow our daughter to remain on a clinical trial.

15 Q And do you know if she knew that
16 information at that time?

17 A She wrote the document.

18 Q No. I'm asking you if she knew the
19 information that you just described. At the time
20 she met with you, do you know whether that was
21 known to her?

22 A I don't know when she wrote the
23 article. It was published 28 days after -- well,
24 20 days after we agreed to allow our daughter to

1 remain on the clinical trial.

2 Q So you asked, are they -- you asked
3 her, What does that mean? Or you asked her
4 whether they are alive or both?

5 A I specifically asked, What does
6 that mean? Are they alive? And she said, They
7 are all doing well.

8 Q And did you ever ask her that
9 question again?

10 A No. I was sold.

11 Q You said numerous times you made
12 the misrepresentation. That's the only one I saw
13 in your complaint. So I'm asking you --

14 A Well, there were numerous times
15 that she continually talked about nelarabine,
16 nelarabine, nelarabine.

17 Q Being a good drug for your
18 daughter?

19 A Being the drug that we needed.

20 Q The drug that might put her into
21 remission, right?

22 A Yes.

23 Q And she achieved that result?

24 MR. CASSIDY: She achieved what

1 result?

2 BY MR. SUSKO:

3 Q Putting the patient into remission?

4 A No.

5 Q I know you disagree with that
6 because you talked to somebody --

7 A No. Because I want to stop up with
8 what you just said. You just said that I agreed
9 that she said that it would get my daughter into
10 remission. No.

11 Q I thought you said yes. Okay. Go
12 ahead.

13 A The goal was never to get my
14 daughter into remission. The goal was to cure my
15 daughter.

16 Q What is the difference, sir?

17 A Well, the difference would be my
18 daughter would be sitting here with me today and
19 you and I wouldn't be having this conversation.

20 Q And somebody actually guaranteed to
21 you they could absolutely cure your daughter?

22 A No.

23 Q I wouldn't think so. So I'm
24 confused by the statement that you put a patient

1 who's got cancer into remission. Are you aware of
2 any -- are you aware from your research that
3 leukemia patients are cured?

4 A Well, again, to my earlier comment:
5 It's my understanding that when they are five
6 years posttreatment they are considered cured.

7 Q And do you have any idea of the
8 percentage of the population that is high risk and
9 have a relapse that fit in that category?

10 A No. That was never disclosed to
11 us.

12 Q Did you ever ask?

13 A I don't remember.

14 Q Did you say, What are the chances
15 for my daughter? How bad is it? And maybe you
16 did. I'm just asking.

17 A I don't remember. I don't
18 remember. I remember in the very first meeting
19 with Dr. Varela where I did ask that question and
20 I was told a hundred or zero. So that's what I
21 went with going forward.

22 Q And Dr. Varela was one of the
23 doctors -- is the first doctor who gave you the
24 first consent?

1 A Yes.

2 Q And Dr. Rheingold's name is on that
3 consent as somebody for you to contact, right?

4 A It probably is.

5 Q And then you had conversations with
6 her following that, right, multiple?

7 A Mm-hmm.

8 Q You have to answer verbally.

9 A Yes.

10 Q And it's one time that you asked
11 how did they do? Are they all alive? And she
12 said they are doing well? That was one
13 conversation.

14 A Well --

15 Q I'm just asking one time when those
16 words were said. I realize --

17 A There was one specific time where I
18 cornered her on that. There were a number of
19 conversations about nelarabine and about that
20 she's had such great success on it.

21 Q Understood. That's -- I appreciate
22 you adding that piece of information. I just
23 wanted to know if when you cornered her that was
24 one conversation or whether if we needed to cover

1 other conversations?

2 A It may have occurred more than
3 once. But I can tell you that I remember one very
4 specifically because she was very matter of fact
5 about her response.

