Consent and Capacity Board
Commission du consentement et de la capacité
Ontario

21-2977-01

IN THE MATTER OF
The ***Health Care Consent Act***
S.O. 1996 c.2, Sch. A
as amended

AND IN THE MATTER OF
KHK
A Patient at
THE HOSPITAL FOR SICK CHILDREN
TORONTO, Ontario

REASONS FOR DECISION

PURPOSE OF THE HEARING

KHK's first birthday was not a happy event. KHK was not aware of it because she was in a coma in this hospital's intensive care unit with no prospect for meaningful recovery. Her family could not have been in a celebratory mood because KHK's birthday coincided with the third day of this Hearing, convened on Dr. Gilfoyle's Application to determine if her parents, as substitute decision-makers, were in compliance with the *Health Care Consent Act* principles for giving or refusing substitute consent to her treatment.

KHK was in a coma because of a "submersion event" at home in the bathtub. She drowned. When paramedics arrived, KHK was in cardiac arrest because, for too long, there was no oxygen to keep her heart pumping blood. After 30 to 45 minutes resuscitation, paramedics got her heart started but the lack of blood flow to her brain caused severe damage, resulting in her comatose condition. Dr. Gilfoyle said KHK would not recover and her best interests therefore required allowing her to die. Her parents disagreed.

Dr. Gilfoyle contended KHK's parents were not in compliance with the principles for substitute consent because they would not consent to a plan of treatment intended to allow KHK to die: palliative care after withdrawal of life support.

DATES OF THE HEARING, DECISIONS AND REASONS

The Hearing took place by video conference on August 26th, 27th, 28th, September 1st, 5th and 6th. We released our Decision September 7th. These Reasons were requested at the start of the Hearing.

LEGISLATION CONSIDERED

Health Care Consent Act, including sections 21 and 37.

PARTIES AND APPEARANCES

KHK was represented by Ms M. Addie.

Dr. E. Gilfoyle was represented by Mr. S. Rogers.

BH was represented by Mr. A. Horton, Mr. M. Kohl and Ms S. Gebresellassi

DK was represented by Ms M. Perez

PANEL

Mark Handelman	Lawyer - Presiding Member
Julie Handsor	Public Member
Gary Strang	Public Member

PRELIMINARY MATTERS

Ms Addie's Role

As is usual at this Tribunal's Hearings, Legal Aid Ontario appointed counsel, in this case Ms Addie, to represent the person whose treatment decisions were in issue. Since KHK was an infant

in a coma, Ms Addie could not obtain instructions. She therefore viewed her role to be in the nature of *amicus*, which imposed on her the obligation of assisting to ensure the Panel had all relevant information upon which to decide.

While in her submissions Ms Addie supported granting the Application, our conclusion would have been the same had she taken no position.

The "Deemed" Capacity Hearing

Capable people make their own treatment decisions and this Board is not involved in them. The HCCA therefore required a "deemed" Hearing to review the capacity of the person whose treatment decision was in issue, in this case, KHK. The parties to the deemed Application to review KHK's capacity were her and Dr. Gilfoyle. Ms Addie conceded that KHK, about a year old and in a coma, was incapable to make her own treatment decisions. We confirmed Dr. Gilfoyle's finding of treatment incapacity on consent.

The Adjournment Request

Counsel for both SDMs requested the Hearing be adjourned for two weeks so they could obtain an expert to assist them. They hoped to find a physician, preferably an expert in pediatric intensive care or pediatric neurology, to help them understand the chart entries that formed the bulk of the exhibits, almost 400 pages (although each Adjudicator was able to figure out the meaning of virtually every entry), to assist them in questioning Dr. Gilfoyle and any other health practitioners her lawyer called as witnesses, and to testify in support of their clients' position that withdrawal of life support was not in KHK's best interests.

Positions of the Parties

Counsel for both SDMs submitted having access to an expert was a matter of procedural fairness, the right to make full answer and defence. Counsel submitted three cases. However, they did not assist us because they related to the right to counsel and not to the right to an expert witness. They also related to the rights of the party who was the subject of the litigation, in this case KHK, whose lawyer opposed the adjournment request. We do not suggest BH and DK do not have a right to

procedural fairness. Rather, KHK's rights came first in this Application because she was the subject of it.

Although the SDMs were offered and declined the option of obtaining a second medical opinion before Dr. Gilfoyle filed this Application, an expert witness might also have provided additional medical information to enable BH and DK to make an informed treatment decision. As SDMs, they were entitled to all relevant information to assist their decision-making process.

Entries made by health practitioners in a patient's hospital record are rife with medical abbreviations, acronyms and arcane terminology. They contain detailed medical information the implications of which can be, to say the least, obscure to a lay person. For example, Mr. Kohl spent over two hours cross examining Dr. Gilfoyle as to whether all of KHK's movements were decerebrate or whether some might have been decorticate. Decorticate movements might indicate some upper brain activity, and/or communication between KHK's upper brain and the rest of her body through her brain stem.

An expert might have assisted Mr. Kohl in preparation of his cross examination, might have identified other chart entries that challenged Dr. Gilfoyle's evidence and might have been prepared to dispute some of her medical conclusions.

SDM counsel also submitted this case did not require an urgent Hearing because KHK's brain damage meant she could not feel any pain, her condition was stable and she was receiving excellent care.

The problem with granting an adjournment was that two weeks would not necessarily result in an expert witness being "ready to go." First, counsel had to locate an expert willing to be involved and obtain his or her *curriculum vitae*. Then, counsel had to submit the request and the CV to Legal Aid Ontario and wait for approval. Then the expert had to review KHK's chart, answer all of counsel's questions about it, possibly be available to hear Dr. Gilfoyle's evidence and then also find a date on which he or she was available to testify that conformed to the schedules of the six lawyers and the three Panel Members.

Mr. Rogers and Ms Addie both objected to an adjournment. Mr. Rogers' first submission was that the request for an adjournment, having been made the afternoon before the Hearing commenced,

was not in accord with the Board's Rules of Practice, which required that all motions be filed not later than 10 AM the day before the Hearing. He did not suggest he was prejudiced. That submission achieved no traction with us in the circumstances of this case. Ms Perez was retained over the weekend preceding the start of this Hearing and had almost 400 pages of hospital chart to review.

Mr. Rogers noted that BH and DK were offered the opportunity to obtain a second medical opinion as to KHK's condition and prognosis as early as July 15th but declined. In reply, SDM counsel noted that their need for an expert witness transcended the benefits of a second medical opinion to assist in making KHK's treatment decision.

Mr. Rogers also submitted that this was the first heard of the need to have an expert witness and this application was the subject of four Case Conferences at which it should have been raised. At the last Case Conference, SDM counsel advised they did not, at that time, have any preliminary issues to raise. In fairness to Ms Perez, she was not retained until the weekend before this Hearing convened and was involved in only the last Case Conference. The issue of counsel for DK arose at the Case Conferences. He was urged to obtain a lawyer but dallied. As at the last Case Conference Ms Perez had not had time to review KHK's medical records and did not say she had no preliminary issues to raise, she said she was not then aware of any.

