## BEFORE THE HUMAN AND CIVIL RIGHTS COMMISSION FOR THE STATE OF DELAWARE

**ROSA JONES**

Complainant,

V.

## A.I. DUPONT NEMOURS CHILDREN'S HOSPITAL, ET AL.

Respondent.

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### ) Case No. K-EA-2520-22

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## MEMORANDUM DECISION AND ORDER

HEARING PANEL:

Gail Launay-Tarlecki,

*Commission Chairperson and Panel Chairperson*

Olga Ramirez

*Commissioner and Panel Member*

Earnest Guiab

*Commissioner and Panel Member1*

APPEARANCES:

Kemba Lydia-Moore, Deputy Attorney General

*Counsel for the Commission and Panel*

Rosa Jones

*Complainant, pro se*

Jennifer Gimler Brady, Potter Anderson & Cooper, LLP

*Counsel for Respondent*

1 At the start of the hearing on October 27, 2022, Commissioner Rosemarie Williams served as a member of the Panel and Commissioner Earnest Guiab, who joined the hearing during the presentation of A.I. Dupont Nemours Children's Hospital's opening statement, served as an alternate in the event that one of the panelist became unavailable. When the hearing resumed on October 28, 2022, Commissioner Williams was unavailable and Commissioner Guiab assumed the role of Panel Member. Chairperson Gail Launay-Tarlecki inquired if the parties objected to proceeding in this manner and neither party objected.

## INTRODUCTION

Pursuant to due notice of time and place of meeting served on all parties in interest, the above-stated cause came before a Panel of the Delaware Human and Civil Rights Commission ("Panel") via Microsoft Teams audio and video conference on Thursday, October 27, 2022 and Friday, October 28, 2022 to determine whether a violation of Delaware Equal Accommodations Law ("DEAL"), codified at 6 *Del.* C. Ch. 45, occurred.2

The Panel convened to determine whether A.I. Dupont Nemours Children's Hospital, located in Wilmington, DE, ("Nemours" or "Respondent") violated 6 *Del.* C. § 4504 as alleged in the Complaint filed by Rosa Jones ("Ms. Jones" or "Complainant"). Ms. Jones alleged Respondent discriminated against her and her son, Cateial Jones ("Cateial"), on the basis of race/color (Black) and disability (physical and mental).

The Panel conducted its deliberations on October 28, 2022 and November 22, 2022.

## SUMMARY OF THE COMPLAINT

In her Complaint, Ms. Jones alleged that Nemours discriminated against her and Cateial by preventing Cateial, who was terminally ill, from transferring to another hospital. According to Ms. Jones, Nemours lied to her about Cateial

2 Unless otherwise specified, the citations to DEAL contained herein reference the version of DEAL that was in effect in February 2022.

returning home, would not allow her to take Cateial home, and prevented family members from visiting Cateial during his admission at Nemours. According to Ms. Jones, Cateial was mentally and physically abused by Nemours staff and when she reported the abuse it was not addressed.

Ms. Jones contends she and Cateial were treated differently because of their race/color (Black) and Cateial's disabilities (mental and physical).

## OPENING STATEMENTS

Both parties made opening statements which are part of the record but are not summarized here because such statements are not evidence to be considered by the Panel during deliberations.

## SUMMARY OF THE EVIDENCE

### Complainant's Case

* 1. **Complainant Rosa Jones**

Ms. Jones, duly sworn, testified that Cateial was transferred to Nemours from Milford HospitaP where he had to leave his specially made wheelchair because it would not fit in the transporting vehicle. Ms. Jones said upon arrival at Nemours the nurses treated Cateial aggressively because they did not understand

3 Based on later testimony, it appears that Ms. Jones was referring to Bayhealth Milford Memorial Hospital ("Bayhealth") located in Milford, DE.

Cateial when he tried to communicate with them. Ms. Jones said one nurse said if Cateial did not stop biting, he would strap Cateial to the bed and the nurse disregarded Ms. Jones when she explained that Cateial's hands cannot be confined because he communicates with his hands.

Ms. Jones testified that Cateial was moved to Nemours' Cardiac Intensive Care Unit ("CICU") because his health was declining. According to Ms. Jones, she introduced Cateial to the CICU staff and informed them Cateial had autism and was nonverbal but he was aware of what occurs around him and he could understand what was said. Ms. Jones testified she told the CICU staff that Cateial had never been in the hospital and having people invade his space would cause him to have attacks like banging his head and biting his hand. Ms. Jones said she explained to the CICU staff that Cateial had never been violent with anyone, but he self-stimulated by biting the palm of his hand. Ms. Jones said she asked the staff to speak to and interact directly with Cateial, but they ignored her request and moved about as they pleased which caused Cateial to bang his head on the bed railing and bite his hand more than usual. According to Ms. Jones, on Saturday, February 5, 2022, another nurse informed her Cateial would be strapped to the bed if he continued that behavior. Ms. Jones said she then asked to speak with a social worker and was informed there were none available during the weekend. Ms. Jones

said she called Courtney Byrne4 for assistance and later received a text message from Ms. Byrne instructing her to ask a nurse to notify a weekend social worker to assist.5 Ms. Jones testified she asked for assistance but to no avail so she wanted to transfer Cateial to another hospital. According to Ms. Jones, her needs were not met and there was no response to her request for assistance until Monday, February 7, 2022.

Regarding the weekend of Saturday, February 5th through Sunday, February 6th, Ms. Jones said she constantly reminded the Nemours staff that Cateial did not know them and they could not grab him without first introducing themselves, but the staff ignored her. Ms. Jones said they grabbed Cateial to take his blood pressure and perform other medical procedures, but Cateial pulled away from them. Ms. Jones testified she told the staff they needed to limit the number of people in Cateial's room at one time because the room was small, but sometimes there were too many people which caused Cateial to scream and bite his hand. Ms. Jones testified that the staff acted as if she was not there, they spoke to her a little as possible, and moved about the room as they pleased.

Ms. Jones testified she spoke with a social worker on Monday, February 7th and was informed about rooms where she could sleep. Ms. Jones said she told the

4 In later testimony, Ms. Byrne identified herself as a Social Worker in Nemours' Cardiac Center.

5 A hardcopy of this text message communication was entered into evidence as Complainant's Exhibit #1 ("CP Ex. #1").

social worker she felt Cateial was unsafe because of how he was treated during the weekend and she would not leave him. Ms. Jones said she stayed with Cateial the entire time he was inpatient at Nemours.

Ms. Jones testified that Ms. Byrne eventually made and posted a sign that stated, "Yes, I'm non-verbal but I understand everything. Please introduce yourself and talk to me." Ms. Jones said after the sign was posted Cateial's care improved, but there were many days prior when he was treated badly.

Ms. Jones testified she was working with someone on transferring Cateial to another hospital, which was ultimately approved, but she opted to keep Cateial at Nemours after being convinced by Nemours that the staff could "do better." Ms.

Jones testified Nemours staff acknowledged that the communication had not "been the best," asked her not to transfer Cateial, promised to "do better by Cateial" and by her, and said they would work on improving the communication.

Ms. Jones testified there was a subsequent time when she requested that Cateial be transferred to another hospital. Ms. Jones said she was made to believe that transfer to Bayhealth or back home with hospice care was feasible, but she was later informed Cateial was too ill and may not survive transport or would only survive transport for a few hours. Ms. Jones said her only choice was to remain at Nemours.

Ms. Jones testified about an incident when a nurse "crammed" a feeding tube down Cateial's throat. Ms. Jones said Cateial screamed "bloody murder" and

when a doctor intervened the nurse said, "I was told it's perfectly fine." According to Ms. Jones, the doctor had Cateial re-sedated and then the tube was inserted. Ms. Jones said when the same nurse returned to check Cateial's blood pressure he was terrified and pulled away from her. Ms. Jones then requested that the nurse be replaced and she was.

Ms. Jones testified about another incident when a draining tube was inserted in Cateial. Ms. Jones said that initially she was permitted to remain in the room but was later instructed to wait in the hallway. Ms. Jones went to the hallway just outside Cateial's room and then to another hallway further away. Ms. Jones testified that when she tried to return to Cateial's room she was locked out and was then instructed to go to the waiting area. According to Ms. Jones, a nurse informed her the procedure would take a while longer. Approximately an hour later, another nurse inquired if Ms. Jones wanted to speak with one of the pastors which scared Ms. Jones because she thought Cateial had passed and she was not there with him.

Ms. Jones testified she felt isolated because she was not permitted to have anyone with her. Ms. Jones said there were two other patients in the CICU-one patient was a young man whose mother, father, and grandmother visited on multiple occasions. Ms. Jones said there was also an Amish couple who visited their child every day.

Ms. Jones testified that when she tried to get information she was spoken to as if she did not understand and she was "talked around." Ms. Jones said she was

treated as if Cateial was a problem and there was no compassion. She said when she asked a question, the Nemours staff seemed bothered. Ms. Jones said the majority of Cateial's time at Nemours was "absolutely horrible" but the last four days were the best. She questioned why Cateial was only treated like a human being and a patient during those final days.

During cross examination, Ms. Jones testified that Cateial had an ultrasound performed at Eden Hill Walk-In Center, located in Dover, DE. Ms. Jones said Cateial' s pediatrician informed her the ultrasound revealed fluid was building around Cateial's lungs and the pediatrician wanted Cateial admitted to Nemours.

According to Ms. Jones, the pediatrician instructed her to go to Bayhealth for quicker transport to Nemours. Ms. Jones said on Thursday, February 3, 2022, Cateial went to Bayhealth which served as a "holding place" for transport to Nemours. Cateial was at Bayhealth for a couple hours and while there staff checked his temperature and made sure he was comfortable.

Ms. Jones testified she was aware of the severity of Cateial's illnesses and she wanted him transferred to Children's Hospital of Philadelphia ("CHOP").

According to Ms. Jones, when she requested that Nemours transfer Cateial, Nemours sought and obtained approval from Medicaid and then she and her fiance, John Jefferson,6 met with Nemours doctors and other staff to further discuss.

6 During later testimony, the Panel learned that Mr. Jefferson is also known as "Duke" and is often identified as Cateial 's stepfather.

According to Ms. Jones, during that meeting, Nemours acknowledged there were mistakes made and asked for another opportunity to "do better."

Regarding the second time Ms. Jones requested transfer from Nemours, Ms.

Jones testified she made contact with CHOP and learned there were no beds available. Ms. Jones also testified she opted to have Cateial remain at Nemours because the distance between CHOP and her home in Milford, DE was too great, but she was also exploring the possibility of placement at a facility in Milford, DE and she did not know ifBayhealth would permit Cateial to return. Ms. Jones said she was also considering the possibility of Cateial returning home with hospice care.

When asked the basis for her contention that she and Cateial were treated differently due to their race and/or disability and her contention that their race and/or disability contributed to the care and services provided, Ms. Jones said on more than one occasion when she asked for an explanation she was told it was too much to explain due to time constraints and a meeting needed to be scheduled to explain in a manner that Ms. Jones could understand. Ms. Jones testified she felt that was one step from saying she was too stupid to understand and a meeting was necessary "to dumb it down" for her. Ms. Jones also said she felt discriminated against because every time she asked for permission to have family or friends come she was told "no," but she saw extended family members visiting other patients. Ms. Jones said when she asked about the other families she was told there

were different circumstances, yet the patients were on the same floor as Cateial.

Ms. Jones testified she called people and had them on speaker listening to hear how Nemours staff spoke to her. Ms. Jones gave an example of a nurse who yelled at her and said he was not going to speak with her while she had someone on speaker. Ms. Jones said she was trying to discuss having someone come and sit with her or sit with Cateial in her place. Ms. Jones said she explained she had the person on the phone because she wanted a witness, but the nurse said he did not care, walked out, shut the door, never returned, and sent someone else. Ms. Jones disagreed that having someone listen on speaker could be received negatively because she had just completed a meeting with Nemours staff where the discussion was recorded.

Ms. Jones testified that initially she was informed Mr. Jefferson could visit during certain hours, but there were family members of other patients who were allowed to visit regularly. Ms. Jones said on one occasion, she was planning to have a friend come, bring food, and stay the entire night, but it was not allowed. Ms. Jones said she was never precluded from leaving to get food, but she did not trust the Nemours staff so she went days without eating. Ms. Jones agreed this occurred during the COVID-19 pandemic.

Ms. Jones testified the visitation rules were later relaxed as Cateial reached the end oflife. She said Cateial's two sisters, Carol Hall, and Mr. Jefferson were permitted to visit, but by then Cateial was not able to interact with them or enjoy

their company because he was dying.

Ms. Jones testified that when Cateial was able to eat there were issues like his food arrived late and cold or he was served fish that smelled horrible. Ms. Jones said the nurse gave Cateial some food from a small refrigerator. Ms. Jones said that type of treatment is not equal or just for a child who is dying or for a mother who is isolated and alone.

In response to Panel questions, Ms. Jones said her race is biracial - Black and White. She described Cateial as a light skinned Black male. Regarding other families and/or patients that she observed at Nemours, Ms. Jones said there was a White Amish family, another White family, one Black family whose child was only there for about 3 hours, and a Black teenager who was there for a couple of days. Ms. Jones said the majority of the time Cateial was inpatient at Nemours her family was the only family of color.

During Panel questioning, Ms. Jones again testified about CP Ex. #1. She said it was a text message communication between her and Ms. Byrne. Ms. Jones said she called Ms. Byrne on Saturday, February 5th and then they exchanged text messages. Ms. Jones said she was informed there were no weekend social workers due to the COVID-19 pandemic so she did not speak with a social worker until Monday, February 7th.

Ms. Brady was permitted to re-cross examine Ms. Jones. Ms. Jones testified she did meet with Ms. Byrne on Friday, February 4th for about 1.5 hours. Ms.

Byrne provided her cell phone number and instructed Ms. Jones to call if she needed anything. According to Ms. Jones, Ms. Byrne informed her there were weekend social workers, but when Ms. Jones asked for a social worker at the hospital she was informed there were none available so Ms. Jones called Ms. Byrne for assistance. In response, Ms. Byrne texted Ms. Jones and said she could ask a nurse about speaking with the weekend social worker. Ms. Jones said when she asked, she was informed there was no weekend social worker because they were short-staffed. Ms. Jones then texted Ms. Byrne and requested a transfer to another hospital. Ms. Jones said she met and spoke with Ms. Byrne and Laura Boyer7 on Monday, February 7th. Ms. Jones denied speaking with a social worker during the weekend.