6 Q And when did -- when exactly do you
7 think that conversation happened?

8 A That was around the third week of
9 January.

10 Q So you had already signed onto the
11 clinical trial, right?

12 A Mm-hmm.

13 Q You have to answer verbally.

14 A Yes. Sorry. You'd think I'd know
15 that by now.

16 Q That's all right. You sued -- you
17 brought your lawsuit against other physicians. I
18 just want to ask you a couple quick questions
19 about them. Dr. Richard Aplenc, did you ever meet
20 Dr. Aplenc to your knowledge?

21 A Yes.

22 Q When did you meet him?

23 A Numerous times. Generally as the
24 doctor that was doing rounds, because he would do

1 rounds, and we'd just be one of the patients that
2 he would see. So, yes, I had met him.

3 Q And in terms of managing your
4 child's oncologic care at CHOP, was he involved in
5 that?

6 A It's my understanding that he was
7 Sue Rheingold's supervisor.

8 Q That wasn't my question. He may
9 be. But my question is, was he involved in the
10 management of the care of your daughter?

11 A As I understand he was a regular
12 participant in the Thursday meetings because of
13 his role. And Sarah was regularly discussed in
14 the Thursday meetings.

15 Q She was regularly discussed?

16 A I had said that earlier.

17 Q I thought there was an issue there.
18 Okay. Maybe not. Did you ever have any
19 conversation with him about Sarah and stem cell
20 transplant or participating in the clinical trial
21 that you can recall?

22 A Not to my -- no.

23 Q Do you know whether your wife ever
24 had any conversation with Dr. Aplenc along those

1 lines?

2 A I don't know. My wife was
3 generally there on weekends. So if he were
4 someone that came through while she was there,
5 maybe. I don't know.

6 MR. CASSIDY: Excuse me for a
7 second. Pull your microphone up higher on
8 your tie. Sorry about that.

9 BY MR. SUSKO:

10 Q Dr. Frank Balis, have you ever met
11 him?

12 A I believe so.

13 Q And do you know -- same
14 questions -- do you know whether he ever -- you
15 and he ever had a conversation about stem cell
16 transplant or entering this particular clinical
17 trial?

18 A I don't recall whether I did or did
19 not. One of them may have been in the
20 February 8th meeting. But I don't remember.

21 Q February 4th? You talking about
22 the second consent?

23 A The second consent.

24 Q Yeah. I think it's February 4.

1 A They may have. I don't recall.

2 MR. SUSKO: Is it the 4th?

3 MS. SCHNALL: 5th.

4 MR. SUSKO: January 4th. Sorry.

5 THE WITNESS: That's okay.

6 BY MR. SUSKO:

7 Q He may have been there but you
8 don't -- so you don't recall any specific
9 conversations that you can recount right now?

10 A No.

11 Q How about are you aware that Frank
12 Balis, Dr. Balis, had any conversations with your
13 wife about Sarah's care?

14 A I'm not.

15 Q I'm not sure I even asked you this
16 with the first consent, but we established it.
17 But the second consent, did you -- do you know who
18 provided that to you, who the doctor was?

19 A The second consent?

20 Q Yeah.

21 A That was Dr. Rheingold. We are --
22 make sure I'm answering your question correctly.
23 But that's the one after induction, correct?

24 Q Correct.

1 A February -- you seem to know dates
2 better than I do.

3 Q 5th. So it should be one of these
4 documents. Let's just get it so the record is
5 clear.

6 A Next one.

7 Q Is it MP-5, sir? Is it MP-5?

8 A Oh. I apologize, yes.

9 Q It's okay. It's all right. After
10 your conversation with Dr. Wood that you
11 referenced earlier where you requested to have
12 Sarah get a bone marrow transplant, are you with
13 me? Late July? Early August of 2010?

14 A Yes.

15 Q After that conversation did you
16 raise with any physician or anyone else at CHOP
17 the issue of a stem cell transplant or bone marrow
18 transplant before your daughter relapse in March
19 of 2011?