Mr. Rogers submitted this was an urgent case. The "therapeutic alliance" between the treatment team and KHK's parents was broken because BH and DK distrusted KHK's doctors and were not consenting to medical interventions required to meet the physicians' day to day standard of care to KHK. He also submitted that because all eleven pediatric intensive care physicians at this hospital agreed KHK had no chance of meaningful recovery it was unlikely opposing counsel could find a credible expert witness who would offer an opposing opinion. Mr. Horton, one of BH's lawyers, disputed Mr. Rogers' submission that the views of the treatment team as to KHK's prognosis were conclusive. It was the central issue to this case and the SDMs were entitled to the time necessary to find an expert to rebut it.

Ms Addie also opposed the adjournment request and supported all of Mr. Rogers' s submissions. During Case Conferences she offered to provide the names of counsel with relevant experience but BH and DK declined her assistance. She submitted her client, as the subject of this Application,

also had a right to procedural fairness, which included prompt adjudication. KHK would be prejudiced by delay because the conflict between SDMs and treatment team impaired the quality of KHK's day to day care.

Our Rulings on the Adjournment Request

Because of scheduling conflicts and by agreement reached at the last Case Conference, Day 1 of this Hearing ended about noon. We decided to reserve our ruling on the adjournment request because Mr. Horton had that afternoon to pursue an expert witness and, were he able to update us on Day 2 with more concrete information and timelines, that might impact our decision. To be clear, we did not instruct him to spend the afternoon in his search, we offered the opportunity.

As at the start of Day 2, Mr. Horton had made some progress in his search for an expert but did not have any concrete information. And, because of spending the previous afternoon in their search, he and Mr. Kohl were not prepared to cross examine Dr. Gilfoyle. Mr. Kohl pressed us for our decision on the adjournment request because he wanted expert assistance to prepare his cross examination of the doctors.

We had two responses to Mr. Kohl. First, we dismissed the adjournment request. Second, we offered SDM counsel a choice. We would finish Dr. Gilfoyle's evidence in chief, then hear from Mr. Rogers' only other witness, Dr. Helmers, in chief. We gave SDM counsel the choice of spending Day 3 cross examining both doctors or beginning to call their witnesses and deferring cross examination. They chose to cross examine rather than present parts of their case.

Why We Dismissed the Adjournment Request

In almost all court and tribunal cases, even the simplest matters take months to get to trial or hearing. This Tribunal is unique for the strident timelines imposed by the HCCA, which is the enabling legislation: Hearings must be convened within seven days of an Application being filed, Decisions must be released the day after the Hearing concludes and Reasons for Decision must be delivered within four business days of the release of the Decision or the date of the request for Reasons. Against that background, two weeks was significant.

Here, a two week adjournment did not mean SDM counsel would be ready to start, it meant they might be ready to start or they might be ready to advise when they would be ready to start. The latter was more likely given the need to locate an expert willing to be involved, able to take the time to promptly review KHK's medical records, willing to provide the evidence counsel hoped for and available to testify at a time in accord with everyone's availability. It was less of a request for a two week adjournment than a request for an adjournment *sine die* (with no fixed date), with an update to be provided in two weeks.

There was prejudice to KHK. When a physician says through counsel and in evidence that, because of breakdown in the therapeutic alliance between the treatment team and SDMs, consent to day to day treatment decisions is not being given with the result that the treatment team is unable to meet their standard of care for that patient, that made the matter urgent even if KHK could not feel pain. We did not need to know the SDMs' view of whether there was a breakdown in that alliance or if there was, the causes of it: as with any "alliance" or relationship, when one side thinks it has broken down, it pretty much has.

Indicative of our view of urgency was our decision to continue the Hearing on Saturday August 28th and September 5th and 6th, the Sunday and Monday of the Labour Day Weekend. The only objection was from BH, who did not want the Hearing to continue on August 28th, KHK's first birthday. We told her the best present anyone, including her parents, could give KHK was resolution of her treatment disputes.

Most significant to our conclusion was a submission made by counsel for the vulnerable person whose treatment decisions were in issue, with which we agreed. This was not a battle of experts over nuanced treatment decisions or over things that might have gone wrong in KHK's treatment to date, it was a Hearing to determine the overall goal of treatment, whether the appropriate plan of treatment was one that was likely to result in KHK's death or one that was likely to continue her life, probably in a coma. Our Decision was not going to be impacted by nuances in medical evidence.

After we exercised our discretion to deny the adjournment request, Mr Kohl's cross examination of Dr. Gilfoyle confirmed our conclusion. Even if we accepted the thrust of where he hoped to get with over two hours spent on whether or not KHK's movements were both decorticate and

decerebrate, none of that evidence furthered our understanding of KHK's best interests *vis a vis* the treatment decision in issue.

In *GS (Re)*[1], a physician applied to determine if an SDM was giving or refusing consent to treatment in accordance with the HCCA principles. GS was a mental health patient whose SDM refused consent to treatment with antipsychotic medications or electroconvulsive therapy. The Applicant physician complained that the Panel did not include a psychiatrist. The Panel wrote in part,

> During his testimony, Dr. Ulric took exception to the absence of a psychiatrist on the Panel. In his view, the issues were nuanced matters of treatment that would have benefitted from a psychiatrist's perspective. We did not feel disadvantaged from the absence of a psychiatrist because the treatment issues were not nuanced. The dispute was antipsychotic medications and/or ECT versus traditional Chinese medicine, valerian and St. John's wort. Or, no treatment.

The issue to be decided for KHK was treatment to keep her alive versus treatment to allow her to die. It was not nuanced.

Further confirming our decision not to grant the adjournment was Mr. Horton's advice near the end of the Hearing that two of the experts he pursued were in the field of hyperbaric oxygen therapy, discussed below under subtitle "The Respondent's Science," in our analysis. Both experts wanted to see a magnetic resonance image ("MRI") of KHK's brain before considering whether to accept the case or not. In any event, one of the experts was not available due to his work load and advised Mr. Horton of such. Given our conclusion that this therapy would not benefit KHK, based in part on our review of a book chapter that expert wrote, an adjournment to retain such an expert would have been fruitless and unnecessarily delayed KHK's hearing.

The Request for Subpoenas

On the first day of this Hearing Mr. Kohl requested subpoenas for three of the doctors who were part of KHK's treatment team. Board staff issued them, but they could not be served promptly

[1] 2019 CanLII 147085 (ON CCB)

because all three doctors were on vacation. Mr. Rogers arranged to have two of them available by telephone and that satisfied Mr. Kohl.