# Carol Hall

Ms. Hall, duly sworn, testified that she has a longstanding relationship with Ms. Jones. When Ms. Jones was 13, Ms. Hall became her "Big Sister" through the Big Brothers Big Sisters Program and that relationship continued until Ms. Jones aged out of the program at 18. Ms. Hall testified she has known Cateial since his birth and when Ms. Hall was employed with The Arc of Delaware she was appointed Ms. Jones' caseworker after Cateial was diagnosed with autism.

7 In later testimony, Ms. Boyer was identified as a Social Worker.

Ms. Hall testified that she participated in one meeting with a Nemours doctor and nurse when Cateial was inpatient at Nemours. Ms. Hall recalled the doctor was very apologetic for the treatment Cateial received at that time, there was discussion about Cateial not surviving transfer to another hospital, and it was stated Cateial needed to remain at Nemours.

Ms. Hall testified she was first able to visit Cateial at Nemours on Sunday, February 13th and she did see a note on the door instructing the staff to introduce themselves to Cateial and to approach him in a friendly, quiet manner. Ms. Hall said she brought Cateial's sisters to visit him on Tuesday, February 15th and she was very impressed with the memory making activities that were provided.

During cross examination, Ms. Hall testified that on Tuesday, February 8th, she was told she could not go upstairs to visit Cateial, but she was not told that was because she was not biologically related. Ms. Hall said she was permitted to visit on Sunday, February 13th and on Monday, February 14th when Mr. Jefferson was also permitted to visit.

In response to Panel questions, Ms. Hall testified she spoke to Ms. Jones approximately once per day during Cateial's admission at Nemours. Ms. Hall described Ms. Jones as very upset and frustrated. Ms. Hall said Ms. Jones was not happy with the care Cateial received and Ms. Hall recalls thinking that Nemours has a sterling reputation. Ms. Hall testified she was dismayed by hearing Ms.

Jones' complaints and because Ms. Jones was alone.

### John Jefferson

Mr. Jefferson, duly sworn, testified he was aware of the complaints that Ms. Jones had with Nemours. According to Mr. Jefferson, Ms. Jones complained about the staff not introducing themselves to Cateial and about the staff trying to convince her not to transfer Cateial to another hospital. Mr. Jefferson said when Ms. Jones asked for the transfer, the staff asked for another chance, but Ms. Jones should have been granted the transfer and the staff should not have tried to convince her to remain at Nemours.

During cross examination, Mr. Jefferson testified he was never informed he could not visit, but when he visited there was a time limit. Mr. Jefferson said when he was available, he was permitted to visit Cateial. Mr. Jefferson testified he recalled a conversation with a doctor and nurse about the distance Cateial had to travel for a hospital transfer, but Mr. Jefferson believed there was equipment available to use during the transfer. In relation to the first request for transfer to CHOP, Mr. Jefferson said there was no discussion about it being a hardship.

During re-direct examination, Mr. Jefferson testified the doctor's main concern about transferring Cateial was his heart condition.

### Rosemary Capell

Ms. Capell, was called by Ms. Jones to testify as a character witness. Ms.

Brady objected on the basis that Ms. Capell did not have personal knowledge about the relevant issues. Ms. Jones conceded that Ms. Capell did not have personal knowledge and agreed to not seek Ms. Capell's testimony.

### Annette Fletcher

Ms. Fletcher, duly sworn, testified that one evening while en route to Nemours to take food to Ms. Jones, they were speaking on the telephone when she heard a male voice speaking to Ms. Jones. According to Ms. Fletcher, the male sounded aggressive and like he had an attitude. Ms. Jones told Ms. Fletcher that the male said additional visitors were not allowed even if the person was simply bringing food. Ms. Fletcher said Ms. Jones started crying and said, "they're not letting me do anything" and that no one was talking to her. After further discussion about who Ms. Jones could speak with regarding her issues with Nemours, Ms.

Fletcher advised her to file a complaint with the Delaware Division of Human and Civil Rights ("Division").8 Ms. Fletcher testified that Ms. Jones said she requested to be transferred to another hospital, but no one was communicating with her.

During cross examination, Ms. Fletcher testified she recalled the tone of the male's voice that she heard, but she did not recall what he said. Ms. Fletcher said

8 The Panel is aware that at the time of her testimony, Ms. Fletcher was an employee of the Division. Nevertheless, Ms. Fletcher's employment with the Division did not impact the Panel's findings and rulings herein.

she was informed she would not be able to access Ms. Jones or Cateial at Nemours. Ms. Fletcher said she did not discuss with Ms. Jones the possibility of just bringing the food because she knew Ms. Jones would not leave Cateial's room.

### Respondents' Case

* 1. **Dr. Colin Meyer-Macaulay9**

Dr. Meyer-Macaulay, duly sworn, testified he has been a Cardiac Intensivist at Nemours for two years and he is one of five attending Cardiac Intensivists that oversees care of children in Nemours' CICU. Dr. Meyer-Macaulay said he is primarily trained in pediatric critical care and he completed one year of training in cardiac intensive care. Dr. Meyer-Macaulay said he was the doctor most involved in Cateial's care and he had the most interaction with Ms. Jones and Mr. Jefferson.

Dr. Meyer-Macaulay summarized Cateial's medical condition and treatment.

He said Cateial was 15 years old and had a history of neurodevelopmental differences characterized by Ms. Jones as autism and cognitive disability in communication and developmental regression with progressive inability to walk due to lower extremity weakness. Dr. Meyer-Macaulay said Cateial presented with symptoms of fluid overload that was attributed to renal dysfunction and this led to Cateial's admission into Nemours' Pediatric Intensive Care Unit ("PICU").

9 Dr. Meyer-Macaulay's testimony began on October 27, 2022 and concluded on October 28, 2022.

According to Dr. Meyer-Macaulay, Cateial was later diagnosed with cardiomyopathy, a severe heart dysfunction on the right and left sides of his heart, which led to his transfer to the CICU. In the CICU, Cateial received oxygen as needed, medicine to remove fluid, and medicine to support heart function. Dr.

Meyer-Macaulay said Cateial initially had excess fluid in his chest that was attributed to dysfunction of his heart and after draining the fluid it was determined there was significantly more damage than initially thought. Consults were obtained and Cateial was observed for several days which determined that he was aspirating, he possibly had been aspirating on food for several weeks, and he might be suffering from an aspiration pneumonia. That determination in conjunction with Cateial's severe heart dysfunction necessitated non-invasive mechanical ventilation-a mask placed on his face to provide pressure to help with breathing. Dr. Meyer-Macaulay said Ms. Jones and Mr. Jefferson were given the option of continuing with non-invasive support or attempting to remove mucus and blockage from the lower part of Cateial's lungs by a bronchoscopy (i.e., a camera and suction device is placed into the airways). They were advised a bronchoscopy

could make him better or significantly worse and they chose bronchoscopy. Cateial got worse and had an ongoing large leakage of air from his lung that required emergent placement of another chest tube. Cateial later developed end stage heart failure and Nemours recommended removal of life sustaining therapies, known as compassionate withdrawal of the endotracheal tube ("compassionate extubation").

Dr. Meyer-Macaulay testified that on Monday, February 7th, "Ms. Jones raised several issues that.. .if accurate as described by Ms. Jones, were quite concerning for care that would not meet the standards that I believe Nemours sets for itself." Dr. Meyer-Macaulay said he did not personally observe any of the events that Ms. Jones described, but he did express empathy and remorse that the events happened.

Dr. Meyer-Macaulay testified that on Tuesday, February 8th following an incident involving the insertion of a nasogastric tube ("NG tube incident") Ms. Jones and Mr. Jefferson requested that Cateial be transferred to another hospital. Dr. Meyer-Macaulay explained that an NG tube is a tube that is placed in the stomach thru the nose to provide nutrition and it was necessary because Cateial was aspirating on food and drink. Dr. Meyer-Macaulay said the NG tube was to be inserted while Cateial was still under sedation from another procedure and although it is not the usual standard of care to sedate the patient, inserting the tube in this manner was appropriate for Cateial. According to Dr. Meyer-Macaulay, due to miscommunication a nurse attempted to insert the NG tube when Cateial was no longer sedated which upset Dr. Meyer-Macaulay. The tube was ultimately inserted while Cateial was under sedation, but Ms. Jones and Mr. Jefferson were angry and asked for a transfer.

Dr. Meyer-Macaulay testified he was part of the discussions about

transferring Cateial to another hospital. He said the documents in "Exhibit A"10 contain notes about these discussions. Dr. Meyer-Macaulay testified he, Ms.

Byrne, and the Case Manager Donna Defillippis had a lengthy discussion with Ms. Jones and Mr. Jefferson about what a transfer would entail, then Nemours staff began the process for transferring Cateial to CHOP, but there was no bed available.11 Dr. Meyer-Macaulay testified that Nemours did not stop the transfer from occurring, but because there were no beds available at CHOP he wanted to try and make up for some of Ms. Jones' experiences at Nemours that she viewed as negative and that "[he] also viewed as creating a negative relationship between her and Nemours' medical care team." According to Dr. Meyer-Macaulay, Ms. Jones was particularly receptive to this and the relationship did improve because Dr.

Meyer-Macaulay timely and efficiently communicated with Ms. Jones. Dr. Meyer­ Macaulay said he spoke with Ms. Jones 30-45 minutes each day about Cateial's medical issues and care. Dr. Meyer-Macaulay said he spoke to her in a manner that one who did not have a medical background could understand, but it was not his intent to "dumb it down" and he does not recall ever expressing by words or conduct to Ms. Jones that she could not understand.

10 "Exhibit A" was entered into evidence as Respondent's Exhibit A ("RP Ex. A") notwithstanding Ms. Jones' objection that she had received Respondents' exhibits just two days prior to the hearing. The Panel ruled that was sufficient time for Ms. Jones to review the exhibits.

11 *See* RP Ex. A, page 629.

Dr. Meyer-Macaulay testified he had a conversation with Ms. Jones about support systems that could be provided to Cateial within the hospital - speech and language therapy, occupational and physical therapy, music therapy, child life strategies for improving communication. But Dr. Meyer-Macaulay did not recall talking to Ms. Jones about visitation because hospital administration and the nurse management team make decisions related to infection control.

Dr. Meyer-Macaulay testified he does not believe Ms. Jones or Cateial were treated differently because of their race and/or disability. He explained that, as reflected in the medical records, the amount of resources utilized to preserve Cateial' s life and body functions were commensurate with his medical condition. Dr. Meyer-Macaulay said Cateial's race and intellectual disability did not play a role in his receipt of those resources.12

Dr. Meyer-Macaulay testified Ms. Jones twice requested that Cateial be transferred. The first time was after the NG tube incident, but the request was ultimately rescinded. Dr. Meyer-Macaulay said when Ms. Jones requested the

12 This is where Dr. Meyer-Macaulay's testimony ended on October 27, 2022. At that time, Dr. Meyer-Macaulay requested an additional twenty minutes to conclude his testimony, but his request was denied. He then expressed anger with having to return another day and possibly interfere with his family vacation. Dr. Meyer­ Macaulay said he was testifying of his own volition and not under subpoena, but a subpoena would be required for him to return. Dr. Meyer-Macaulay said he was not being treated fairly, he was present and had been patient, and he insisted that he had as much right to a fair hearing as Ms. Jones, but the Panel was not extending the same level of patience to him as it had Ms. Jones. On October 28, 2022, Dr.

Meyer-Macaulay apologized for this behavior.

transfer, Nemours immediately took action which included reviewing Cateial's course of hospitalization with an accepting physician and discussing with Ms. Jones the concerns and reasons for the transfer. Dr. Meyer-Macaulay said he did not discuss with Ms. Jones why she opted to not pursue the transfer, but Ms. Byrne documented that the travel distance was a factor. Dr. Meyer-Macaulay said Ms.

Jones may have misunderstood about the possibility of transferring to a closer hospital, but she ultimately understood there was not a hospital closer than CHOP that could provide the necessary level of care and perhaps she determined that location was not feasible for the family.

Dr. Meyer-Macaulay testified he initiated the second discussion about transferring Cateial to another hospital. According to Dr. Meyer-Macaulay, when it became apparent that Cateial's heart condition advanced to the point where medications and other non-invasive supports were no longer adequate, he initiated discussions with CHOP's heart failure and transfer team regarding Cateial's suitability for further therapeutics including mechanical support of his heart or transplant, but as Cateial's condition deteriorated Ms. Jones and Mr. Jefferson declined those options.

Dr. Meyer-Macaulay testified that Dr. Demare, a physician who occasionally provides care in the CICU, discussed with Ms. Jones Cateial's end of life state and Ms. Jones had requests that Nemours would try to honor-transfer to another hospital and transfer closer to home. Dr. Meyer-Macaulay said he spoke

with staff at Bayhealth about the possibility of transferring an end of life patient to their Adult Intensive Care Unit, but Bayhealth was unable to accommodate and he informed Ms. Jones. Regarding transfer closer to home, Dr. Meyer-Macaulay said when they began having discussions about Cateial's deterioration, it was explained to Ms. Jones that he had significant dysfunction of the heart which required medications and Cateial also had severe pneumonia which required non-invasive mechanical ventilation and he could not be discharged home for long term care.

Dr. Meyer-Macaulay said he explained that Cateial may be able to go home ifhe could take heart medicine by mouth and if the pneumonia got better so that a machine could be provided to use at night, but Cateial would also need help with breathing that could be accomplished with a tracheostomy.

Dr. Meyer-Macaulay testified he also informed Ms. Jones that Cateial may not recover from heart dysfunction and pneumonia and that is when they began discussing end of life care at home. According to Dr. Meyer-Macaulay, Ms. Jones may have initially misunderstood the resources available for end of life care at home, but once she realized that there was danger in transferring Cateial and that the breathing tube would be removed soon after Cateial arrived home, she voluntarily elected to have Cateial remain at Nemours. Dr. Meyer-Macaulay said he did not tell Ms. Jones that Cateial could not go home and he never refused the family's request to transfer Cateial to another hospital. Dr. Meyer-Macaulay testified that the notes written by Cardiac Intensivist Caroline Boyd on page 727 of

RP Ex. A pertain to this discussion with Ms. Jones.