20 A No. I dropped it. He talked me
21 out of it and I dropped it.

22 Q So it was one conversation. You
23 had the conversation and you dropped it?

24 A I stopped pushing, yes.

1 Q Is that how you thought of it
2 before that conversation that you had been pushing
3 for it all along?

4 A I had been pushing for the meeting
5 for us to -- I had been pushing for the meeting to
6 find out what my son's test results were and when
7 we were going to meet with the bone marrow team to
8 understand that option. So, yes, I was pushing.

9 Q So Wood, and that you've identified
10 two things but -- and I want to probe this a bit
11 further. If you had, which you did, gone into
12 this ARM of a study which you knew did not have
13 bone marrow transplant as a treatment option, and
14 you certainly understood you were choosing a path
15 with that as referenced in your earlier email, why
16 would you think that the team would consider that
17 as an option if they thought your daughter was in
18 remission and you were looking to undergo two
19 years of chemotherapy?

20 A Because that was always the
21 agreement with Dr. Rheingold and Dr. Wood. These
22 are the same people who ordered the testing for my
23 son after the February 5th consent.

24

1 Q Right. Because they didn't know
2 how she was going to fare in the response to the
3 nelarabine, right?

4 MR. CASSIDY: Objection.

5 THE WITNESS: No.

6 BY MR. SUSKO:

7 Q I thought we established earlier
8 that induction failure, getting her into
9 remission, was one of the situations that might
10 lead you to further investigate stem cell
11 transplant?

12 A No. I don't recall that. The plan
13 was always, even when we signed on February 5th,
14 February 5th was all about getting Sarah
15 nelarabine. Because they felt that they needed
16 that to get her into remission.

17 Q And we've understood though that
18 that did not include -- that study did not include
19 stem cell, correct?

20 A The study didn't.

21 Q Did not, right?

22 A But you had to go on the study to
23 get -- to have a possibility to get nelarabine.

24 Q Understood. And you also

1 understood it was a two, two and a half year chemo
2 course, right? That was explained to you upfront?

3 A That may have, yeah.

4 Q Well, I guess my question is why
5 would you be expecting a discussion with the stem
6 cell transplant folks if you had made the choice
7 to go down the path of having the chemotherapy for
8 two years?

9 A No. We made a choice to continue
10 on a study so that we could have access to a
11 critical drug that the doctors felt my daughter
12 needed to get into remission.

13 Q So you needed --

14 A The agreement -- please let me
15 finish.

16 Q Go ahead.

17 A The agreement with those doctors
18 was that we were going to have the follow-up
19 meeting regarding stem cell transplant. But that
20 you could never have that meeting until she was in
21 remission. That is why the same doctors ordered
22 testing on my son in March or April --

23 Q I think you are mistaken in this
24 regard and I'm going to take issue with you. So

1 first of all are you saying when you went on this
2 study and signed on, understanding you could leave
3 at any time, it was not your intent to finish out
4 the course of chemotherapy identified in this
5 study?

6 A No. Our intent was get nelarabine
7 and then have a conversation. And they were going
8 to make recommendations based upon the test result
9 of my son.

10 Q And then you raised the issue and
11 she went -- and the test results at least as
12 interpreted by them were in remission, right?

13 MR. CASSIDY: No. Test results --

14 THE WITNESS: I'm talking about
15 test results from my son.

16 BY MR. SUSKO:

17 Q Okay. Well, and that's where I was
18 going to take issue with you. Isn't the reason
19 why, and we looked at Rheingold's note, the reason
20 why they did the matching test was because of a
21 concern over whether your -- how your daughter was
22 going to fare in induction and how slowly she was
23 progressing? Wasn't that the concern at the time?