Mr. Rogers called both doctors as his witnesses, asked some introductory questions then tendered them for cross examination.

The Order Excluding Witnesses

Counsel for the SDMs requested an Order excluding witnesses. It is a common request in legal proceedings, designed to ensure witnesses testify without being influenced by the evidence of previous witnesses. The Order also obliged a witness or party who has testified not to talk about the case with other witnesses and generally not to talk about the case with anyone if he or she has not finished testifying. Dr. Gilfoyle expressed concern that this might impair her ability to treat patients. We clarified that no part of the Order was intended to or should be interpreted to do that. She had counsel available to advise her.

We Met KHK

With agreement of counsel, Dr. Gilfoyle arranged for us to meet KHK. A member of her treatment team went to her bedside, joined the video conference Hearing and "introduced" us to KHK. We toured the medical equipment to which she was attached and Dr. Gilfoyle explained the purpose of each.

At times there were up to 25 observers at this video-conferenced Hearing. Out of respect for KHK's dignity and privacy, none was invited to meet KHK.

Scientific Authorities

In testimony the second last day of this Hearing, DK said his and BH's decision to refuse consent to withdrawal of KHK's life support rested on wanting to give KHK every chance of recovery. He and BH split the research load. He followed up on infrared light therapy and BH researched hyperbaric oxygen treatment. I told DK that his research might be relevant to our Decision and suggested he forward to other counsel and the Panel the research that supported his desire to try those therapies. Overnight we received Exhibits 7, 8 and 9. They are reviewed below under title "The Respondents' Science."

THE EVIDENCE

Dr. Gilfoyle testified. Mr. Rogers called Dr. Helmers, another of the Hospital's pediatric intensive care physicians. As set out above under title, "The Request for Subpoenas," Mr. Rogers called two additional doctors as witnesses. Their evidence spoke only to the reasons the therapeutic alliance between the treatment team and the SDMs broke down and did not assist us in determining which plan of treatment was in KHK's best interests.

Exhibits

1. Applicant's Document Brief, 305 pages.
2. Applicant's penultimate Document Brief, 34 pages.
3. Applicant's ultimate Document Brief, 4 pages.
4. Applicant's list of key documents, 4 pages.
5. CV of James Anderson.
6. CV of Tina Garnette.
7. Ms Gebresellassi's list of medical authorities on behalf of BH.
8. Book chapter, *HBO Therapy in Global Cerebral Ischemia/Anoxia and Coma*, written by Dr. P. Harch, tendered by Mr. Horton.
9. Ms Perez' medical authorities on behalf of DK.

Mr. Rogers tendered the first four Exhibits, Ms Addie tendered Exhibits five and six. The first three Exhibits contained all entries by health practitioners in KHK's medical chart from her admission to this hospital until the day before the Hearing commenced. Ms Addie tendered Exhibits 5 and 6 because there were questions about the involvement of Mr. Anderson and Ms Garnette in KHK's care. Mr. Anderson was the hospital's bioethicist, Ms Garnette the hospital's Advisor for Equity, Diversity and Inclusion.

Exhibits 7, 8 and 9 were tendered the night before and the morning of the last Hearing day. They were authorities on the topics of the benefits of Hyperbaric Oxygen Therapy and infrared light for persons with brain injuries.

Mr. Rogers called Dr. Gilfoyle and Dr. A. Helmers as witnesses. As explained above under title "Subpoenas," he also called Doctors Muratta and Proulx. DK and BH both testified. Neither called additional witnesses. Ms Addie did not call evidence.

THE LAW

Form G Application: Determination of Compliance With the Principles of Substitute Decision-Making

A Form G application under s. 37 of the *HCCA* required the Board to determine whether SDMs were acting in accordance with the principles set out in s. 21 of the *HCCA* for giving or refusing consent to treatment.

21. (1) A person who gives or refuses consent to a treatment on an incapable person's behalf shall do so in accordance with the following principles:

1. If the person knows of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, the person shall give or refuse consent in accordance with the wish.

2. If the person does not know of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, or if it is impossible to comply with the wish, the person shall act in the incapable person's best interests.

21.(2) In deciding what the incapable person's best interests are, the person who gives or refuses consent on his or her behalf shall take into consideration,

(a) the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable;

(b) any wishes expressed by the incapable person with respect to the treatment that are not required to be followed under paragraph 1 of subsection (1); and

(c) the following factors:

1. Whether the treatment is likely to,

i. improve the incapable person's condition or well-being,

ii. prevent the incapable person's condition or well-being from deteriorating, or

iii. reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate.

2. Whether the incapable person's condition or well-being is likely to improve, remain the same or deteriorate without the treatment.

3. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.

4. Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed.

37. (1) If consent to a treatment is given or refused on an incapable person's behalf by his or her substitute decision-maker, and if the health practitioner who proposed the treatment is of the opinion that the substitute decision-maker did not comply with section 21, the health practitioner may apply to the Board for a determination as to whether the substitute decision-maker complied with section 21.

(2) The parties to the application are:

1. The health practitioner who proposed the treatment.
2. The incapable person.
3. The substitute decision-maker(s).
4. Any other person whom the Board specifies.

(3) In determining whether the substitute decision-maker complied with section 21, the Board may substitute its opinion for that of the substitute decision-maker.

(4) If the Board determines that the substitute decision-maker did not comply with section 21, it may give him or her directions and, in doing so, shall apply section 21. . .

If we determined that the SDMs did not follow the s. 21 principles, we could substitute our own opinion for that of the SDMs and direct them to comply with the provisions of s. 21. An analysis of whether an SDM has complied with the principles of substitute decision-making in refusing to consent to a plan of treatment for an incapable person involves two branches: first, did the incapable person express a prior capable wish applicable to the circumstances, and second, if the person had no prior capable wish, what decision was in the person's best interests.

Since KHK's first birthday occurred during the Hearing, she could not have developed any wishes, values or beliefs. We therefore made our Decision based on her best interests.

There is a difference between a capable person making treatment decisions on his or her own behalf and an SDM making decisions on behalf of an incapable person. Every capable individual has an absolute right to make foolish or selfish decisions, including decisions relating to treatment, notwithstanding how others might view those decisions given the person's best interests.

SDMs do not have a right to make decisions on behalf of an incapable person that do not comply with the principles for consent set out in the *HCCA*. In the absence of wishes expressed by the incapable person when he or she was capable, the SDM must weigh all of the factors in s. 21(2) of the *HCCA* and make a decision that is objectively in the best interests of the incapable person rather than a decision based on what they want for the incapable person. The Supreme Court described this test in the following terms in *Cuthbertson v. Rasouli*,[2]

> The substitute decision-maker is not at liberty to ignore any of the factors within the best interests analysis, or substitute her own view as to what is in the best interests of the

[2] 2013 SCC 53 (CanLII), par 88

> patient. She must take an objective view of the matter, having regard to all the factors set out, and decide accordingly. This is clear from the mandatory wording of the opening portion of s. 21(2): the decision-maker "shall take into consideration" the listed factors. The need for an objective inquiry based on the listed factors is reinforced by s. 37, which allows the decision of the substitute decision-maker to be challenged by the attending physician and set aside by the Board, if the decision-maker did not comply with s. 21. The intent of the statute is to obtain a decision that, viewed objectively, is in the best interests of the incapable person.