Dr. Meyer-Macaulay testified that when he first met with Ms. Jones she expressed concerns about the care Cateial received in Nemours' Emergency Department ("ED"), PICU, and CICU. Dr. Meyer-Macaulay said they had a lengthy discussion and he expressed empathy that it must have been difficult for Ms. Jones and Cateial due to Cateial's developmental disabilities which place him at higher risk of experiencing the things that Ms. Jones described. Dr. Meyer­ Macaulay said they discussed the available options, including consults with speech and language therapy for communication strategies, assistance from the Child Life Department ("Child Life"), and music therapy which can provide coping and relaxation strategies for children who experience the world in an atypical neurological way. According to Dr. Meyer-Macaulay, those supportive services were provided to Cateial as is documented in the medical records found in "Exhibit E."13 Dr. Meyer-Macaulay described RP Ex. E as notes generated by the allied health providers who provide services that are not classified as medical services to CICU patients. The services include physical therapy, occupational therapy, speech and language therapy, and Child Life strategies for children who are hospitalized and experiencing acute medical distress.

According to Dr. Meyer-Macaulay, children with cognitive disabilities,

13 "Exhibit E" was entered into evidence as Respondent's Exhibit E ("RP Ex. E").

expressive and receptive language delays, and who suffer from other neuropsychiatric conditions such as autism may have difficulty communicating pain, fear, or need and providers may mistake their attempts to communicate as agitation or aggression so those children are more likely to be physically or chemically restrained during episodes of agitation. Dr. Meyer-Macaulay said although some people are more familiar with caring for children with these disabilities than others, it is important to note that some physical actions are not safe and need to be managed in the moment even if the management may be perceived as rough or unnecessary.

Dr. Meyer-Macaulay identified an accommodation that Nemours provided Cateial which he said evinces Nemours effectively responding to Ms. Jones' concerns. According to Dr. Meyer-Macaulay, Ms. Jones was concerned about Cateial removing invasive lines so a central line (also known as an arterial line) was not placed, instead a central catheter was placed when Cateial was under sedation so he could not remove the line. Dr. Meyer-Macaulay explained this not a typical approach, but it was appropriate to prevent Cateial from harming himself or causing an adverse event by pulling out the line.

Dr. Meyer-Macaulay testified that he did his best to care for Cateial like he would want for his child and that he was very sad this was the outcome. Dr.

Meyer-Macaulay apologized that the care received at Nemours did not meet Ms. Jones' expectations. Dr. Meyer-Macaulay said he has no reason to believe

visitation rules were applied inconsistently, accommodations were offered to the families of White children that were not offered to Cateial, Ms. Jones and Cateial received fewer or lesser resources, or Ms. Jones and Cateial were treated differently. Dr. Meyer-Macaulay said when there is a lot of information about a child who is experiencing acute severe deterioration in their condition, it is common practice to arrange a formal meeting apart from the day-to-day bedside rounds so that there is sufficient time to describe medical conditions, procedures, and therapies in simple language and respond to questions. Dr. Meyer-Macaulay explained that Cateial' s situation was very complex and even people in the medical field may find it challenging to understand. Dr. Meyer-Macaulay said it is not his practice to treat parents as incapable of understanding, but it is his practice to explain things in a way that ensures they understand.

During cross examination, Dr. Meyer-Macaulay testified as follows:

* He denied saying Cateial was given a communication board, but he did say that was a potential resource to be offered;
* He does not remember if Cateial was restrained to the bed but it was a possibility;
* He tried to be calm and speak to Cateial in a relaxing way to avoid frightening Cateial and his communication with Cateial was better than many others';
* He did say Cateial' s heart was severely dysfunctional and he might

not survive transfer to another hospital or home;

* Based on his medical evaluation, it was safer and more appropriate to insert the NG tube while Cateial was under sedation;
* After the NG tube incident, he informed Kristen Daniels 14 that Ms.

Jones did not want the involved nurse assigned to Cateial's care and he agreed that was best for Ms. Jones' psychiatric safety, Cateial's psychiatric safety, and the nurse's ability to provide effective care.

During re-direct examination, Dr. Meyer-Macaulay testified the NG tube incident was the result of miscommunication and not malice. Dr. Meyer-Macaulay said although the procedure is typically done without sedation, it was appropriate in Cateial's situation, but there was a breakdown in communication that resulted in the nurse's attempt to insert the tube after the sedation had worn off. Dr. Meyer­ Macaulay confirmed that when he learned what happened, he stopped the procedure and had the anesthetist return to provide sedation until the procedure was completed.

In response to Panel questions, Dr. Meyer-Macaulay testified he first examined Cateial on Monday, February 7th when Ms. Jones and a nurse were present. Dr. Meyer-Macaulay said he did not observe anyone using American Sign Language; he gently spoke to Cateial to explain his actions; Cateial was not afraid

14 In later testimony, Ms. Daniels identified herself as a Registered Nurse and the Nurse Manager for the CICU.

during the examination; and Cateial used body language that Ms. Jones interpreted. Dr. Meyer-Macaulay said Ms. Jones expressed concern that Cateial was treated roughly by several nurses when placing intravenous therapy ("IV"), applying IV dressings, and restraining him, and they did not appreciate how fearful he was of what many might assume are normal operating procedures. Dr. Meyer-Macaulay said Ms. Jones felt such mistakes may be excusable one time, but she said they were repeatedly made.

Dr. Meyer-Macaulay said he later determined Cateial needed the NG tube after observing Cateial coughing, having trouble swallowing, and food falling out of his mouth when he ate. Dr. Meyer-Macaulay said he requested a speech and language consultation which was followed by a barium swallow study in which an x-ray was used to look at the mechanics of swallowing. According to Dr. Meyer­ Macaulay, the study determined that Cateial was aspirating food and liquids and he was not able to receive nutrition by eating on his own.

Dr. Meyer-Macaulay testified Cateial was properly sedated for the chest tube placement procedure performed because Cateial had developed fluid in his lungs that was impairing his breathing. The chest tube was for removing the fluid. Dr.

Meyer-Macaulay said the NG tube was to be inserted after the chest tube procedure but before sedation wore off and that did not happen. Cateial was no longer under sedation when initial attempts were made to insert the NG tube which caused Cateial to be very distressed and combative. Dr. Meyer-Macaulay said he stopped

the procedure and instructed that Cateial be re-sedated before inserting the NG tube. Dr. Meyer-Macaulay said this is the incident that Ms. Jones referred to as distressing and he said it also caused him distress. Dr. Meyer-Macaulay said the NG tube incident is the catalyst for Ms. Jones' request to transfer Cateial to another hospital as she was understandably upset about the entire incident. Dr. Meyer­ Macaulay said during his two years of employment with Nemours he cannot specify how many times an order was disobeyed, but he does not believe there was willful disobedience in relation to the NG tube incident.

Dr. Meyer-Macaulay testified that prior to the bronchoscopy, the procedure was explained to Ms. Jones and Mr. Jefferson. Dr. Meyer-Macaulay said after the bronchoscopy Cateial developed acute pneumothorax-air within the chest that could not be drained by the chest tube that was previously placed. Dr. Meyer­ Macaulay said Cateial became very unstable and the breathing tube needed to be emergently reinserted, but Cateial's heart did not tolerate the stress of inserting the breathing tube (i.e., he had high fevers and low blood pressure) so he needed more support.

Dr. Meyer-Macaulay testified it is normal procedure to discuss any risks with parents who request a hospital transfer. Dr. Meyer-Macaulay said regarding the possibility of transferring to CHOP for ongoing medical care, Ms. Jones opted to stay at Nemours due to proximity to her home. Dr. Meyer-Macaulay said regarding the possibility of transferring Cateial home there were two concerns-

the risk related to the transfer itself and the fact that the time spent at home would be much shorter than what Ms. Jones had hoped-which Dr. Meyer-Macaulay believed contributed to Ms. Jones' decision to remain at Nemours.

Regarding Ms. Jones' testimony about placing Cateial in restraints, Dr.

Meyer-Macaulay said he believes that was in reference to placement of the chest tube when Cateial was still breathing on his own. He said accidental dislodgement of a chest tube carries risks and it would not have been unreasonable to use soft loose restraints on someone who may not fully understand the risks of removing the chest tube.

Dr. Meyer-Macaulay testified that overall Cateial was not afraid of him, Cateial did not find him to be distressing, and Cateial was calm when Dr. Meyer­ Macaulay interacted with him. According to Dr. Meyer-Macaulay, when Cateial was very sick he probably did not recognize Dr. Meyer-Macaulay and probably did not know what was happening because he was sedated, his heart was not functioning well, and his brain was not getting enough oxygen. Dr. Meyer­ Macaulay said Cateial had an unusually large amount of communication compared to his other patients.

### Courtney Byrne

Ms. Byrne, duly sworn, testified that she serves as a Social Worker in Nemours' Cardiac Center. Ms. Byrne explained that she provides support for

families during hospitalization, which includes emotional support and finding resources to help ease stress. Ms. Byrne said she provided support for and addressed some of Ms. Jones' concerns when Cateial was inpatient at Nemours. Ms. Byrne said she spent a lot of time with Ms. Jones and Mr. Jefferson to address their concerns and make sure their needs were met. Ms. Byrne said she also spent time with them in meetings talking about plan of care, providing support, and when Cateial was at the end of his life she ensured there was an exception to the visitation rules enabling the family to visit and make meaningful memories.

Ms. Byrne testified that when Cateial was admitted to Nemours the visitation policy permitted two designated caregivers who were over 18 years old, but they did not have to be biological parents. Ms. Byrne said 14 days after admission, the visitation policy permitted two additional caregivers. She explained that the visitation policy was for infection control as Nemours wanted to limit exposure to other patients. According to Ms. Byrne, Ms. Jones and Mr. Jefferson were identified as Cateial's caregivers upon his admission and Mr. Jefferson did visit Cateial during the initial two weeks.

Ms. Byrne testified she became involved with the family on Friday, February 4th and she spent 1.5 hours meeting with them on that date. According to Ms. Byrne, Cateial was initially admitted to the ED and then he transferred to the PICU. Ms. Byrne testified that Ms. Jones said there were communication challenges when Cateial was in the ED and PICU and Ms. Byrne made sure

Cateial' s entire care team was aware of those challenges. Ms. Byrne testified that Ms. Jones also raised concerns about accommodations necessary due to Cateial being autistic. Ms. Byrne said she contacted specialists in Child Life to assist with getting communication boards or placing signs in Cateial's room to help accommodate his needs. Ms. Byrne said she shared with Cateial's bedside nurse the signs that Ms. Jones believed would help improve communication.

Ms. Byrne testified she informed Ms. Jones about sleeping in the "sleep room" since there was nowhere for Ms. Jones to sleep in the CICU. Ms. Byrne identified the documents contained in "Exhibit B" as social work, creative life, and child specialists notes.15 Ms. Byrne said page 601 of RP Ex. B contains a summary of her meeting with Ms. Jones on Friday, February 4th.16

Ms. Byrne testified that on Saturday, February 5th, she missed two calls from Ms. Jones-at 3 A.M. and 5 A.M. Ms. Byrne said she responded by texting Ms. Jones that she was not at the hospital and that Ms. Jones should ask the nurse to assist her with contacting the weekend social worker. Ms. Byrne confirmed that CP Ex. #1 contains the text message she sent Ms. Jones and Ms. Jones' response thereto. Ms. Byrne testified Nemours has social workers to address urgent needs and emergencies. Ms. Byrne said a social worker, Laura Boyer, did meet with Ms. Jones on Sunday, February 6th and discussed Ms. Jones' request to transfer Cateial

15 "Exhibit B" was entered into evidence as Respondent's Exhibit B ("RP Ex. B").

16 The Panel notes that the summary continues on page 602.

to another hospital. Ms. Byrne said page 609 of **RP** Ex. **B** contains Ms. Boyer's progress notes about this meeting.

Ms. Byrne testified that on Monday, February 7th, she again discussed with Ms. Jones availability of a "sleep room" and she informed Ms. Jones of resources for getting food, but Ms. Jones was hesitant to leave Cateial's bedside. Ms. Byrne testified that on the same date, she and Ms. Daniels spoke with Ms. Jones about the communication challenges that occurred during the weekend and about transferring Cateial to another hospital. According to Ms. Byrne, Ms. Jones was unhappy about the care received at Nemours and she wanted to transfer Cateial to another

hospital. Nemours identified CHOP as the hospital able to care for Cateial's complex needs, but the family felt it was too far away and decided not to transfer.

Ms. Byrne testified she discussed the NG tube incident with Ms. Jones. Ms. Jones expressed concern that Cateial was awake during placement of the tube and this was addressed with Dr. Meyer-Macaulay. Ms. Byrne said Cateial was supposed to be sedated when the tube was placed, but Cateial was not under sedation which agitated him and in tum Ms. Jones was agitated. Ms. Byrne said she assisted by supporting and advocating for Ms. Jones and she assured Ms. Jones there would be proper communication in the future. Ms. Byrne said her notes appearing on page 682 of RP Ex. B pertain to her discussion with Ms. Jones about the NG tube incident.

Ms. Byrne testified she was aware of the procedure for which Ms. Jones

thought she could be present-Cateial's bronchoscopy. According to Ms. Byrne, one of the pulmonology team members informed Ms. Jones she could be present, but that is inconsistent with CICU policy that family members be instructed to wait in the waiting room where they will receive updates. Ms. Byrne testified that after Ms. Jones was informed she could stay in the room she was asked to go to the waiting room. Ms. Byrne explained that the door separating the patient rooms and the waiting room is secured and anyone attempting to gain entry from the waiting room to a patient room must be granted access. Ms. Byrne said there was no intention to only keep Ms. Jones from re-entering the area where patient rooms are located. Ms. Byrne identified pages 694 through 695 of RP Ex. B as her notes related to discussions with Ms. Jones about the bronchoscopy.

Ms. Byrne testified that when Cateial was quickly becoming very sick, she and the CICU providers spoke with Ms. Jones and Mr. Jefferson about Cateial's plan of care. Ms. Byrne said the family was granted an exception to the visitation policy because Cateial' s status was critical. Ms. Byrne identified the notes on page 714 of RP Ex. B, authored by Casey M. Lynch on Sunday, February 13, 2022 at 1:07 PM, as notes pertaining to the granted visitation exception.