24 MR. CASSIDY: Whose concern?

1 MR. SUSKO: The doctors. That they
2 are communicating to him.

3 MR. CASSIDY: Well, you can ask him
4 what did they say --

5 MR. SUSKO: I am.

6 MR. CASSIDY: You can't ask him
7 what did they think.

8 MR. SUSKO: I didn't say what did
9 they think.

10 MR. CASSIDY: Or what their concern
11 was. If it was an unexpressed concern --

12 MR. SUSKO: Well, he would know if
13 they expressed it to him.

14 MR. CASSIDY: Sure. And I got no
15 problem --

16 MR. SUSKO: He could say I don't
17 know. He doesn't need you coaching him.

18 BY MR. SUSKO:

19 Q So my question. Let me just
20 rephrase it if it's lacking clarity. And I
21 thought you already agreed to this. That one of
22 the reasons to do the matching was there was a
23 slowness in this induction phase and the doctors
24 wanted to be ready to go in case there was a

1 failure of induction?

2 A No. I think I actually had to
3 correct you on this earlier.

4 Q The transcript will read the way it
5 reads. I'm pretty certain of what you said.

6 A That's fine.

7 Q So you think now -- tell me what
8 your thought is now.

9 A You keep saying induction failure
10 as --

11 Q Let's get the exhibit out because
12 we covered it.

13 A Induction failure is not as I
14 understand what sends you to transplant or not.

15 Q Will type Sarah and her brother due
16 to high risk of induction failure or early relapse
17 if obtains remission.

18 A Yeah. You are referring to the
19 meeting that I just said never occurred, or if it
20 did occur it was not discussed as is written
21 there.

22 Q Well, in fairness to myself and you
23 I don't think we're talking that this was a
24 meeting. There was another note where they talked

1 about meeting with father. That was in June.

2 This is a note in on January 28th.

3 A Oh, okay.

4 Q The end of the second --

5 A You are correct. I'm sorry.

6 Q Okay. But in any event why
7 don't -- I'm pretty sure that you agreed with me
8 that at risk of induction failure was one of the
9 things that might lead the team to go to
10 transplant. But your testimony is under oath. It
11 will speak for itself.

12 Let's -- why don't we conclude on
13 the following: So in terms of the relapse of your
14 daughter, did you understand that when she
15 relapsed that the medical goal given the nature of
16 her relapse, the extent of the recurrence of the
17 disease, was such that that needed to be brought
18 under control into remission, and we can define
19 that if we need to, in order for her to get the
20 stem cell transplant at that point?

21 A Yes.

22 Q Did she ever get the stem cell
23 transplant?

24 A No.

1 Q Did she ever achieve any stability
2 in her condition that would allow her to get the
3 stem cell transplant?

4 A You are asking me to be a doctor.

5 Q Okay. Fair enough. You took her
6 to St. Jude right after CHOP?

7 A Mm-hmm.

8 Q You have to answer verbally?

9 A Yes.

10 Q And they did not do the stem cell
11 transplant?

12 A They could not.

13 Q But the question was they did not
14 do one, correct?

15 A They did not.

16 Q They could not because she was not
17 in remission. And we'll put that in quotes
18 because that needs to be defined, right?

19 A That's my understanding.

20 Q Well, did you want your daughter at
21 that point to undergo a stem cell transplant?

22 A Yes.

23 Q Were you asking them when you
24 transferred her to St. Jude to do a stem cell

1 transplant?

2 A Yes. If I can just make one
3 comment, though. And I think you are using stem
4 cell transplant just because it's a generic term.
5 But there is two types. There is a stem cell and
6 there is a bone marrow. They are actually
7 different approaches. They are both transplants.
8 It was never decided whether it would be stem cell
9 or bone marrow. And it may just be a point of
10 clarification on the term.

11 Q Would it make a difference in
12 actually what they were going to transplant from
13 your son; do you know?

14 A I think -- again, I'm not the
15 doctor. But I think the difference is how they
16 actually do the transplant. But it's all I know
17 is it's two different types.

18 Q As opposed to stem cell being a
19 broad category, one of which would be bone marrow.
20 You can have bone marrow stem cells. You can have
21 skin stem cells. You can have all kinds of
22 different stem cells, right?