If SDMs fail to adhere to these principles, the Board may direct them to make a decision that accords with the Board's determination of the person's best interests.

In order that an SDM can make an informed decision as to the treatment of the incapable person, subsection 22(1) of *HCCA* requires the health care practitioner to provide sufficient, necessary, information to the SDM:

Before giving or refusing consent to a treatment on an incapable person's behalf, a substitute decision-maker is entitled to receive all the information required for an informed consent as described in subsection 11 (2).

Section 11 sets out the elements involved when consent is given and the information that must be provided to any person when that person must make a decision regarding consent to treatment:

11. (1) The following are the elements required for consent to treatment:
1. The consent must relate to the treatment.
2. The consent must be informed.
3. The consent must be given voluntarily.
4. The consent must not be obtained through misrepresentation or fraud.

(2) A consent to treatment is informed if, before giving it,
(a) the person received the information about the matters set out in subsection (3) that a reasonable person in the same circumstances would require in order to make a decision about the treatment; and
(b) the person received responses to his or her requests for additional information about those matters.

(3) The matters referred to in subsection (2) are:
1. The nature of the treatment.
2. The expected benefits of the treatment.
3. The material risks of the treatment.
4. The material side effects of the treatment.
5. Alternative courses of action.
6. The likely consequences of not having the treatment.

(4) Consent to treatment may be express or implied.

Capacity to Consent to Treatment

Under the *HCCA*, a person is presumed to be capable to consent to treatment (s. 4(2)). The test for capacity to consent to treatment is in s. 4(1) of the *HCCA*:

A person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.

Ms Addie conceded her client, an infant in a coma, did not have capacity to consent to her own treatment. We confirmed the finding of treatment incapacity on consent.

Onus and Standard of Proof at Hearing

At the hearing of a Form G application like this, the onus was on the health practitioner to satisfy the Board that the SDMs did not comply with the principles of substitute decision-making under the *HCCA*. The standard is proof on a balance of probabilities. The Board must be satisfied on the basis of cogent and compelling evidence that the health care practitioner's onus has been discharged. There was no onus on the SDMs. The Board must consider all evidence properly before it. Hearsay evidence may be accepted and considered, but it must be carefully weighed.

Hospital Records/Chart Entries

Health practitioners have a duty to accurately record everything relevant to the patient's condition and treatment. Each patient has a "chart" in which those notes are compiled and retained. Other health practitioners treating that patient frequently review what their colleagues have written to assist their understanding of the patient's condition and to formulate treatment proposals. These chart entries are not "hearsay," or second-hand evidence, they are presumptive proof of what they say to the extent they record the health practitioner's own observations. The Supreme Court of Canada identified this "exception" to the hearsay rule in *Ares v. Venner*,[3]

> Hospital records, including nurses' notes, made contemporaneously by someone having a personal knowledge of the matters then being recorded and under a duty to make the entry or record should be received in evidence as *prima facie* proof of the facts stated therein.

[3] 1970 S.C.R. 608, at p. 626

> This should, in no way, preclude a party wishing to challenge the accuracy of the records or entries from doing so. Had the respondent here wanted to challenge the accuracy of the nurses' notes, the nurses were present in court and available to be called as witnesses if the respondent had so wished.

While BH did not directly challenge the accuracy of chart entries, her testimony contained a different version of events than at least one of them recounted, as set out below under title, "Credibility." We concluded the chart entry in question was likely more accurate than BH's evidence. Saying a chart entry is wrong, or testifying differently than what it records, was only a valid challenge to the accuracy of the entry if the opposing evidence was accepted.

ANALYSIS

The Breakdown in Therapeutic Alliance

As noted above under title, "The Adjournment Request," the relationship between SDMs and treatment team was not good. That situation, although relevant to our decision not to grant the requested adjournment, was not relevant to our Decision in the Application. If we granted Dr. Gilfoyle's Application and directed the SDMs to consent to a plan of treatment intended to allow KHK to die, we doubted the therapeutic alliance would improve but it would be a short-term problem.

If we dismissed Dr. Gilfoyle's Application, the treatment team's lobbying for consent to allow KHK to die would be at an end because of our Decision. That was the major impediment to rehabilitating the therapeutic alliance. As well, the treatment team had all the resources of this Hospital available to help them work things out with their patient's parents.

How Long Should the SDMs Have to Comply With Our Direction?

If we granted Dr. Gilfoyle's Application, the result would be a Direction to consent to the proposed treatment, with a time limit. The issue first arose when Ms Perez asked Dr. Gilfoyle how long she suggested. Dr. Gilfoyle did not have an immediate answer but on reflection and presumably after consulting counsel, she said seven days.

If we decided to grant this Application, the sole reason would be that we concluded being allowed to die was in KHK's best interests. There was no benefit to her in delay. On the other hand, her parents were entitled to some time to prepare for the death of their child.

As well, while we had to limit the time within which the SDMs had to consent, that did not mean the treatment team was obliged to act on that consent immediately. Dr. Gilfoyle testified that part of the palliative care approach included involving a patient's family in the last moments of the patient's life, if they wished. That could include a family gathering, privacy and the opportunity to cradle the KHK in their arms as she died. Those arrangements could be scheduled within a few days of any deadline we imposed.

Credibility

Dr. Gilfoyle and Dr. Helmers testified thoughtfully, carefully and entirely credibly. They were adamant that KHK had no prospect of meaningful recovery. The closest either came to being shaken on cross examination was Mr. Kohl's detailed exploration with Dr. Gilfoyle of whether KHK's movements were decorticate or decerebrate, because some of the nursing notes indicated both types of movement. Dr. Gilfoyle's conclusion was that the nurses were wrong and needed training to help better identify the distinctions between the two types of movement, but she would not concede both types of movement. Even though DK testified he observed KHK making purposeful movements, we accepted Dr. Gilfoyle's and Dr. Helmers's evidence that none of KHK's movements was generated from her upper brain. They were generated by her brain stem and were not purposeful movements.

DK testified carefully and credibly. However, his evidence was based on rejection of the tragic reality of his daughter's condition. He refused to accept that KHK had no prospect of recovery, or that there was no activity in her upper brain.

We were less comfortable with BH's evidence. On multiple occasions recorded in different chart entries, BH said she would never consent to withdrawal of KHK's life support but in evidence she testified she wanted KHK alive long enough to try alternate therapies but did not want KHK to spend the rest of her life in her current condition and would, eventually, agree to withdrawal of life support if KHK did not improve.