Ms. Byrne also testified about a family meeting that occurred on Sunday, February 13th for which she was not present. Ms. Byrne is aware that there was discussion about Cateial's status and that he was nearing the end of life. Notes about the family meeting appear on page 714 of RP Ex. B. There was discussion

about plan of care options which included Cateial going home with hospice services, but there was a risk of him not surviving transport and a risk he would expire sooner because the tubes and medicine would be removed once he arrived home, being transferred to a hospital closer to home and receiving palliative care until the family decides to withdraw care, or remaining at Nemours and the CICU team would organize family and friend visitation before compassionate extubation.

Ms. Byrne testified that after the family meeting she spoke with Ms. Jones and Mr. Jefferson about their plans and wishes for Cateial's end of life. They discussed that a palliative care team was not able to manage Cateial at home and if Cateial was transported with the breathing tube there was a risk it would come out during transport causing him to expire.

Ms. Byrne testified that Nemours did not outright refuse or deny the family's wishes, neither Ms. Jones, Mr. Jefferson, nor anyone else expressed concern that the services and care were provided in a discriminatory manner, the family was not treated differently because of their race or disability, the visitation rules were applied consistently for all families, and there were non-White children in CICU during Cateial's admission.

During cross examination, when asked if she recalled the complaints Ms. Jones made regarding treatment upon first arrival at Nemours, Ms. Byrne testified there were complaints about Cateial's wheelchair, nurses being aggressive when Cateial was admitted to the ED, and the possibility that restraints would be used on

Cateial. Ms. Byrne said these issues were referred to patient relations and she was unsure of the resolution. During cross examination, Ms. Byrne also testified as follows:

* If a procedure is occurring bedside, parents are not allowed in the room because there needs to be a sterile environment;
* She could not speak to whether it is common practice to keep parents out of the hallway;
* She did not see Mr. Jefferson when Cateial was first admitted to the CICU and she did not recall when he first visited;
* According to Ms. Lynch's notes, the visitation policy exception occurred on Sunday, February 13t\
* Ms. Jones said she did not feel comfortable leaving Cateial's bedside because of the NG tube incident; and
* There were memory making activities with Cateial that included making handprint molds.

During re-direct examination, Ms. Byrne testified as follows:

* Mr. Jefferson was not prohibited from visiting Cateial;
* On Sunday, February13th, the family decided to initiate a do not resuscitate order;
* Page 737 of RP Ex. B contains notes about Ms. Jones' plan to proceed with compassionate extubation on Wednesday, February 16th

after Carol Hall's visit; and

* Page 737 of RP Ex. B contains notes about some of the memory making activities.

In response to Panel questions, Ms. Byrne again testified she provided Ms. Jones emotional support and counseling. According to Ms. Byrne, she spent a lot of time listening to Ms. Jones and providing support around other stressors like having other children at home who were not able to visit due to COVID-19 restrictions. Ms. Byrne said she helped ensure Ms. Jones had somewhere to sleep and was able to access food. Regarding Cateial's wheelchair, Ms. Byrne said it was left at Bayhealth and patient relations assisted with that issue. Ms. Byrne said patient relations also assisted with the other concerns raised by Ms. Jones.

### Dr. Aisha Frazier

Dr. Frazier, duly sworn, testified she has been employed with Nemours for nine years, is a Pediatric Cardiologist Intensivist, and is currently the Interim Division Chief of the CICU. Dr. Frazier testified she provided care for Cateial on Saturday, February 5th when she was on 24-hour call and at other times.

Dr. Frazier testified that when Cateial was admitted to Nemours he was in severe end stage heart failure and he had fluid around his lungs and belly. Dr.

Frazier said due to Cateial's heart condition, his blood flow was not moving swift enough out of his heart and he had abnormal heart rhythms and thrombus (i.e., a

clot) in his left heart ventricle which is common when the blood is not moving out of the heart in a normal way. According to Dr. Frazier, Nemours initiated some very aggressive therapies including medication to improve Cateial' s heart function, but his health did not improve.

Dr. Frazier testified Nemours initially thought Cateial also had a muscle disorder called myopathy because he had developed weakness in his extremities that required use of a wheelchair, but Cateial was later diagnosed with Duchenne Muscular Dystrophy ("DMD") which is consistent with progressive muscle weakness. Dr. Frazier said Nemours performed genetic studies on Cateial which revealed the DMD diagnosis and it was surprising that an extensive work up was not previously done before he developed end stage heart failure which is a result of DMD. Dr. Frazier reviewed page 1903 in "Exhibit D"17 and identified it as the results of Cateial's genetic study. According to Dr. Frazier, DMD is a genetic disorder that can affect skeletal muscles as well as other muscles like the lungs, diaphragm, heart, and the muscles used for swallowing.

Dr. Frazier testified she had numerous conversations with Ms. Jones when Cateial was inpatient at Nemours. Dr. Frazier noted that these conversations usually occurred in the presence of a Nemours staff member and on occasion Mr. Jefferson was on the phone. Dr. Frazier recalled Ms. Jones had concerns that

17 "Exhibit D" was admitted into evidence at Respondent's Exhibit D ("RP Ex.

D").

Cateial would regress because his outpatient autism education would not be continued while inpatient. Dr. Frazier said she wanted to ensure Ms. Jones' concerns were addressed so she spoke with Ms. Byrne, Ms. Daniels, and Nurse Manager Janet Presil about how to address them. Dr. Frazier said she also put in numerous orders to help address Ms. Jones' concern about Cateial regressing. Dr. Frazier said that she also wanted to ensure Ms. Jones was aware of the severity of Cateial' s illnesses.

Dr. Frazier testified she and Nemours assume care for the entire patient's family, family centered conversations are necessary to identify what is important, and it is necessary to provide information about the care plan. Dr. Frazier said when there are complex medical problems, she repeats herself and reviews the information as often as the patient's family needs to hear it and there may be family meetings with a primary Cardiac Intensivist who advocates for the family and relays the information about ongoing care. According to Dr. Frazier, Cateial had a lot of medical problems that would be complicating to any layperson and she made sure there were opportunities for the family to ask questions. Dr. Frazier said she had a conversation with Ms. Jones ensuring Ms. Jones that she was a welcomed advocate for Cateial.

Dr. Frazier testified that during one weekend, Ms. Jones said she wanted to transfer Cateial to another hospital and Dr. Frazier relayed that information to Ms. Byrne and Ms. Daniels. Dr. Frazier said she has no knowledge of Nemours

refusing to honor Ms. Jones' wishes. According to Dr. Frazier, Nemours always facilitates a transfer upon request and a transfer typically requires the following: putting together the medical chart, contacting the discharge coordinator and consultation line at the receiving hospital, talking to insurance to get approval, and speaking with the receiving hospital doctors who decide if they will accept the patient as there needs to be an available bed.

Dr. Frazier testified that on Thursday, February 10th, it was determined Cateial needed extra breathing support and she had a conversation with Ms. Jones about placing Cateial on BiPAP (i.e., bilevel positive airway pressure) and not a ventilator because it may be difficult to remove the ventilator if Cateial had weakened muscles. According to Dr. Frazier, when the staff tried to place the BiPAP, Ms. Jones because frustrated because it was a new technology and she felt it would irritate Cateial's face. Dr. Frazier said Ms. Jones also expressed frustration about the number of people in the room and although it was the necessary number, Dr. Frazier saw that it was overstimulating and she strategized with Ms. Jones about how to proceed. Dr. Frazier said she was trying to follow Ms. Jones' lead on how best to place the BiPAP and once it was placed Cateial gave a "thumbs up" and he looked much more comfortable. Dr. Frazier said she and Ms. Jones then stepped out of the room and discussed the severity of Cateial's illnesses as well as how Dr. Frazier could be a resource and support to Ms. Jones. Dr. Frazier said she explained to Ms. Jones what occurs when technological support is removed and

discussed Ms. Jones' wishes for when that occurred. Dr. Frazier said she was the person that removed Cateial's technological support and identified page 441 in "Exhibit C"18 as the discharge summary pertaining to withdrawal of that support.

Dr. Frazier testified that in some circumstances it may be appropriate to use restraints. According to Dr. Frazier, restraints can only be used if the physician orders it and they are used to keep patients safe. Dr. Frazier said if the patient receiving life sustaining therapies is a baby, toddler, or child with learning differences, it is important to prevent them from dislodging life sustaining therapies so restraints are necessary. Dr. Frazier described the restraints as soft and said they are for the sole purpose of preventing removal of necessary tubes. Dr.

Frazier said she is unsure if restraints were used on Cateial, but he did receive therapies that if removed prematurely could make him decompensate very quickly and lead to life threatening problems.

Dr. Frazier testified she has no reason to believe Nemours enforced different visitation rules for Ms. Jones and Mr. Jefferson. Dr. Frazier recalls Ms. Byrne and Ms. Daniels coming to her with concerns about the visitation policy, but due to the COVID-19 pandemic and to protect the staff and patients there were no policy exceptions made. Dr. Frazier said she was aware of a number of families asking for exceptions, but their requests were denied, including when Dr. Frazier spoke with a

18 "Exhibit C" was entered into evidence as Respondent's Exhibit C ("RP Ex. C").

Nemours executive on one family's behalf. Dr. Frazier testified she was personally aware of two families who were at Nemours for a lengthy time (i.e., 8 months to 1 year) who were denied an exception---one family was White and the other family was Black.

Dr. Frazier testified she does not know why Ms. Jones felt she did not have family support. Dr. Frazier recalled a conversation with Ms. Jones about having support from Mr. Jefferson and Ms. Jones provided reasons why he could not be at the hospital, but the reasons had nothing to do with the visitation policy. According to Dr. Frazier, Ms. Jones said Mr. Jefferson could not come due to his work schedule and due to having to care for another child at home.

Dr. Frazier testified Cateial was an extraordinarily sick child to whom an endless amount of time and therapies were devoted and the same care would have been provided any child with the same medical problems. Dr. Frazier said the amount of time spent with Ms. Jones to review, discuss, and relay information was probably more than that afforded other families in the same situation because that is Dr. Frazier's job. Dr. Frazier said Cateial received "above and beyond" medical care and therapies and he received every resource available within Nemours­ consultation about heart failure, consultation with the transplant team, consultation with outside hospitals, determining if Cateial was suitable for a heart pump or transplant, insertion of a tube to remove fluid, insertion of a tube to remove the air leak, examination to determine if aspirating, nutrition therapy, BiPAP therapy,

insertion of a breathing tube, therapies offered related to learning differences (i.e. music, art, physical, occupational, and speech therapies, and Child Life services), investigation into additional educational options, and psychology.

Dr. Frazier testified there is no reason to believe Cateial or Ms. Jones received inferior services due to their race or disability. Dr. Frazier said there were mostly children of color in the CICU when Cateial was inpatient and Nemours' patient population is very diverse. Dr. Frazier recalled that another of her patients at the time was a person of color. According to Dr. Frazier, the amount of support, medical care, and technological care that Cateial received was exemplary.

During cross examination, Dr. Frazier testified she is not a behavioral psychologist or a behavioral specialist and she has not received school training specifically related to children with autism. Dr. Frazier said she tried to follow Ms. Jones' lead during conversations with Cateial and she listened when Ms. Jones said Cateial is fine when he smiles or gives a "thumbs up." Dr. Frazier said she spoke to Cateial in a manner that she would speak to any child in the hospital-with a gentle and calming voice. Dr. Frazier said she is a big proponent of parent advocates providing direction on how to interact with their children because they know the child best. Dr. Frazier said she was not aware that Ms. Jones requested a learning board and Cateial would have received the board if Ms. Jones expressed that he needed one.

Dr. Frazier testified that on Saturday, February 5th, she spoke with Ms.

Daniels, Ms. Byrne, and Ms. Presil about Cateial receiving speech and language therapy and asked them to further discuss that with Ms. Jones. Dr. Frazier does not recall if she put in an order for that therapy, but it is possible that Cateial was not able to receive therapy due to his medical condition which would be documented in his records. Dr. Frazier said it is possible for staff to first focus on necessary medical care and so receiving therapy may not occur.

Dr. Frazier testified that on Thursday, February 10th, she walked into Cateial' s room and saw that he was agitated as staff tried to place the BiPAP support. Dr. Frazier said BiPAP support was used because it was better than the alternative ventilator that involves inserting a breathing tube. Dr. Frazier said she previously discussed with Ms. Jones the high risk involved in inserting a tube and she took into consideration Ms. Jones' fears that Cateial may never come off a ventilator so BiPAP support was chosen. Dr. Frazier said she explained to Ms.

Jones that BiPAP was necessary because Cateial needed support for his breathing and the number of people in the room were needed to place the BiPAP over his face in a less stimulating manner. Dr. Frazier said she and Ms. Jones talked about strategies that would enable placement to occur swiftly, the BiPAP was placed, and Cateial smiled and gave a "thumbs up." Dr. Frazier said the conversation she and Ms. Jones had outside Cateial's room was lengthy and she deduced Ms. Jones was comfortable enough with Cateial's care to leave his bedside for that conversation.

Dr. Frazier testified she had good communication with Ms. Jones. Dr.

Frazier said no one could be an expert regarding Cateial like Ms. Jones, but Nemours' staff were the experts from a medical and therapy standpoint and they were on a "medical battlefield" trying to provide the care that Cateial needed. Dr. Frazier said she would have her own children and brother, who had issues similar to Cateial, cared for by this staff. Dr. Frazier said the Nemours staff was not averse to learning how best to talk to Cateial, but they needed to immediately act to provide medical care for Cateial as the goal was to provide life sustaining measures for his critical illness. Dr. Frazier said Cateial received every bit of medical therapy to help keep him alive, not be in critical condition, and possibly go home.

Dr. Frazier testified she was present on Wednesday, February 16th when Cateial's technology was removed (i.e., compassionate extubation) and she did not recall if he was restrained at that time as she was focused on making sure Cateial was comfortable and did not suffer. Dr. Frazier said there was a lot of preparation with the staff, including multiple meetings and conversations, to ensure everyone was on the same page because "I do not play around with that process."