23 A Again, as I understand it there is
24 two different approaches to it. I don't think

1 stem cell is just a term. I think it is the way
2 that they actually -- I think one they actually
3 inject the bone marrow. I think another they take
4 stem cells and select certain ones. Again, I'm
5 not the doctor. It's just I have a little bit
6 more understanding. I just wanted to make sure
7 that you knew that when I agreed that stem cell,
8 I'm not agreeing that it was with stem versus bone
9 marrow. I don't know which one of those ways they
10 were going to go.

11 Q Okay. So let's just clarify that
12 point. When we were talking earlier what was
13 CHOP -- what were you and CHOP talking about?

14 A Well --

15 Q Both?

16 A The term was bone marrow
17 transplant. But when you go to the transplant
18 wing they can go either of those approaches.

19 Q It's a little more detail on the
20 approach that they might use?

21 A Yeah.

22 Q Okay. Fair enough. So in your
23 mind you are thinking of it as a bone marrow
24 transplant, right?

1 A Yes.

2 Q But you wouldn't say we need to
3 throw out all of your testimony you just gave
4 today because I may have used stem cell --

5 A No. No. No.

6 Q I didn't think so.

7 A I just wanted to make sure you
8 didn't think that I was going one versus the
9 other. I don't know which way they would have
10 gone.

11 MR. SUSKO: Fair enough. Okay.
12 Fair enough. Let's go off the record for a
13 minute.

14 THE VIDEOGRAPHER: 2:19, off the
15 video record.

16 BY MR. SUSKO:

17 Q So cell phones and text messages.

18 A Yes.

19 Q What were your cell phone numbers
20 at that time?

21 A They are probably the same.

22 Q I would think. But, you know, it's
23 always possible.

24 A You never know. I went from

1 Comcast to Verizon and went back and got my old
2 phone number. So they are probably the same cell
3 phone numbers.

4 Q What are they?

5 A Mine is (267)249-9715. I am
6 currently with T-Mobile. I don't know if I was
7 with them back then.

8 Q How about your wife?

9 A My wife is (215)435-4052. I'm
10 pretty sure she's been with Verizon the whole
11 time.

12 Q Okay. So you can reflect on that.
13 You can look for these other documents. I'll send
14 a letter to your lawyer to give him a little bit,
15 you know, recounting so that nobody --
16 reidentifying these so we are not like sort of
17 working off of a list. And if anything changes on
18 the cell phone we'd like to try to get the text
19 messages around that time. It might be more
20 information since you said you were texting --

21 A Great. Yeah.

22 Q -- that information. So okay. I
23 think we can -- why don't we go back on the video
24 just to close it out.

1 THE VIDEOGRAPHER: 2:21, back on
2 video record.

3 MR. SUSKO: Thank you, Mr. Pulaski.
4 That's all we are going to accomplish today.
5 I know there are some weather issues. We've
6 agreed by discussions off the record that we
7 are going to suspend the deposition here and
8 will pick up at a mutually agreeable time and
9 hopefully relatively soon so I don't have to
10 re-prepare and you don't have to get ready
11 all over again. We'll try to do it
12 relatively promptly. Okay?

13 THE WITNESS: Okay.

14 MR. SUSKO: Thank you.

15 THE VIDEOGRAPHER: 2:21. We are
16 off the record.

17 (Deposition adjourned at 2:21 p.m.)
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C E R T I F I C A T I O N

I, JARED CAREY, Court Reporter,
certify that the foregoing is a true and accurate
transcript of the foregoing deposition, that the
witness was first sworn by me at the time, place
and on the date herein before set forth.

I further certify that I am neither
attorney nor counsel for, not related to nor
employed by any of the parties to the action in
which this deposition was taken; further, that I
am not a relative or employee of any attorney or
counsel employed in this case, nor am I
financially interested in this action.

Jared Carey
Court Reporter
and Notary Public
Date: January 31, 2015