As well, BH's testimony relating to prior events was sometimes inaccurate. For example, there was a meeting attended by BH, DK, two doctors and a nurse. Dr. G. Annich was one of the doctors and wrote the chart entry included in Exhibit 1 about that meeting. One issue discussed was the possibility of a bowel perforation caused by the lack of oxygen that did so much damage to KHK's brain. There was evidence of damage to KHK's bowel and Dr. Annich told BH and DK a perforation was likely, but recommended against surgery for two reasons, one being the damage to KHK's brain and the inability to reverse it and the second being the risk of the operation itself. Dr. Annich's chart entry included this comment:

> Mother was very upset with me because I could not say anything positive about KHK's condition. She stated "They are going to kill her in the OR, just to prove that they are right"

In her evidence, which we rejected, BH's version of that event was to the effect that the doctors wanted to do the bowel surgery even though they knew KHK would die as a result.

At one point while being cross examined, BH said she "did not feel comfortable" answering the question. Her lawyers did not object to the question, it was a proper question and I told her she had to answer it. After a moment's thought, BH answered that she did not remember. How could she feel uncomfortable answering a question if she did not remember the answer?

KHK's Condition

As part of the process of attempting to obtain consent from KHK's SDMs to her proposed treatment and to give notice that this Application might be made if they did not consent, Dr. Gilfoyle wrote BH and DK a detailed letter outlining KHK's medical condition, the proposed treatment, their obligations as SDMs and that this Application could be made. The letter, dated August 10th, 2021, was part of Exhibit 1. Dr. Gilfoyle set out KHK's condition:

> Currently, (KHK) is in a deep unresponsive coma following her drowning: she does not have any awareness of herself or her environment, has no clinical signs of any wakefulness, has no purposeful or voluntary movements in response to any stimulation (visual, sound, touch, or pain), no ability to communicate (comprehension or expression), and a persistent absence of most brain-stem (cranial nerve) reflexes (in particular, an absence of pupillary, corneal, vestibulo-ocular, gag, and cough reflexes, with an inconsistent respiratory drive). She is reliant upon desmopressin administration for diabetes insipidus as she lacks an ability for her brain to release this and will have dangerously high sodium levels in her

> blood unless this is given. She is reliant upon a warming device to maintain her temperature as her brain cannot regulate this effectively. In other words, (KHK) cannot experience anything in the environment around her, nor does she experience any self-consciousness or even wakefulness of any kind. (KHK) has been in this state for more than one month, and our prognosis (prediction of her outcome) has been communicated to you on multiple occasions. Namely, based upon the severity of (KHK's) brain injury and her persistence in the above-described state, she will remain in this state for as long as she lives, and will only live if invasive and intense medical therapies remain in place 24 hours a day, seven days a week. We are deeply sorry that this is the case.

When we "met" KHK by videoconference, we observed that her legs were distended out from her body at about a 45 degree angle and bent inwards at the knees. Her elbows were straight and turned outward and her fingers were contracted inwards, claw-like and difficult to straighten. She was connected to a ventilator by way of a tube going into her mouth and down her throat. One tube down her nose delivered nutrition to her stomach or possibly her small intestine, Dr. Gilfoyle was unsure which. KHK was normally covered with a "Bair Hugger," a blanket into which warm air could be pumped to maintain her body temperature.

There was another tube in KHK's nose to drain air from her stomach because sometimes air from the ventilator went there instead of into her lungs. Nurses had to drain that air because KHK could not burp. Although not in evidence when we met KHK, she also needed equipment to suction her airways because she could not cough or otherwise clear them of the mucous her lungs produced.

There were sensors attached to KHK's chest and a monitor to show what they sensed, as well as to show what the sensor on her breathing tube disclosed. The monitor displayed KHK's pulse, the electrical activity of her heart, her internal core temperature, the carbon dioxide released by her lungs and her oxygen saturation as determined by a sensor on her foot. She had a blood pressure cuff on her arm, activated whenever blood pressure was checked.

KHK had an intravenous line surgically installed into the large vein at the top of her right leg. It was used to deliver fluids, medications and blood products and was capped off when we visited.

KHK rested on a foam sheet to reduce skin injury of the type commonly referred to as bedsores. There was an infrared light device at her bedside and turned on intermittently because BH and DK believed that the light could help cure KHK. While the treatment team disagreed, they did not object because it could not harm her.

The lack of oxygen caused two types of injury to KHK's brain. Some brain cells died and others were injured. It also caused "bilateral uncal herniations" of her brain stem. In her clinical summary contained in Exhibit 1, Dr. Gilfoyle explained these conditions:

> Uncal herniation is a condition where the brain is compressed due to elevated pressure causing parts of the brain to herniate (push out) at the base of the skull. This causes direct pressure on the brainstem, causing further damage in addition to the initial injury from low oxygen levels. This herniation is permanent and causes irreversible injury to the brainstem, which contains vital structures essential to life including breathing, control over circulation of blood and heart function, and wakefulness. The MRI also showed widespread "diffusion restriction" in bilateral cerebral white matter, deep gray structures, brainstem, and hippocampi which are MRI patterns associated with significant, widespread brain swelling and widespread areas of lack of oxygen to the most important structures of the brain.

The effect of the uncal herniation on KHK was that electrical signals could not flow through her brain stem to her brain. KHK's brain would never receive information from her body or be able to send instructions. KHK would never move purposefully, hear, see, smell or feel.

The treatment team tested KHK's upper brain activity with a 12-hour continuous electroencephalogram ("EEG"). There was none. DK said the test should have been for 24 hours. The treatment team said 12 hours was long enough to establish a lack of brain activity. We accepted the conclusion that KHK had no upper brain activity.

The treatment team also conducted two "neurological determination of death" (NDD") tests to see if KHK was "brain dead." Although KHK had no activity in her upper brain proper, there was some in her brain stem, so she did not meet the criteria to be declared "brain dead."

KHK's Prognosis

The Treatment Team

This hospital had eleven doctors who were specialists in pediatric intensive care. Theirs was the largest pediatric intensive care unit in Canada, with 11 "general" beds (to the extent a pediatric intensive care bed can be described as a general bed) and another 11 beds for cardiac intensive care. This hospital was recognized as a center for research excellence. Trite to say, a PICU physician is a highly trained expert.

KHK's "submersion event" took place on or about July 8th, 2021. Given how long it took to resuscitate KHK, all eleven doctors were surprised she was still alive. Dr. Gilfoyle testified that all eleven PICU physicians agreed KHK had no chance of meaningful recovery.

Brain cells do not regenerate, so although some of her other organs may have healed, her brain could not. She would never be aware of, or be able to interact with, her environment. She would never have awareness of sights, sounds, smells, touch or pain.