In response to Panel questions, Dr. Frazier testified Cateial arrived at Nemours on Thursday, February 3rd and his technology was removed by her on Wednesday, February 16th. Dr. Frazier said the family visited Cateial before the technology was removed and they had an opportunity to engage in memory making activities. According to Dr. Frazier, she made sure the family's wishes were honored.

Regarding scheduling in the CICU, Dr. Frazier testified that during the day on Monday thru Friday, there is a doctor who provides care to all the patients and there are also helper doctors, nurse practitioners, and physician assistants. During the evenings on Monday thru Friday, there is an on-call doctor. On Saturday and Sunday there are two doctors who have 24-hour shifts. Dr. Frazier said Dr. Meyer­ Macaulay had more involvement in Cateial' s care than her as she was only involved on February 5th, 10th, and 16th.

# Kristin Daniels

Ms. Daniels, duly sworn, testified she is a Registered Nurse and has been employed with Nemours for two years where she serves as the Nurse Manager for the CICU. Ms. Daniels said she was the Unit Nurse Manager when Cateial was inpatient at Nemours and she is familiar with Ms. Jones.

Ms. Daniels testified she and Ms. Byrne met with Ms. Jones to address Ms. Jones' concerns about things that happened when Cateial first arrived at the ED. Ms. Daniels explained she and Ms. Byrne regularly address patient and family concerns. Ms. Daniels said when she arrived at work on Monday, February 7, 2022 she was advised by a charge nurse of Ms. Jones' concerns. According to Ms.

Daniels, it sounded like Ms. Jones had a bad experience from the time that Cateial arrived at the ED. Ms. Daniels said Ms. Jones expressed concern because she was unable to contact the weekend social worker and because she was informed there

was no available social worker. Ms. Daniels testified she was confused by that because there is always a social worker available and during the weekend there is an on-call social worker. According to Ms. Daniels, Ms. Jones also expressed concern about the lack of support she received while Cateial was in the ED and that the staffs communication with Cateial was lacking. Ms. Jones informed Ms. Daniels that although Cateial was non-verbal, he could hear and understand words and it was important to talk to him. Ms. Daniels testified she informed Ms. Jones about working with Child Life to find ways to communicate with Cateial. Ms.

Daniels discussed making signs to be posted outside Cateial's room reminding staff to talk to Cateial, introduce themselves, and explain what they were doing. According to Ms. Daniels, Child Life did create the signs and there was no indication that Cateial was able to communicate with American Sign Language.

Ms. Daniels testified she also informed Ms. Jones about resources available to her, like rooms with beds for where Ms. Jones could sleep and bathrooms where she could shower. Ms. Daniels also talked to Ms. Jones about how to get food since Ms. Jones was not amenable to leaving Cateial's room.

Ms. Daniels recalled Dr. Meyer-Macaulay also started working with Cateial on Monday, February 7th and Ms. Jones informed him she wanted to transfer Cateial to another hospital because of what occurred during the weekend. Ms.

Daniels said Dr. Meyer-Macaulay apologized to Ms. Jones and ultimately Cateial was not transferred, but Ms. Daniels was not involved in any discussions about or

actions taken in relation the requested transfer.

Ms. Daniels testified Dr. Meyer-Macaulay informed her about the NG tube incident. Ms. Daniels said after that incident, the involved nurse was re-assigned because Ms. Daniels determined it was inappropriate to have the nurse continue to work with Cateial and Ms. Jones when Ms. Jones distrusted the staff and was so upset by the incident. Ms. Daniels said the communication issue that led to the NG tube incident did not amount to a violation of the standard of care, but Ms. Daniels felt it was best to assign another nurse in an effort to salvage the relationship between Ms. Jones and the remaining staff.

Ms. Daniels testified that due to the COVID-19 pandemic, the Nemours' visitation policy in effect when Cateial was inpatient permitted two designated caregivers who did not have to be biologically related to the patient, but they had to be specifically identified at the time of admission. After fourteen days, if the patient was still inpatient, two additional caregivers were permitted. Ms. Daniels testified that on occasion a pastor, priest, rabbi, or other spiritual person was permitted to visit for purposes of performing a spiritual/religious ritual. Ms.

Daniels also testified there was an exception to the visitation policy for end of life patients and they were permitted an unlimited number of caregivers and guests.

According to Ms. Daniels, when Cateial became an end of life patient, she informed Ms. Jones there was no longer a restriction on visitors and she discussed with Ms. Jones the Child Life services available, which included memory making

activities.

Ms. Daniels testified Nemours' patient population was diverse in February 2022 when Cateial was a patient and it remains diverse. Ms. Daniels testified that the Nemours staff is also diverse. According to Ms. Daniels, there is nothing to indicate that the care and services Nemours provided Cateial was less than that provided to White patients. Ms. Daniels said if she observed that, she would have taken steps to address it, like notifying a direct manager and/or consulting trusted colleagues.

During cross examination, Ms. Daniels again testified that Ms. Jones' main complaint was about the need for better communication with her and Cateial and that Ms. Jones wanted Cateial transferred to another hospital. Ms. Daniels said she and Ms. Byrne spoke with Ms. Jones about working with Child Life to help create different ways of communicating with Cateial. She said they discussed finding ways to get Ms. Jones food and a bed to sleep in. Ms. Daniels agreed communication was an issue throughout Cateial's admission and re-confirmed that Child Life posted signs about how to communicate with Cateial, but Ms. Daniels is unsure when the signs were posted. During cross examination, Ms. Daniels also testified as follows:

* The nurse involved in the NG tube incident was permitted to explain what happened and it was determined the nurse did not commit a medical error so she was not disciplined;
* There is a note in Cateial's records that a social worker spoke with Ms. Jones and then on Monday, February 7th, Ms. Daniels and Ms. Byrne spoke with Ms. Jones. Thereafter, there were no additional conversations about lack of communication and resources; and
* She does not know who informed Ms. Jones that only biological relatives could be caregivers.

In response to Panel questions, Ms. Daniels said she was never the bedside nurse for Cateial. Ms. Daniels said she re-assigned the NG tube incident nurse because Ms. Jones did not trust the staff and had already expressed concern about the communication issue. Ms. Daniels felt reassignment would help Ms. Jones feel comfortable and not mistrustful. Ms. Daniels said she was not apprised of any concerns with the replacement nurse. Ms. Daniels said none of the nurses reported to her that they had difficulty communicating with Cateial. Ms. Daniels said her involvement in Cateial's care was a little more than usual due to the Ms. Jones' concerns and because Ms. Daniels helped coordinate the memory making activities.

During re-direct examination, Ms. Daniels testified there were opportunities for which the communication could have been clearer, like the NG tube incident. Ms. Daniels said for some reason there was a communication issue that led to that incident. Ms. Daniels said there was an opportunity to do better to ensure there was proper communication with Ms. Jones and Cateial, but during the times when the

focus was on making him better there were missed opportunities to communicate to him what was happening. Ms. Daniels explained that this often occurs in the CICU because time is sensitive when taking care of sick children and staff have to address the child's needs. But, the staff has to also make sure that there is communication on the patient's developmental level. Ms. Daniels said this is an issue when caring for all children and race and disability have no bearing.

# Respondent's Exhibits

The following is documented in Respondent's Exhibits A through E:

* + - *214/22* @ 3:01 PM - Courtney Byrne - Social Work Assessment -

Ms. Byrne noted the following: she submitted a sleep room request for the weekend; Cateial was transferred from PICU to CICU the morning of 2/4/22; she encouraged Ms. Jones to provide guidance on the meaning of Cateial's gestures; and Ms. Jones advised that Cateial becomes anxious when a lot of people come near him at once. RP Ex. B, pages 601-602.

* + - 2/4/22 @ 4:12 PM - Molly Bogan - Progress Notes (Child Life Specialist) -This appears to only be part of the progress notes. Ms. Bogan noted "adjustment to hospitalization" as the problem and then identified goals established to address the problem. RP Ex. **B,** page 602.
		- 2/5/22 Cateial's blood sample was collected for genetic testing and results were reported on 2/23/22. Cateial was diagnosed with **DMD. RP** Ex. **D,** pages 1841-1843.
		- 2/6/22@ 2:17 PM- Laura Boyer- Social Work Progress Note - Ms. Boyer noted the following: the weekend social worker spoke with Ms. Jones; Ms. Jones was not happy with treatment and requested that Cateial be transferred to a hospital closer to home; and Ms. Boyer explained that CHOP was the closest pediatric hospital. RP Ex. B,

page 609.

* + - 2/7/22@8:28 AM-Dr. Meyer-Macaulay-Progress Note-Dr. Meyer-Macaulay noted the following: Ms. Jones had concerns about the care Cateial received in CICU; and he had a long discussion with Ms. Jones about her concerns. **RP** Ex. A, pages 613-614.
		- 2/7/22@ 8:39 AM-Christopher Schmitt- Creative Arts Therapy Progress Note - Mr. Schmitt noted that he received an order for a music therapy inpatient consult. **RP** Ex. A, page 615.
		- 2/8/22 @ 11:28 AM - Dr. Meyer-Macaulay - Progress Note - Dr. Meyer-Macaulay noted the following about Cateial's care: he drained the right sided pleural effusion and pneumothorax under moderate sedation which was tolerated well; he intended the NG tube to be placed while Cateial was under sedation but due to miscommunication an attempt was made after sedation wore off; Cateial was agitated from the NG tube incident; Ms. Jones was upset about the NG tube incident and requested Cateial be transferred to another hospital; he would try to arrange the transfer; and speech-language evaluated Cateial on 2/7/22 and suspected he was aspirating. RP Ex. A, pages 627-629.
		- 2/8/22 @ 2:13 PM - Donna Defillippis - Case Management Progress Note - Ms. Defillippis noted the following: Dr. Meyer-Macaulay asked her to begin the process of transferring Cateial to CHOP; she discussed the process with Ms. Jones; she spoke to CHOP and was informed there were no available beds; she contacted Cateial's insurance regarding the transfer request; and Ms. Jones expressed concern about the cardiac team and nurses' miscommunication which was an issue being addressed by social work and the nurse manager. RP Ex. A, pages 629-630.
		- 2/8/22 @ 3:17 PM - Alexandra Schubert - Child Life Progress Note - Ms. Schubert noted the following: Ms. Jones expressed frustration related to communication regarding the NG tube incident; she discussed with Ms. Jones the benefit of medical play to normalize medical equipment/treatment; and Ms. Jones was receptive to medical play. RP Ex. A, page 630.
		- 2/8/22 @4:50 PM-Dr. Joslyn Kenowitz -Inpatient Family Based

Psychology Assessment - Dr. Kenowitz noted that a consult was requested by the cardiac team to assess Cateial and his family's coping and to provide support throughout his admission. Dr.

Kenowitz also noted the following: Ms. Jones described a number of distressing events including the NG tube incident; Ms. Jones was frustrated regarding the communication related to Cateial's care; Ms. Jones said although Cateial is nonverbal he understands and wants to be part of the conversation; and Ms. Jones said she recently met with Child Life and identified communication strategies which will be hung on the door. RP Ex. B, pages 524-525.

* + - 2/8/22 @ 5:01 PM - Karil Negrin - Speech-Language Pathology Evaluation: Modified Barium Swallow Study. RP Ex. B, page 525.
		- 2/8/22 @ 11:23 PM - Marcy Nase - Physical Therapy Treatment Note

-Ms. Nase noted that physical therapy assisted Cateial to and from a chair for the barium swallow study. RP Ex. E, pages 636-640.

* + - 2/9/22@ 10:06 AM - Dr Meyer-Macaulay-Progress Note - Dr. Meyer-Macaulay noted that the barium swallow study confirmed aspiration and Cateial was started on enteral nutrition. RP Ex. A, pages 640-643.
		- 2/9/22@ 12:26 PM -Alexandra Schubert- Child Life Progress Note

-Ms. Schubert noted she met with Ms. Jones to assess her needs and she encouraged Ms. Jones to practice self-care. RP Ex. A, page 643.

* + - 2/9/22 @ 1:01PM - Sarah Russell - Physical Therapy Treatment Note. RP Ex. E, pages 644-647.
		- 2/9/22 @ 3:57 PM - Karil Negrin - Speech-Language Pathology Treatment- Ms. Negrin noted the following: she discussed the results of the barium study with Ms. Jones; she informed Ms. Jones of the risk for aspiration; and Cateial needs a modified diet. RP Ex. E, pages 648- 651.
		- 2/9/22 @ 3:57 PM - Laura Cerulli - Creative Arts Therapy Progress Note. RP Ex. E, page 652.
		- 2/10/22 @ 8:11 AM - Kelsey Matika - Physical Therapy Treatment Note. RP Ex. E, pages 659-662.
		- 2/10/22@ 10:36 AM - Dr. Meyer-Macaulay - Progress Note - Dr. Meyer-Macaulay noted the following: BiPAP was started; Cateial was comfortable; and he needed to discuss Cateial's suitability for transplant. RP Ex. A, pages 669-672.
		- 2/10/22 @ 1:35 PM - Claire Munshi - Speech-Language Pathology Treatment. RP Ex. E, pages 672-675.
		- 2/10/22@ 3:30 PM-Lily Tran -Neurology Consult. RP Ex. E, page 677.
		- 2/10/22 @ 3:54 PM - Isabel Mueller - Occupational Therapy Progress Note. RP Ex. E, pages 677-681.
		- 2/10/22 @ 3:57 PM - Courtney Byrne - Social Work Progress Note - Ms. Byrne noted the following: she spoke with Ms. Jones about her concerns and provided support; she discussed resources available while Cateial was hospitalized; she discussed the NG tube incident and Ms. Jones' request for a transfer; the medical team and nurse case manager will work on the transfer; Ms. Jones ultimately said she was not ready to transfer Cateial because the new hospital would be further away than Nemours. RP Ex. B, page 682.
		- 2/11/22@ 12:26 AM-Katricia Thompson - Social Work Progress Note - Ms. Thompson noted the following: Ms. Jones did not agree to have Cateial intubated so a CPAP (i.e., continuous positive airway pressure) machine was utilized; Ms. Jones wanted to know her options for transferring Cateial; and she told Ms. Jones CHOP was the comparable option. RP Ex. C, page 687.
		- 2/11/22@ 1:30 PM-Dr. Meyer-Macaulay-Progress Notes-Dr. Meyer-Macaulay noted the following: Cateial was not a candidate for ECMO (i.e., extracorporeal membrane oxygenation), VAD (i.e. ventricular assist device), or transplant; Cateial tolerated BiPAP; Ms. Jones was given the option to continue Cateial on BiPAP or have a bronchoscopy to clear his secretions and she opted for bronchoscopy; and he had a long talk with Ms. Jones and Mr. Jefferson about Cateial' s end stage condition and their expressed goal was to get Cateial home to spend time with family with the understanding that his life span would be short. RP Ex. A, page 690-693.
		- 2/11/22 @ 3:17 PM - Dr. Carl Levy - Progress Notes - This note pertains to a palliative care consult. Dr. Levy noted that Ms. Jones was not bedside and Cateial was headed for a bronchoscopy so the consult was re-scheduled. RP Ex. A, page 693.
		- 2/11/22@ 3:26 PM-Jessica Kee - Creative Arts Therapy Progress Note - Ms. Kee noted that Cateial was preparing for intubation when she tried to engage. RP Ex. B, page 694.
		- 2/11/22 @ 4:17 PM - Courtney Byrne - Social Work Progress Note - Ms. Byrne noted the following: she spent time with Ms. Jones after the meeting and during the bronchoscopy; she learned that Ms. Jones was frustrated waiting outside the CICU; Ms. Jones said she was told she could be present for the bronchoscopy, but that was not permitted and then the procedure took longer than expected. RP Ex. B, pages 694-695.
		- 2/11/22@ 8:03 PM-Tyler Bohanan- Nursing Progress Note -Mr. Bohanan noted the following: a family meeting was held at 12:00 to discuss the family's wishes; the risks and benefits of potential options were explained to Ms. Jones and Mr. Jefferson; they both agreed to pursue intubation and bronchoscopy; after the procedure Cateial was extubated, but he decompensated and had to be reintubated. RP Ex. B, page 695.
		- 2/13/22@ 12:50 PM- Casey Lynch-Progress Notes -According to Ms. Lynch, Ms. Jones was advised that because of Cateial's condition he was permitted to have an additional visitor for the weekend (3 total). RP Ex. **B,** page 714.
		- 2/13/22@ 3:52 PM- Casey Lynch-Progress Notes - Ms. Lynch noted the following: she attended the family meeting; the doctors presented care options to the family which included inserting a tracheotomy and going home, going home with hospice services but once home the tubes and medications would be removed and Cateial would expire sooner, going to a hospital closer to home where palliative care can be provided, or staying at Nemours; Ms. Jones and Mr. Jefferson expressed frustration and felt they were lied to about Cateial remaining on a breathing tube at home. RP Ex. B, page 714.
		- 2/13/22@ 6:02 PM-Dr. Jeffrey Demare -Progress Notes -Dr. Damare noted the following: there was a family meeting to discuss Cateial' s condition and prognosis; the family expressed interest is taking Cateial home to die; Dr. Damare informed them if Cateial went home on a ventilator, it could be a long process before death; Dr. Damare informed them of other options as noted above in Casey Lynch's Progress Notes. RP Ex. C, page 745.
		- 2/14/22@ 12:42 PM- Sarah Russell-Therapy Services Contact Note. RP Ex. E, page 719.
		- 2/14/22 @2:21 PM-Dr. Caroline Boyd-Progress Notes -Dr. Boyd noted the following: a palliative consult occurred last week; Ms. Jones requested hospice options closer to home; palliative care explored hospice options but there was no available facility; Ms. Jones was planning family visits to occur the next few days and then she intended to withdraw technologies on 2/16/22. **RP** Ex. A, page 726- 728.
		- 2/14/22@ 5:35 PM-Alexandra Schubert- Child Life Progress Note
			* Ms. Schubert noted that she worked with the family to provide opportunities for legacy building and memory making activities. **RP** Ex. B, page 728-729.
		- 2/15/22@ 4:05 PM - Dr. Katie Parislo - Palliative Care Note - Dr. Parislo noted visitors would come the next day and then Ms. Jones would proceed with compassionate extubation. RP Ex. B@ 737.
		- 2/15/22 @4:42 PM- Courtney Byrne- Social Work Progress Note­ Ms. Byrne noted she spent time with the family to arrange visitor exceptions and meaningful moments leading to compassionate extubation that was planned for 2/16/22. **RP** Ex. **B@** 737.
		- 2/16/22 @ 10:30 AM - Lisa Keating - Progress Notes - Ms. Keating noted Cateial was extubated and he expired at 10:19 am. **RP** Ex. C, page 743.
		- 2/16/22@ 11:00 AM- Courtney Byrne - Social Work Progress Note
			* Ms. Byrne noted she provided end of life services as Cateial was compassionately extubated. **RP** Ex. **B,** page 744.
		- Discharge Summary - Filed 2/16/22 @ 720 pm - Dr. Aisha Frazier - Dr. Frazier noted the following: Cateial was seen at Bayhealth ED and then transferred to Nemours for further evaluation; Cateial was initially admitted to the PICU and then transferred to the CICU; on 2/5/22, Cateial had a genetic consult; on 2/8/22, Cateial had a swallow test and a catheter was placed for drainage of the right pleural effusion and pneumothorax; on 2/10/22 Cateial received BiPAP support; on 2/11/22, Cateial had a bronchoscopy with intubation but after extubation he was reintubation; Cateial was not a candidate for VAD or transplant at Nemours and his parents did not want a second opinion; Cateial was transitioned to comfort care; Cateial's technological support was discontinued on 2/16/22 and he expired at 10:19 AM. RP Ex. C, page 441.

### Complainant's Closing Arguments

In closing, Ms. Jones said there was a big loss and missed opportunity for communication between Ms. Jones and Nemours which caused difficulty while Cateial was inpatient at Nemours and difficulty in Nemours providing care for him. Ms. Jones said she twice asked for a transfer but agreed to give Nemours another chance because the staff said, "let us prove to you we can do better." Ms. Jones believed Nemours would do better with communicating and involving the family and would treat them better. She said that did not occur and the lack of communication continued which led to Cateial being afraid of the nurses and fighting the mask because he did not understand what was going on.

Ms. Jones said because of Cateial's fear she could not focus on the medical care he was provided, instead she had to focus on his mental state. Ms. Jones felt a need to control Cateial 's mental state so that the doctors would be able to provide

medical care. Ms. Jones said Cateial's medical care only improved during the last four days he was at Nemours as that is when things started running smoothly.

Ms. Jones asked the Panel to put themselves "in my shoes." She saw her son fighting for his life and his freedom because he had no idea what was happening.

He only saw strangers attacking him and the only person in the room that he knew was Ms. Jones, but Cateial thought she was allowing the staff to hurt him. Ms.

Jones said Dr. Meyer-Macaulay's entitlement showed throughout the entire time Cateial was at Nemours. Ms. Jones said ifhe spoke to the Panel, who has "power," the way that he did on the first day of the hearing,19 then imagine how he treated a mom who has no power sitting in a hospital by herself. Ms. Jones said the staff perceived her as a waste of time and her opinion did not matter-although it was not explicitly stated it was implied.

Ms. Jones said more than once she shed tears and asked for help. She acknowledged that Courtney Byrne and Kristin Daniels helped her, but it took a while before she received that help. Ms. Jones said when Nemours was first recommended for Cateial, based on past experiences she knew he would get the best care, but that did not happen and the treatment he received was heart breaking.

Ms. Jones said she would like to see the Nemours staff, especially the nurses that administer medications and inject needles, receive training in providing

19 *See* Footnote 12.

medical care to non-verbal children. She would also like to see resources and services provided to parents who need help with non-verbal children.

### Respondent's Closing Arguments

In closing, Ms. Brady said understandably Ms. Jones was going through a difficult time where she was not sleeping, eating, or able to engage in self-care, and in such a situation there may be issues with perception and recollection. But the allegations that Ms. Jones and Cateial received different and inferior care and services based on their race and Cateial' s disability are not true.

Ms. Brady argued it is inaccurate to characterize Cateial's hospital admission as one flawed communication after another. Ms. Brady said look at the Respondent's exhibits which are clear evidence that Ms. Jones' recollection is erroneous. There was a meeting with the social worker over the weekend as documented in the records. The records are extensive and consist of thousands of pages which were too voluminous to produce, but the records that were provided show that the Nemours staff had contact with Ms. Jones.

Ms. Brady said the records reflect numerous discussions about Ms. Jones' concerns related to Cateial's medical care and about her request to transfer him to another hospital. These entries were made in real time and specifically RP Ex. E has multiple pages regarding the therapy visits and services that Cateial received in response to Ms. Jones' concerns. Ms. Brady admitted that sometimes Cateial

would not get the services, but the contention that he did not get any is contrary to the records. Ms. Brady also admitted there may have been flaws, but that does not mean Ms. Jones' concerns were minimized and ignored. Although Ms. Jones' concerns may not have been addressed to her satisfaction, Nemours provides medical care for the sickest children and sometimes Nemours has to act urgently to provide care even if the child may be uncomfortable because in the moment the service has to be provided for the child's well-being.

Ms. Brady reminded the Panel that quality of care is not within the purview of DEAL. Although the Panel may have heard some troubling things or have the opinion that some interactions could have been better or more respectful or more supportive, the question is whether Ms. Jones and Cateial were treated different than other similarly situated children and families because of their race and/or disability. Ms. Brady said the evidence does not support that there was any type of discriminatory motive or conduct by Nemours. Ms. Brady said even if the communication could have been better or some things could have been done differently, that is not attributed to their race or disability and this case should be dismissed.

## FINDINGS OF FACT AND CONCLUSIONS OF LAW

Ms. Jones alleges Respondent violated DEAL and denied her and her minor son, Cateial Jones, access to a public accommodation because of their race/color

(Black) and Cateial's disability (mental and physical). Section 4504(a)(l) of DEAL provides that "no person being the owner... manager... agent or employee of any place of public accommodation, shall directly or indirectly refuse, withhold from or deny to any person, on account of race, age, marital status, creed, color, sex, disability, sexual orientation, gender identity, or national origin, any of the accommodations, facilities, advantages, or privileges thereof."20 The provisions of DEAL are to be "liberally construed" to safeguard the rights set forth therein.21 "The ultimate purpose [of DEAL] is to eliminate the inconvenience, unfairness, and humiliation of... discrimination."22

Under Delaware law, claims alleging a direct or indirect refusal or denial of public accommodation based upon unlawful discrimination are decided using the guidance of the U.S. Supreme Court's three-part analysis in *McDonnell Douglas Corp.* v. *Green.23•24* This analysis requires the following steps:

1. The Complainant must establish a *prima facie* case of discrimination.
2. Once a *prima facie* case is established, the burden shifts to the respondent to present evidence of a legitimate, non-discriminatory

20 6 *Del.* C. § 4504(a)(l).

21 6 *Del.* C. § 4501.

22 *Uncle Willie's Deliv. Whittington,* 1998 WL 960709, at \*4 (Del. Super. Dec. 31, 1998) (citations and internal quotations omitted).

23 411 U.S. 792 (1973).

24 *See, DP, Inc.* v. *Harris,* 2000 WL 1211151, at \*6 (Del. Super. July 31, 2000) ("Delaware Courts have applied the standard articulated in *McDonnell Douglas Corporation* v. *Green* for cases alleging unlawful discrimination.") (citations omitted); *Uncle Willie's,* 1998 WL 960709, at \*4 (applying the *McDonnell Douglas* analysis to a case brought under DEAL).

reason for denying plaintiff access.

1. After this production of evidence, the complainant retains the burden of persuading by a preponderance of the evidence that the respondent's proffered reason was a pretext for discrimination.25

To meet the initial burden of going forward and establishing a *prima facie* case of discrimination, Ms. Jones must show: (a) they were members of a protected class; (b) they were denied access to a public accommodation; 26 and (c) non­ members of their protected class(es) were treated more favorably.27 Further, because Equal Accommodations hearings before the Delaware Human and Civil Rights Commission ("Commission") are subject to the provisions of Delaware's Administrative Procedures Act ("APA"),28 "the burden of proof shall always be upon the applicant or proponent."29

***McDonnell Douglas* Test** - **Part** I

***Prima Fade* Case**

There is no dispute that Ms. Jones is Black and therefore a member of the protected class "race/color." There is no dispute that Cateial was Black or that he

25 *Salty Sam's Pier 13 v. Washam,* 2000 WL 1211227, at \*2 (Del. Super. Aug. 3,

2000) (citations omitted).

26 According to DEAL, it is illegal to "directly or indirectly refuse, withhold from, or deny [members of the specified protected classes] any of the accommodations, facilities, advantages, or privileges" of a place of public accommodation. 6 *Del.* C.

§ 4504(a)(l)a. The Panel uses the term "denied" to encompass "refuse, withhold from, or deny" and uses the term "access" to encompass "accommodations, facilities, advantages, or privileges."

27 *Uncle Willie's,* 1998 WL 960709, at \*4.

28 29 *Del.* C. Ch. 101.

29 29 *Del.* C. § 10125(c).

had mental and physical disabilities, and therefore, Cateial was a member of the protected classes "race/color" and "disability." The Panel must now determine whether Ms. Jones and/or Cateial were denied access to a public accommodation. As "an... establishment which caters to or offers goods or services ... to... the general public... ,"30 Nemours is a place of public accommodation and access must be equally provided. Denial of access to a public accommodation can be proven by evidence of an outright denial or an indirect denial. An indirect denial can occur even if a protected class member ultimately receives access.31 A delay that results in "something less than an 'outright denial... "'32 can be a denial if there is "an intentional delay... used to frustrate the [protected class member], especially when the delay tactic is repeatedly rebuffed ...."33 Determining if a delay that results in something less than an outright denial satisfies the second *prima facie* element is fact-intensive and dependent upon the circumstances of a particular case." 34

30 6 *Del.* C. § 4502(14).

31 *Hadfield's,* 2001 WL 1456795, at \*4.