It was possible KHK could be kept alive for months or even years. However, her overall condition would continue to deteriorate. Pressure or "bed" sores were a possibility in spite of the foam sheet on which she rested and frequent repositioning carried out by nurses. Lack of movement would cause her muscles to atrophy and contract, her knees and elbows to lock in place and her fingers to become more "claw like." KHK already had pneumonia twice and it was likely to recur. The pneumonia resolved with antibiotic treatment but caused scarring to KHK's lungs. It was treated with antibiotics but there was the possibility she would become resistant to them.

Asked if KHK could be cared for at home, Dr. Gilfoyle testified that was impossible. Even if the conditions of a pediatric intensive care bed could be replicated, KHK would still have to attend a hospital from time to time and transporting her would be dangerous.

The SDMs

BH and DK rejected the medical conclusion that KHK had no prospect of her brain healing. They thought there was a chance of recovery and wanted her to have that chance. They pointed to KHK's bowel healing instead of becoming perforated, to her recovery in hospital from two bouts of pneumonia and to the swelling of her brain going down as evidence that she could heal herself and therefore also possibly that her brain could heal itself. They also pointed out KHK was still alive, to the surprise of her treatment team. They wanted access to therapies not offered by KHK's treatment team, such as infrared light and hyperbaric oxygen treatment, which they believed might help heal KHK's brain. They wanted to look for other possible therapies as well. They thought KHK should be given those chances and testified they would reconsider in a year if she showed no improvement.

The treatment team did not object to infrared light therapy because, although they had no faith it would assist KHK, they were satisfied it would not harm her or interfere with other treatments. BH and KHK acquired an infrared light. It was at KHK's bedside and turned on at times.

Our Conclusions as to KHK's Prognosis

A 12-hour EEG established that KHK had no upper brain activity. Other tests disclosed the "bilateral uncal herniation" in her brain stem, for which there was no treatment and which prevented signals going from KHK's body to her brain. Every member of KHK's treatment team, including eleven pediatric intensive care specialists and a neurologist, concluded she had no prospect of recovery, meaning she would never have an awareness of her environment or the use of any of her senses. While we denied SDM counsel the opportunity of an adjournment to find an expert witness, we doubted they could have found a credible expert who would disagree, or persuade us to disagree, with the medical conclusions in evidence.

We found as fact that KHK had no prospect of recovering use of her brain.

We also accepted the medical evidence that, while acute medical conditions such as pneumonia could be treated, KHK's overall condition would continue to deteriorate. Her muscles would continue to atrophy and contract from lack of use and lack of signals from her brain. She was likely to have further bouts of pneumonia. While they could be treated, each would leave more scar tissue. Bedsores remained a possibility, if not a probability.

KHK's Treatment Alternatives

Dr. Gilfoyle proposed withdrawal of life support followed by such palliative care as KHK required. Because KHK could not breathe on her own, death would likely follow in minutes or possibly a few hours. In the unlikely event KHK could breathe on her own, the withdrawal of nutrition and hydration would eventually result in her death. KHK could not be aware she was dying and her passing would be painless.

BH and DK wanted active care to continue. They did not want KHK to die.

The SDMs' Science

The night before the last day of this Hearing we received scientific journal articles and a book chapter, as well as a newspaper article from *The Houston Chronicle,* all regarding the benefits to persons with brain injuries of infrared light therapy and hyperbaric oxygen therapy ("HBOT"). Those were the two treatments BH and DK said they wanted to try before they agreed to discontinue KHK's life support.

As noted under title "Preliminary Matters," we received scientific journal articles through counsel from both BH and DK. DK researched red light, near infrared and infrared light therapy. Ms Perez sent us three articles upon which DK relied.

The first article was *Multi-watt near-infrared light therapy as a neuroregenerative treatment for traumatic brain injury,* Henderson, Theodore A., Neural Regeneration Research, April 11, 2016. The author discussed multi-watt near-infrared light therapy as a neuroregenerative treatment for traumatic brain injury, the uses of infrared light therapy on sprain (not brain) injuries, bone fractures and to speed the healing of wounds, all within the scope of veterinarian medicine. It also discussed its use in brain injuries from stroke or external trauma. But KHK did not have a traumatic brain injury, stroke or external trauma, she had hypoxic (deprivation of oxygen) brain injury. That might be similar to the symptoms of brain injury caused by stroke. Though not clear from the article, the participants apparently had brain function, unlike KHK.

DK's second authority was, *Pulsed Transcranial Red/Near-Infrared Light Therapy Using Light-emitting Diodes Improves Cerebral Blood Flow and Cognitive Function in Veterans with Chronic Traumatic Brain Injury: A Case Series*, Hipskind, G. *et al,* 2018 Photomedicine and Laser Surgery Volume XX, Number XX, 2018. This paper reported the study of 12 symptomatic veterans who suffered some form of traumatic brain injury caused by a slip and fall, sport related injuries and a helicopter crash. The study discussed the use of infrared light therapy and the relevant light frequencies used to increase perfusion (blood flow) within the brain. The document concluded suggesting its use in neuropsychiatric dysfunction, improved cognition and decreased deficits of traumatic brain injuries was worthy of further investigation. Again, there was no indication any of the study's subjects lacked brain function, as KHK's EEG showed she did.

The third document was, *Brain Photobiomodulation Therapy: A Narrative Review*, Salehpour, f. *et al.*, Mol Neurobiol, 2018 August ; 55(8): 6601–6636. This 57 page document was a discussion paper on the use of photobiomodulation therapy using near-infrared light. The paper discussed the technology, mechanisms of action of photobiomodulation therapy, current approaches for light delivery, penetration through the scalp, skull, and brain tissues and impacts of said treatments. The paper discussed clinical applications such as, Alzheimer's disease, Parkinson's disease, traumatic brain injury, strokes, depression and applications assisting healthier subjects with improved cognition.

These papers did not discuss the application of infrared light therapy on individuals in KHK's condition.

BH was working toward hyperbaric treatment for KHK. Hyperbaric Oxygen Therapy involved putting a patient in a pressurized chamber and administering pure oxygen for the patient to breathe. It was a recognized therapy for decompression sickness ("the bends"), carbon monoxide poisoning and the treatment of intractable wounds and infections.

BH had an intake appointment at Toronto HBOT scheduled for Thursday September 9th. With consent of all counsel, we looked at their website.

Toronto HBOT's web site displayed two classes of treatments. Treatments for listed conditions, OHIP paid for. Neither of KHK's main conditions, hypoxic brain injury and uncal herniation, was on that list. Dr. Gilfoyle testified this treatment was not part of the standard of care for those conditions. Dr. P. Harch, whose book chapter on HBOT was in evidence, wrote that someone like KHK whose hyperbaric oxygen therapy started more than two months after brain damage would need 200 to 300 treatments before showing improvement.