32 *Hadfield's Seafood v. Rouser,* 2001 WL 1456795, \*4 (Del. Super. Aug. 17, 2001) (A customer filed a DEAL complaint against a restaurant after the cashier withheld the food order and insisted on explaining the reason for the long wait despite the customer's repeated request to just provide the food. In considering the second *prima facie* element, the Court concluded the delay resulted in an indirect denial of service and said, "If used to frustrate the customer,... a lengthy explanation takes on a different tone, especially when the explanation was repeatedly rebuffed."). *See also, Stewart v. Human Relations Commission,* 2010 WL 2653453, \*3 (Del. Super. July 6, 2010); *Witcher v. Breeding,* 2012 WL

3518079, \*3 (Del. Super. July 31, 2012).

33 *Witcher,* 2012 WL 3518079, at \*3 (internal quotations omitted).

34 *Stewart,* 2010 WL 2653452, at \*6.

Ms. Jones testified that upon arrival at Nemours' ED the nurses treated Cateial aggressively because they could not understand him. Ms. Jones said she informed the staff Cateial was autistic and nonverbal, but she said he was aware of his surroundings and could understand when spoken to. Ms. Jones said she asked the staff to speak to and interact directly with Cateial, but they ignored her request. She said between Saturday, February 5th and Sunday, February, 6th, the staff ignored her reminders that because Cateial did not know them they could not make physical contact without first introducing themselves. Ms. Jones said she explained Cateial had never been in the hospital and having people invade his space would cause him to have attacks like banging his head and biting his hand. Ms. Jones said she explained to the CICU staff that Cateial had never been violent with anyone, but he self-stimulated by biting the palm of his hand. She said because the staff continued their normal operating procedure and did not adhere her instructions, Cateial banged his head on the bed railing and bit his hand more than usual. Ms.

Jones said on one occasion, because the staff did not limit the number of people in the room as she requested, Cateial screamed and bit his hand, and on another occasion, a nurse grabbed Cateial to perform medical procedures, but Cateial pulled away. Ms. Jones said when she explained Cateial's hands could not be restrained because he communicated with his hands, that was ignored. According to Ms. Jones, the staff acted as if she was not there; they spoke to her as little as possible; her needs were not met; there was no response to her request for

assistance until Monday, February 7t\ and eventually a sign was posted stating, "Yes, I'm non-verbal but I understand everything. Please introduce yourself and talk to me." Ms. Jones said after the sign was posted Cateial's care improved, but she did not say when the sign was posted.

Ms. Jones' witnesses bolstered her testimony. Carol Hall, John Jefferson, and Annette Fletcher each testified that Ms. Jones shared with them her concerns about Nemours. Likewise, some of Nemours' witnesses testified about the concerns that Ms. Jones raised with them.

Dr. Meyer-Macaulay said when he first met Ms. Jones on February 7th,

" [she] raised several issues that...if accurate ... were quite concerning for care that would not meet the standards that I believe Nemours sets for itself." He said her concerns were about the care Cateial received in the ED, PICU, and CICU. Dr.

Meyer-Macaulay said they had a lengthy discussion and he expressed empathy that it must have been difficult for Ms. Jones and Cateial due to Cateial's developmental disabilities which placed him at higher risk of experiencing the things that Ms. Jones described.

Courtney Byrne said when they first met, Ms. Jones complained about communication challenges in the ED and PICU, and Ms. Jones was concerned about Cateial not receiving accommodations necessary due to his autism. Ms. Byrne said she spoke with Child Life about posting signs to address the communication concern, but Ms. Byrne did not specify when she spoke with Child

Life.

Kristin Daniels said Ms. Jones expressed her concerns, and it sounded like Ms. Jones had a bad experience from the time Cateial arrived at the ED. According to Ms. Daniels, Ms. Jones' main complaint was about the need for better communication, and Ms. Jones said although Cateial was non-verbal, he could understand so it was important to talk to him. Ms. Daniels said she spoke with Ms. Jones about working with Child Life to find ways to communicate, including posting signs. Ms. Daniels confirmed that the signs were posted, but she was uncertain when that occurred. Ms. Daniels admitted there was an opportunity to do better to ensure proper communication with Ms. Jones and Cateial and when the focus was on making him better there were missed opportunities to communicate to him what was happening.

The Panel finds Ms. Jones' testimony about her and Cateial's experience during the initial days at Nemours to be credible and in tum the Panel finds by a preponderance of the evidence that the second *prima facie* element has been satisfied because there was an indirect denial of access to public accommodation due to a delay that resulted in something less than an outright denial and that delay frustrated Ms. Jones and Cateial.35 While there was no outright denial of medical

35 One of the three panelist determined the evidence supports a finding that there was an outright denial of a public accommodation, but "[d]ecisions of the panel shall be made by a majority of the members of the panel," 6 *Del.* C. § 4508(f), and therefore there is no finding here of an outright denial.

care, the staff delayed making modifications to how they communicated with and in tum provided medical care for Cateial that were necessary due to his disabilities. According to Ms. Jones, communication with Cateial and in tum his medical care did not improve until after signs were posted. Therefore, the Panel finds Nemours failed to make the necessary modifications until after Child Life posted the signs.

Although there is no direct evidence of when the signs were posted, the Panel infers they were posted after Tuesday, February 8th. Alexandra Schubert noted in her Child Life Progress Note for February 8th at 3:17 PM that Ms. Jones expressed frustration related to communication regarding the NG tube incident.36 Dr. Joslyn Kenowitz documented in her Inpatient Family Based Psychology Assessment notes for February 8th at 4:50 PM37 that Ms. Jones reported having a meeting with Child Life during which they identified communication strategies that would be hung on the door. Based upon this evidence, it appears that the signs were posted after February 8th and it follows that there was a delay in making modifications of at least 6 days-between February 3rd when Cateial was transported to Nemours' ED and February 9th. Based on Ms. Jones' testimony and Nemours' exhibits, the Panel finds that on or about February 9th, the staffs communication with Cateial improved and in tum that is when he started to receive care commensurate with his disabilities.

36 **RP** Ex. A, page 630.

37 **RP** Ex. **B,** pages 524-525.

The Panel notes that the NG tube incident occurred on February 8th, before the signs were posted. Ms. Jones said a nurse "crammed" the tube down Cateial's throat which caused Cateial to scream "bloody murder." Dr. Meyer-Macaulay said although it is not the usual standard of care, the NG tube was to be inserted following another procedure while Cateial was still sedated because it would be safer and more appropriate for Cateial. According to Dr. Meyer-Macaulay, due to a miscommunication, that did not happen and a nurse attempted to insert the NG tube when Cateial was no longer sedated. Likewise, Ms. Daniels indicated there was a communication issue that led to the NG tube incident, but Ms. Daniels determined the nurse did not commit a medical error or violate the standard of care.

Because Cateial was not under sedation when the nurse first attempted to insert the NG tube but was later placed under sedation for the procedure, there was a delay in making modifications that were clearly necessary per Dr. Meyer­ Macaulay's expectation that the procedure would occur when Cateial was sedated because it was safer and appropriate. Although Dr. Meyer-Macaulay did not specify why sedation was safer and appropriate, based upon the evidence about Cateial' s mental and physical conditions, the Panel concludes sedation during the NG tube procedure was safer and appropriate because of Cateial's disabilities.

Although Ms. Daniels concluded that the nurse involved in the NG tube incident did not commit a medical error or violate the standard of care, it appears Ms.

Daniels considered the usual standard of care and not the standard of care necessary for Cateial who needed modifications due to his disabilities. And the possible existence of a miscommunication does not change the fact that there was a delay of necessary services. There is no evidence about the substance of the purported miscommunication, but the Panel believes had the signs been posted earlier the NG tube incident could have been avoided because a posted sign stating "Yes, I'm non-verbal but I understand everything. Please introduce yourself and talk to me." would have alerted the nurse that modifications to the usual standard of care and procedure were warranted.

The Panel finds that the staff's failure to comply with Ms. Jones' requests for at least 6 days38 was intentional and that failure frustrated Ms. Jones and Cateial. Throughout Ms. Jones' testimony, the Panel could see and hear Ms. Jones was frustrated during her experience at Nemours. Ms. Jones was tearful and emotional as she testified about feeling ignored, being treated as if she was bothersome, not having her needs met, seeking a hospital transfer as early as Saturday, February 5th,39 and again seeking a hospital transfer on Tuesday, February 8th following the NG tube incident. Additionally, Ms. Hall testified that

38 The Panel references Nemours' staff in its entirety but acknowledges there may not have been failure to heed Ms. Jones' instructions by all the staff providing care for Cateial. Nevertheless, as the employer of the responsible persons, Nemours is accountable under DEAL.

39 *See* CP Ex. #1.

she spoke with Ms. Jones at least once per day and saw that Ms. Jones was frustrated by the care that Cateial received. And Cateial's reactions to the treatment are clear evidence of his frustration-banging his head, biting his hand, pulling away from medical staff, and "screaming bloody murder."

This case is similar to the *Hadfield* 's case where a customer filed a DEAL complaint against a restaurant after its employee withheld the customer's food order and insisted on explaining the reason for the long wait despite the customer's frustration and repeated request to just provide the food. In considering the second *prima facie* element, the *Hadfield* 's Court concluded the delay resulted in an indirect denial of service and said, "[i]f used to frustrate the customer,... a lengthy explanation takes on a different tone, especially when the explanation was repeatedly rebuffed."40

Here, Ms. Jones repeatedly asked for modifications to the communication with and in tum the medical care provided to Cateial, but there was a delay for at least 6 days. Unlike *Hadfield's,* it is unclear why the delay occurred here, but like *Hadfield's,* it is clear that the delay in making the modifications was an intentional decision (as opposed to just an oversight) and it caused frustration. From the evidence presented, the Panel infers that the Nemours staff made a conscious decision to delay in accommodating Ms. Jones' requests which resulted in Ms.

40 *Hadfield's,* 2001 WL 1456795, at \*4.

Jones and Cateial's frustration. Even if the staff did not purposefully cause Ms. Jones and Cateial frustration, that is of no consequence as evidenced by *Hadfield's* where it seems the cashier did not purposefully cause frustration but wanted to explain the reason for the long wait in an effort to provide good customer service. The Nemours staff were privy to Ms. Jones' continued complaints and requests and the staff must have realized she was frustrated, yet they did not timely make modifications to the manner in which they communicated with Cateial, and that adversely affected his medical care.

Also like *Hadfield 's,* by continuing her requests for modifications notwithstanding the Nemours' staff's failure to comply, Ms. Jones repeatedly rebuffed the staff's provision of care sans modifications. She rebuffed the staff providing care via normal operating procedures as early as February 3rd when Cateial arrived at Nemours ED, and her rebuffs continued throughout the 6 day delay. Ms. Jones' exhibit, Respondent's Exhibits, and all of the witnesses' testimony include evidence about the concerns that Ms. Jones raised.

The Panel finds that Nemours' decision to provide medical care consistent with normal operating procedure without regard for Cateial's disabilities resulted in a delay of making modifications necessary to provide medical care commensurate with Cateial' s disabilities and that delay was an indirect denial of access to public accommodation. The Panel is aware that the version of DEAL in effect in February 2022, when Cateial was inpatient at Nemours, does not

explicitly contain a requirement that modifications be made for persons with disabilities,41 but Delaware case law dictates that the Panel consider whether Nemours failed to make reasonable modifications and if there was a failure whether it amounted to denial of access to public accommodation.

In *Ray v. State of Delaware Human Relations Commission, et. al.,* the Delaware Superior Court reversed and remanded the Commission's order dismissing Ray's complaint after holding that "the Commission... erred in determining reasonable accommodations under DEAL are required only for gender identity."42 The *Ray* Court identified "three important provisions that speak to DEAL's purpose and construction under 6 *Del.* C. § 4501" that the Commission failed to consider.43 First, the *Ray* Court said there is Delaware case law that states DEAL's purpose is to "'implement reasonable accommodations to ensure equal access to all Delaware citizens."'44 Second, the *Ray* Court said DEAL expressly mandates that it "be liberally construed to the end that the rights... provided for all

41 The Panel notes that the current version of DEAL, requires places of public accommodation to "make reasonable modifications in policies, practices, or procedures... to individuals with disabilities, unless the place of public accommodation can demonstrate that making the modifications would fundamentally alter the nature of the goods, services, privileges, or accommodations." 6 *Del.* C. § 4504(a)(4)b. (eff. Oct. 10, 2022).

42 *Ray v. State of Delaware Human Relations Commission,* et. al., 2021 WL 5492664, at \*8 (Del. Super. Nov. 22, 2021).

43 *Id.,* at \*6.

44 *Id.* (citing *Delaware Tech. and Cmty. College,* 2017 WL 2180544, at \*3 (citing 6

*Del.* C. §§ 4501, 4504(a)-(d))).

people ... be effectively safeguarded."'45 Third, the *Ray* Court noted that 6 *Del.* C. § 4501 "tells us to consider - not disregard- 'higher or more comprehensive obligations established by otherwise applicable federal, state, or local enactments"'46 and the Commission redirecting *Ray* to pursue claims under the federal Americans with Disabilities Act ("ADA")47 was "insufficient where DEAL clearly signals us to... consider the obligations established by both federal and state systems."48

According to ADA,

... discrimination includes... a failure to make reasonable modifications in polices, practices, or procedures, when such modifications are necessary to afford such goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities, unless the entity can demonstrate that making such modifications would fundamentally alter the nature of such goods, services, facilities, privileges, advantages, or accommodations 49

Consistent with *Ray* and ADA, the Panel considered whether modifications were warranted, and found that Nemours' delay in making the necessary modifications was an indirect denial of access to public accommodation. The Panel further finds

45 *Id.,* at \*7 (citing 6 *Del.* C. § 4501).

46 *Id.*

47 "No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation." 42 U.S.C. § 12182(a).

48 *Ray,* 2021 WL 5492664, at \*7.

49 42 U.S.C. § 12182(b)(2)(A)(ii).

that the requested modifications were reasonable. Ms. Jones said after the signs were posted Cateial's care improved. Apparently, once the signs were posted the staff complied with Ms. Jones' requests which caused Cateial less agitation and he became receptive of the care provided. Given the result and the inconsequential burden of posting the signs, clearly the requests were reasonable, as confirmed by Dr. Meyer-Macaulay who said when he spoke calmly and relaxingly to Cateial, Cateial was not afraid of him, Cateial was calm when they interacted, and Cateial did not find Dr. Meyer-Macaulay to be distressing. The reasonableness of Ms.