Dr. Harch's book chapter talked about treating hypoxic brain injury. It did not talk about using HBOT for uncal herniations. Nor did any of the other authorities submitted.

Even granting that either therapy might "heal" the damaged cells in KHK's brain, neither could result in KHK reacquiring any awareness of her environment or use of her senses. That was because neither therapy addressed KHK's other major problem: the uncal herniation.

KHK's uncal herniation prevented signals from getting to her brain. KHK's brain could not communicate with her body, so even recouping some brain function would be of no benefit.

DK also testified about wanting to give KHK's brain a chance to develop neuroplasticity: sometimes, when part of a brain is damaged or the cells in it die, other parts of the brain assume the jobs of the injured or dead part. We accepted Dr. Helmers's evidence that, even if that happened, it would not benefit KHK because the uncal herniation could not be treated with the continued result that KHK's brain had no way to receive signals from her body.

The Statutory Criteria

Section 21 of the HCCA set out what SDMs had to consider as part of "best interests" in making treatment decisions for an incapable patient. Since KHK could never have formed wishes, values or beliefs, the factors in paragraph 21(2)(c) governed. As per the Supreme Court in *Rasouli, supra*, "The intent of the statute is to obtain a decision that, viewed objectively, is in the best interests of the incapable person."

Almost all legislation is written to cover multiple situations and these provisions are in that category. While we did consider and apply them, they were not comprehensive in addressing KHK's central issue: whether the goal of her treatment should be to keep her alive or to allow her to die. While the "best interests" considerations set out in the legislation had to be considered, we did not consider the list exhaustive. In using the phrase, "shall take into consideration," the legislation recognized that other factors could be relevant:

21.(2) In deciding what the incapable person's best interests are, the person who gives or refuses consent on his or her behalf shall take into consideration,

Did KHK express any wishes while she was capable that was applicable to the circumstances?
What were the values and beliefs that SP knew KHK held while she was capable and believed KHK would still act on if capable?
What were the wishes expressed by KHK with respect to the proposed treatment plan that were not prior capable wishes applicable to the circumstances?

Given her age, KHK could never have expressed or held any wishes, values or beliefs.

Was the proposed treatment likely to prevent KHK's condition or well-being from deteriorating?

Was the proposed treatment likely to reduce the extent to which, or rate at which, KHK's condition or well-being would deteriorate?

Without the proposed treatment was KHK's condition or well-being likely to improve, remain the same or deteriorate?

Questioned by Ms Perez, Dr. Helmers agreed that treating and curing KHK's pneumonia prevented her condition from deteriorating in consequence of pneumonia. The foam mattress and constant repositioning would prevent, delay or reduce the seriousness of bedsores and thereby prevent, delay or reduce that type of deterioration. Other acute health events could also be treated, thereby preventing, delaying or reducing the deterioration they might cause. In submissions, Ms Perez said that there were therefore treatments other than withdrawal of life support available to prevent KHK's condition from deteriorating.

The problem with Ms Perez' submission was that it spoke to discrete medical conditions and not to KHK's overall medical condition. The legislation directed us to consider KHK's "condition," not "conditions." We rejected the submission that we could conclude KHK's condition would not deteriorate, or deteriorate more slowly, if we ignored the fact that her brain could not function.

Continuing KHK's life would continue deterioration of her overall condition. Allowing her to die would stop it. Treating individual acute medical conditions would prevent, reduce or delay deterioration from them but would not improve her overall condition because she would never regain useful brain function.

Was there a less restrictive or less intrusive treatment that would be as beneficial to KHK as the proposed treatment?

Was Dr. Gilfoyle's proposed treatment likely to improve KHK's condition or well-being?

Did the benefit that KHK was expected to obtain from the proposed treatment outweigh the risk of harm to her?

The damage to KHK's brain was irreversible. She would never see, hear, smell or feel. Her other internal organs might heal by themselves to some extent but there was nothing that could be done for her underlying brain damage. In that sense, there was no way to improve her condition.

In the context of KHK's condition these three questions are more philosophical than practical. Is death always a harm? Is life always a benefit? What does it mean to be alive? The answers to those questions ran the gamut. We were aware that many people have "no heroic measures" provisions in their Powers of Attorney for Personal Care and in our view KHK was being kept alive by heroic measures. Medical Assistance in Dying is available in Canada and has become somewhat commonplace for persons whose death is foreseeable and whose condition is intolerable to them. At the other end of the spectrum are people to whom every moment of life is sacred, no matter the pain, no matter the suffering or futility, to the point that being kept on a ventilator, even after brain death, is valuable to them.[4]

KHK had no wishes, values or beliefs to guide us. Her absence of brain function meant she was not enduring pain or suffering, other than possibly suffering in an existential context. The overarching question was whether KHK should be kept alive or allowed to die. Which, as objectively as possible to determine, was in her best interests?

Quantitively, KHK was so close to the line between life and death that her treatment team twice conducted the NDD (neural determination of death) test. Qualitatively, what were her life's prospects? Examining the statutory considerations alone led us to find as fact that KHK's best interests required allowing her to die. Considering KHK's well-being led us to the same conclusion.

KHK's Well-being

Well-being is a phrase with broader meaning than "condition." *Scardoni v. Hawryluck*[5] was an appeal from this Board in which the definition of the term was canvassed:

> [45] A question of statutory interpretation that was more directly in issue in the appeal concerned the meaning of the word "well-being" in s. 21(2)(c) of the Act. The interpretation accepted by the Board was central to its finding that further treatment in the intensive care unit was not in Mrs. Holland's best interests. At p. 20 of its Reasons for Decision, the Board stated:
>
> > We thought "well-being" involved more than mere life itself. The phrase is subjective as used because it was used in conjunction with the word "condition," which connoted to us a more objective assessment of the status of a person's

[4] See for example *McKitty v. Hayani*, 2019 ONCA 805 (CanLII)
[5] 2004 CANLII 34326 (ONSC)

> illnesses and physical situation. "Well-being" includes considerations such as the person's dignity and levels of pain.

[46] This interpretation was challenged by Ms. Chan who submitted that matters that are to be considered relevant to the well-being of a patient were intended to be confined to those relating to her health. In her submission, the Board erred in law in taking into consideration evidence with respect to Mrs. Holland's quality of life and, particularly, that of the discomfort and indignity she had experienced in undergoing treatment in the intensive care unit and would experience again if she was returned there.

[47] The phrase "quality of life" is used in other sections of the Act in connection with decisions with respect to an incapable person's best interests. It does not appear in the sections relating to consent to treatment. Whether or not the considerations on which the Board relied are aptly encapsulated by the phrase, I am satisfied that the Board's interpretation of the reference to the "well-being" of a patient is to be preferred to the more narrow definition that Ms. Chan urged me to accept.