Jones' requests is also clear given that Dr. Meyer-Macaulay determined placing Cateial under sedation for the NG tube procedure was safer and appropriate and given that the procedure was a success once Cateial was sedated. There is no indication that making these modifications fundamentally altered the nature of the service provided by Nemours. In fact, it appears that making these modifications ensured that the service was properly provided.

Having found that Ms. Jones has satisfied the second *primafacie* element by a preponderance of the evidence, the final question for purposes of establishing a *prima facie* case is whether non-members of the protected class(es) were treated more favorably. Ms. Jones satisfies this element if she can show either "[she and/or Cateial were] deprived of services while similarly situated persons outside her protected class were not deprived of those services... or... [she and/or Cateial] received services in a markedly hostile manner and in a manner which a reasonable

person would find objectively unreasonable."50 The Panel finds that Cateial received services in a markedly hostile manner that a reasonable person would objectively find unreasonable.

The Nemours staff was aware of Cateial's physical condition and in tum aware of his physical disability. Ms. Jones informed the staff Cateial was autistic and non-verbal and she requested that they make contact and communicate with Cateial in a certain manner so the staff was aware of Cateial's mental disabilities. Ms. Jones informed the staff that Cateial communicated with his hands and there was no indication that Cateial communicated using American Sign Language so the staff knew they needed assistance with interpreting Cateial's communications. Ms. Byrne noted in her Social Work Assessment, dated February 4, 2022, that she encouraged Ms. Jones to provide guidance on the meaning of Cateial's gestures51 so the staff knew Ms. Jones' assistance was needed to interpret Cateial's communications. Dr. Frazier testified that she ensured Ms. Jones knew she was a welcome advocate for Cateial, so the staff knew Ms. Jones' guidance with regards to providing care was necessary. But for at least 6 days, the staff disregarded Ms. Jones and proceeded in the ordinary course of providing medical services as if Cateial did not have disabilities that warranted modifications. The Panel finds that

50 *Hadfield's,* 2001 WL 1456795, at \*5 (citing *Callwood v. Dave & Buster's, Inc.,*

98 F. Supp.2d 694, 707 (D. Md. 2000). *See also* Witcher, 2012 WL 3518079, at

\*4.

51 RP Ex. B, pages 601-602.

service provided in such a manner is markedly hostile. According to Merriam Webster Dictionary, "hostile" is defined as "openly opposed or resisting."52 The Nemours staff repeatedly resisted Ms. Jones' requests for modifications for at least 6 days despite that she was most knowledgeable about Cateial's capabilities and that she was his best advocate.

The Panel also finds that an objectively reasonable person would find service provided in such a manner to be unreasonable. An objectively reasonable person would expect the mother of a severely ill, autistic, and non-verbal child to know what is best for her child. An objectively reasonable person would expect that the medical service provider adhere to the mother's guidance about how to interact and communicate with the child assuming her guidance does not interfere with the provision of medical care, and there is no evidence that Ms. Jones' requests caused an interference. An objectively reasonable person would expect all medical and non-medical staff providing care to timely adhere the mother's guidance and not delay in complying with her requests for reasonable modifications.

As previously noted, Ms. Jones is a member of the protected class "race/color" and Cateial was a member of the protected classes "race/color" and "disability." In addressing the second and third *primafacie* elements, the Panel has

52 *See* [https://www.merriam-webster.com/dictionery/hostile.](http://www.merriam-webster.com/dictionery/hostile)

only discussed Cateial' s disability. The Panel finds there is insufficient evidence that Ms. Jones and Cateial's race was a factor during Cateial's Nemours admission in February 2022. As such, Cateial's disability is the only protected class for which a *prima facie* case has been established.

***McDonnell Douglas* Test - Part II Legitimate Non-Discriminatory Reason**

Ms. Jones has satisfied the three elements for establishing a *prima facie* case and there is a presumption that Nemours unlawfully discriminated against Cateial.53 Moving to part two of the *McDonnell Douglas* test, Nemours has the burden of showing that there is a legitimate, non-discriminatory reason for the presumptively discriminatory behavior. Nemours' burden is one of production, not persuasion. Nemours is not required to persuade the Panel that its actions were

non-discriminatory.54

Nemours contends the manner in which it provided medical care to Cateial was necessary due to the severity of his illnesses. According to Nemours, it provides medical care for the sickest children and sometimes the staff has to act urgently to provide care even if the child may be uncomfortable because in the moment the service has to be provided for the child's well-being.

Dr. Frazier described providing medical care for Cateial as being on a

53 *See St. Mary's Honor Center v. Hicks,* 509 U.S. 502, 502-503 (1993).

54 *Boggerty v. Stewart,* 14 A.3d 542, 552 (Del. 2011).

"medical battlefield" and she said Nemours' staff were not averse to learning how best to talk to Cateial, but they needed to immediately act to provide medical care as the goal was to provide life sustaining measures for his critical illnesses.

Cateial's diagnoses included autism, myopathy, fluid overload that attributed to renal dysfunction, cardiomyopathy, food and drink aspiration, end stage heart failure, and after undergoing genetic testing, Cateial was diagnosed with DMD. Cateial' s treatment included medication, CPAP, and BiPAP. Cateial had various procedures including chest tube insertion, bronchoscopy, and NG tube insertion.

Regarding the NG tube, both Dr. Meyer-Macaulay and Ms. Daniels said there was a miscommunication that led to the nurse's attempt to insert the tube without sedation contrary to Dr. Meyer-Macaulay's expectation that Cateial be under sedation, but the nurse did not commit an error and she did not violate the standard of care because the procedure usually occurs without sedation.

The Panel finds that the proffered reasons satisfy Nemours' burden of production and Nemours has provided a legitimate, nondiscriminatory reason for the manner in which it provided Cateial medical care.

***McDonnell Douglas* Test- Part III Pretext for Discrimination**

Turning to part three of the *McDonnell Douglas* test, Ms. Jones must prove by a preponderance of the evidence that Nemours' proffered reasons were pretext

for discrimination. "[Ms. Jones'] burden is twofold. [She] must convince the [Panel] that the... stated reason[s] w[ere] false... [and she] must prove discrimination was the real reason... " that Cateial did not receive service commensurate with his disabilities.55 The law requires"... specific and significantly probative evidence that [Nemours'] alleged purpose is a pretext for discrimination."56 Ms. Jones "must point to weaknesses, implausibilities, inconsistencies, incoherencies, or contradictions in the... proffered reasons such that a reasonable fact-finder could rationally find [the reasons] unworthy of credence."57 The Panel finds that there are weaknesses and implausibilities in Nemours' proffered reasons which renders its reasons unworthy of credence.

Nemours staff did not heed Ms. Jones' instructions about how to make contact and communicate with Cateial. Nemours explains that the staff had to act quickly due to the emergent nature of Cateial's illness. According to Dr. Frazier, when Cateial came to the ED he had severe end stage heart failure and he had fluid around his lungs and belly, so it is true that Cateial was gravely ill, needed significant medical care, and perhaps when Cateial first arrived at the ED the staff could not immediately comply with Ms. Jones' requests because they had to quickly make a diagnosis and determine the necessary care and treatment. But

55 *Ennis v. Del. Transit Corp.,* 2015 WL 1542151, at \*7 (Del. Super. Mar. 9, 2015).

56 *Boggerty,* 14 A.3d at 554.

57 *Ennis,* 2015 WL 1542151, at \*8 (citing *Keller v. Orix Credit Alliance Inc.,* 130 F.3d 1101, 1108-1109 (3d Cir. 1997) (internal quotations omitted)).

Cateial was at Nemours for 13 days-Thursday, February 3rd through Wednesday February, 16th-and once there was the initial renal dysfunction diagnosis58 that resulted in Cateial's transfer to the PICU on February 3rd,59 certainly the staff could have slowed down a bit to hear and implement Ms. Jones' requests. After all, Cateial remained in the PICU until the morning of February 4th when he was transferred to the CICU.60 But modifications were not made when Cateial was in the PICU and it was another 5 days in the CICU-February 4th through February 8th-before modifications were actually implemented. It is implausible that the staff was unable to implement the requested modifications until 6 days after Cateial arrived at Nemours.

A review of RP Exs. A through E, which is only a portion of Cateial' s voluminous records, reveal that various staff persons provided care for Cateial during those 6 days, yet no modifications were made to accommodate Cateial's disabilities and the modifications were only implemented after the Child Life signs were posted. It is beyond comprehension that the signs needed to be posted before the staff acquiesced and it is beyond comprehension that what was possibly the worse thing to have occurred due to the delay in implementing modifications-the NG tube incident-had to occur before the signs were finally posted. Dr. Meyer-

58 *See* Dr. Meyer-Macaulay's testimony.

59 RP Ex. B, pages 601-602.

60 *Id.*

Macaulay and Ms. Daniels said there was a miscommunication that led to the NG tube incident, but they did not provide details about the content of the purported miscommunication and there is no indication they were privy to it. The nurse who had first-hand knowledge of the purported miscommunication did not testify so the Panel has no clear understanding of the substance. As such, the Panel finds that the proffered reasons for Nemours' failure to timely implement modifications necessary due to Cateial' s disability-the need to quickly provide medical care and miscommunication-are unworthy of credence. The Panel notes Ms. Daniels' testimony that when the focus was on making Cateial better there were missed opportunities to communicate to him what was happening.

Because the Panel does not find the proffered reasons to be credible, the Panel has determined that the reasons are false. The Panel has also determined there is sufficient evidence that discrimination on the basis of disability was the real reason for how Cateial was treated. In making this determination, the Panel is aware that the existence of a *prima facie* case and a pretextual reason only permits the Panel to presume there was unlawful discrimination and does not compel a judgment in favor of Ms. Jones because Ms. Jones maintains the burden of proof and must prove by a preponderance of the evidence that Nemours discriminated against Cateial.61 This Panel finds that Ms. Jones has met that burden and has

61 *St. Mary's Honor Center,* 509 U.S. at 502-503.

proven discrimination against Cateial.

As discussed, Cateial had mental and physical disabilities which necessitated modifications to the manner in which Nemours provided medical care. The staff needed to speak directly to Cateial and introduce themselves before making contact notwithstanding that he was autistic and nonverbal. The staff needed to inform Cateial of what they were doing so that he would be comfortable with and receptive of the service they provided. But the staff did not do that. They proceeded in the ordinary course and for at least 6 days did not take into consideration that Cateial could not be treated like the "average" child. In tum, Cateial was agitated and resistant to treatment to the extent that he banged his head on the bed, bit his hands, and retracted from the staff when they tried to care for him. Only after Nemours heeded Ms. Jones' requests was Nemours able to properly provide the necessary treatment without agitating Cateial. The failure to timely implement necessary modifications was discrimination based on disability.

The Panel notes that Dr. Meyer-Macaulay said, "Ms. Jones raised several issues that.. .if accurate ... were quite concerning for care that would not meet the standards that I believe Nemours sets for itself." The Panel finds this testimony compelling and supportive of its finding that Nemours discriminated against Cateial. Given that the Panel has found Ms. Jones to be credible it follows that the care Cateial received "[did] not meet the standards that... Nemours sets for itself' which was due to Nemours' discrimination on the basis of disability.

The Panel also notes that each Nemours witness testified that Ms. Jones and Cateial were not discriminated against or treated differently based on their race or Cateial' s disability, however, that testimony was generic and conclusory and does not overcome the extensive and detailed evidence showing discrimination. Their testimony appears to only consider purposeful discrimination and does not consider discrimination due to an indirect denial of access to public accommodation. Nemours' failure to timely make modifications necessary due to Cateial' s disabilities is germane to the Panel's finding of discrimination.

Finding that Ms. Jones has proven Nemours discriminated against Cateial because of his disability in violation of 6 *Del.* C. § 4504, the Panel has discretion to order "such relief as may be appropriate." The Panel may order "actual damages... 'including damages caused by humiliation and embarrassment,' costs, expenses, reasonable attorneys' fees[,] and injunctive or other equitable relief."62 The Panel may also assess a civil penalty to be paid to the Commission's Special Administration Fund "to vindicate the public interest."63

The Panel believes it is appropriate to award Ms. Jones $5,000 per day for the 6 days of delay amounting to $30,000 in compensatory damages for the humiliation, embarrassment, and mental anguish caused by Nemours. Ms. Jones and Cateial's pain and suffering were evident throughout her testimony. The Panel

62 6 *Del.* C. § 4508(h).

63 *Id.*

also believes Nemours should pay a $5,000 civil penalty to vindicate the public interest. Lastly, the Panel believes Nemours staff should participate in training related to alternate forms of communication.

## CONCLUSION

After careful consideration of the evidence presented, the Panel, by unanimous vote, concludes that Ms. Jones has shown that Nemours violated DEAL, 6 *Del.* C. § 4504.

## ORDER

The Panel has found that Nemours violated§ 4504 of DEAL. Pursuant to§ 4508(h) of DEAL, the Panel hereby orders the following:

1. Nemours shall pay $30,000 in compensatory damages to Ms. Jones within 90 days after the date of this Order;
2. Nemours shall pay a civil penalty of $5,000 within 90 days after the date of this Order. Payment shall be made to the Delaware Human and Civil Rights Commission and mailed to 820 North French Street, 4th Floor, Wilmington, DE 19801;
3. Nemours shall ensure that all staff who provide medical care or other patient/family related services receive training in the area of working with children and other vulnerable populations who utilize alternate

forms of communication. The training shall last at least one hour, shall occur within 6 months from the date of this order, and shall be repeated on an annual basis. Nemours shall self-report compliance with this training requirement by submitting a report that includes the name of the contractor who provided the training, a summary of what the training entailed, the date the training was held, the employees who attended the training and their job titles, and the results from participant evaluations. The report shall be mailed to Chairperson Gail Launay-Tarlecki at Delaware Human and Civil Rights Commission, 820 North French Street, 4th Floor, Wilmington, DE 19801.

**IT IS SO ORDERED** this  *4th* day of  *May* -' 2023.

Gail E Tarlecki (May 3, 2023 EDT)

Gail Launay-Tarlecki

*Commissioner and Panel Chair*

Olga Ramirez

*Commissioner and Panel Member*

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*Commissioner and Panel Member*