[48] The interpretation accepted by the Board is supported by dictionary definitions of wellbeing that refer to a person's state of happiness, contentment and prosperity as well as good health: see for example, the New Oxford Shorter Dictionary; Random House Unabridged Dictionary; and Nelson's Canadian Dictionary of the English Language. Generally, the dictionaries treat the term as synonymous with "welfare". Similarly, in Inland Revenue Commissioners v. Baddeley, [1955] A.C. 572, [1955] 1 All E.R. 525 (H.L.), at p. 616 A.C., Lord Somervell of Harrow referred to a person's "wellbeing" as meaning "a happy or contented state".

[49] Finally, in Janzen v. Janzen (2002), 44 E T.R. 217 (Ont. S.C.J.) in which the interpretation of s. 21(2) of the Act was considered in the context of competing applications for appointment as an incapable person's guardian of the person, Aitken J. stated:

> Treatment in the form of a ventilator, medications and periodic heroic interventions as required might improve other medical conditions suffered by Mr. Janzen, such as pneumonia or kidney or heart failure; but according to the medical evidence it would not improve Mr. Jansen's quality of life. I consider the concept of "well-being" a very broad concept which encompasses many considerations, including quality of life. Many of the interventions contemplated as being necessary to prolong Mr. Janzen's life involve procedures that could be painful or uncomfortable for Mr. Janzen. Maria Janzen's Guardianship Plan focuses on keeping Mr. Janzen comfortable and pain free. I find that this focus will improve his overall well-being.

[50] I accept that interpretation and find no error of law in the Board's conclusion on the meaning of "well-being" in the Act.

Many of the considerations referred to in both *Scardoni* and in *Janzen v. Janzen*, cited in par. 49 of *Scardoni*, did not apply to KHK because she could not feel any pain. However, to the extent quality of life was relevant to her well-being, KHK had virtually none. She never would.

KHK's well-being also included consideration of the dignity to which she, like every human being, was entitled. Dr. Gilfoyle testified that every member of KHK's treatment team felt "moral distress" at having to treat KHK. She defined the term as pertaining to the feelings health practitioners felt at having to deliver care they did not think was in KHK's best interests.

How doctors, nurses and other health practitioners felt about treating KHK was not a consideration the law allowed. However, that moral distress reflected on something about which the English House of Lords commented in *Airedale NHS Trust v. Bland*.[6] Mr. Bland was a young man in a persistent vegetative state with no meaningful prospect of recovery. His family and doctors wanted to take him off life support, knowing he would likely die. The National Health Service Trust opposed that decision. Various of the Lords Justice in *Bland* made these observations, also quoted in another infant "end of life" decision of this Board and included in Mr. Rogers' Brief of Authorities, *Re EJG:*[7]

> (The mentally incompetent patient) has the right to be respected. Consequently he has a right to avoid unnecessary humiliation and degrading invasion of his body for no good purpose. I was dismayed to hear the argument of the Official Solicitor that, if Mr. Bland suffered a cardiac arrest or a renal failure, it would be the duty of the doctors to perform a heart bypass operation or a kidney transplant. I cannot believe that a patient in the situation of Mr. Bland should be subjected to therapeutically useless treatment contrary to good medical practice and medical ethics which would not be inflicted upon those able to choose. It is an affront to his right to be respected.
>
> …The considerations as to the quality of life of Mr. Bland now and in the future in his extreme situation are in my opinion rightly to be placed on the other side of the critical equation from the general principle of the sanctity and inviolability of life. In this appeal those factors which include the reality of Mr. Bland's existence outweigh the abstract requirement to preserve life…The duty of the doctors towards a PVS patient at the extreme end of the spectrum does not extend to prolonging his life at all costs. (Lord Justice Sloss)
>
> But, for my part I cannot see that medical treatment is appropriate or requisite simply to prolong a patient's life when such treatment has no therapeutic purpose of any kind, as where it is futile because the patient is unconscious and there is no prospect of any improvement in his condition. It is reasonable also that account should be taken of the invasiveness of the treatment and of the indignity to which, as the present case shows, a person has to be subjected if his life is prolonged by artificial means, which must cause considerable distress to his family—a distress which reflects not only their own feelings

[6] [1993] 1 All ER 821
[7] 2007 CanLII 44704 (ON CCB)

> but their perception of the situation of their relative who is being kept alive. But in the end, in a case such as the present, it is the futility of the treatment which justifies its termination. (Lord Goff of Chieveley)
>
> While the respect accorded to human life always raises a presumption in favour of prolonging it, that presumption is not irrebuttable. Mere prolongation of the life of a PVS patient such as Mr. Bland, with no hope of any recovery, is not necessarily in his best interests, if indeed such prolongation is in his interests at all.
> …
> An objective assessment of Mr. Bland's best interests, viewed through his eyes, would in my opinion give weight to the constant invasions and humiliations to which his inert body is subject…
> (Sir Thomas Bingham, Master of the Rolls)

The Reasons for Decision in *EJG* also contained this observation, with which we agreed:

> Since the withdrawal of treatment Dr. Choong proposed was likely to result in EJG's death, it might be argued that continuing his mechanical respiratory assistance could not logically be a risk because the greatest risk is death. We disagreed. Every living thing eventually dies and the risk is not whether, but when and how, as well as what happens to a person until he or she dies. Those factors had to form part of the discussion of EJG's "well-being," which is a much broader term than "condition."

In *Bland,* Sloss, L.J. also quoted with approval from an American case, *Re Conroy*:[8]

> The medical and nursing treatment of individuals in extremis and suffering from these conditions (persistent vegetative state) entails the constant and extensive handling and manipulation of the body. At some point, such a course of treatment upon the insensate patient is bound to touch the sensibilities of even the most detached observer. Eventually, pervasive bodily intrusions, even for the best motives, will arouse feelings akin to humiliation and mortification for the helpless patient. When cherished values of human dignity and personal privacy, which belong to every person living or dying, are sufficiently transgressed by what is being done to the individual, we should be ready to say: enough.

While Mr. Bland and Mr. Conroy were in a vegetative state and might feel pain but KHK was in a coma with no ability to feel pain, in our view all of their Lordship's observations were still relevant to KHK's dignity and well-being.

KHK's treatment team said, "enough." We felt heartbreak for KHK, not only for having drowned, but also for her complete absence of well-being and the treatment imposed upon her with no

[8] (1985) NJ 321, 398-399

prospect of recovery. We could not imagine any objective observer able to feel otherwise. It was time to say, "enough."

RESULT

By Decision released September 7, 2021, we directed BH and DK to consent to Extubation, discontinuance of artificial nutrition, hydration and desmopressin, no CPR and, the provision of palliative care. If they did not comply by 5 PM Friday September 10th, 2021, they would cease to be KHK's SDMs.

Dated: September 11, 2021

Mark Handelman,
Presiding Senior Lawyer Member