ONTARIO HOSPITAL ASSOCIATION

Coroner's Jury Verdict & Recommendations **UPDATE**

INQUEST INTO THE DEATH OF:
Negus Tafari Topey

Details

Name of Deceased:	Negus Tafari Topey
Date of Death:	August 9, 2004
Place of Death:	McMaster University Medical Centre
Cause of Death:	Complications arising from Ornithine Transcarbamoylase Deficiency
By what means:	Natural Causes
Age of Deceased:	20 years
Location of Inquest:	Milton, Ontario
Date of Inquest	May 2 to May 16, 2005
Release date of verdict:	June 17, 2005

Key Recommendations of Note to Hospitals

The jury made several recommendations. Although not all of the recommendations are directed at hospitals, they may still be of interest.

To the Ministry of Health and Long-Term Care:

1. **The jury recommended** that hospitals and health care providers facilitate the rapid exchange of life-saving health information to other providers and hospitals within the circle of care using existing technology. Additionally, the jury recommended a study be commissioned to evaluate the creation of an electronic information interchange of medical records for all Ontario healthcare facilities.

2. **The jury recommended** that efforts be made to identify whether electronic medical records systems at Ontario Hospitals are available to facilitate communication of medical information among members of a healthcare facility. If this is not the case, electronic medical record systems should be implemented as deemed appropriate.

   Coroner's Comment: The jury heard evidence from an expert that persons suffering from untreated Ornithine Transcarbamylase Deficiency (OTC) are known to have very poor judgment and fluctuating neurological function so that one person may elicit a clear and comprehensive response to a question that the patient could not answer a short time before. By the time Mr. Topey was admitted to Oakville Trafalgar Hospital he was suffering from significant neurological dysfunction. Information elicited from him was crucial in identifying his rare disease. The jury heard evidence that a nurse doing an admission nursing assessment found out that Mr. Topey has been at the Hospital for Sick Children (HSC) and recorded this information on her nursing assessment form. However, this form was not kept in the chart, it was kept by the nurses to formulate the nursing plan. It was tragic that this information was not available when the neurologist examined Mr. Topey but the nurse had no access to it. The jury heard that since that time, nursing assessments are stored in the electronic patient records and all health providers have access to that record.

   The jury also heard that Maplehurst faxed their records within a short time of the request but the neurologist did not see the record for 2 days because she did not write an order to be called when the records arrived and did not come to see Mr. Topey again for two days. The request for records from

HSC and St Michael's Hospital went through the medical records departments of Oakville Trafalgar, HSC and St. Michael's. There was no urgency indicated on the request for information.

3. **The jury recommended** that hospitals that are equipped to provide care to persons with rare inherited metabolic disorders such as the Hospital for Sick Children are encouraged to be equipped and prepared to ship drugs for these disorders to another hospital immediately on request.

   Coroner's Comment: This recommendation was made to the jury by the expert witness who suggested that there might have been a delay in transferring the drugs to Oakville Trafalgar Hospital.

4. **The jury recommended** that all hospitals in Ontario develop and post protocols for the investigation of acute encephalopathy, which include measurement of plasma ammonium, along with toxicology screens and the measurement of glucose electrolytes, liver and kidney function tests, etc., commonly included in what many refer to as a 'metabolic screen'.

   Coroner's Comment: The jury heard evidence that plasma ammonium is a test that is technically difficult to do with a lot of false positives. It is therefore not commonly done in hospitals that are not tertiary care. The recommended protocol is not suggesting that plasma ammonium be available in all hospitals but that all doctors be made aware that a metabolic screen is incomplete without one and in patients with acute encephalopathy with an otherwise normal toxicology screen and standard metabolic tests, they should consider sending the blood to a tertiary center for a plasma ammonium.

5. **Arising from this inquest the jury recommended** that expensive, limited use drugs for the treatment of rare inherited metabolic diseases should be available to all residents of Ontario free of charge, irrespective of their age.

   Coroner's Comment: The jury heard evidence that once persons suffering from rare inherited metabolic diseases reach adulthood they have to pay for their medications which are expensive. I believe the jury said "Arising from this inquest…" because they were told that they could make recommendations from matters arising from the inquest even though the jury did not find the issue to be a factor in the death.

To the Ministry of Community of Safety and Correctional Services:

6. **The jury recommended that** all Correctional Facilities cross-reference records from Police Services with their records for all pertinent health information. On admission, all medical information documented by Police Services should be recorded by the intake nurse into the inmate's medical record. In addition, the jury recommends these procedures be uniformly adopted by the Ministry of Community Safety and Correctional Services.

   Coroner's Comment: The jury heard evidence that the Toronto Police Service "record of arrest" contains notations regarding illnesses and medications and allergies and that Toronto Police Services transport officers take the record of arrest to correctional facilities and detention centers with the prisoner. Correctional officers who worked in the Admitting and Discharge area of Maplehurst testified that the only document they looked at was the Remand Warrant. They said that other documents are in an envelope and that they don't open. They also said that many police services bring prisoners to Maplehurst and the documentation accompanying the prisoner varies but that they all bring the Remand Warrant.

   The nurse in Admitting and Discharge at Maplehurst testified that she never sees any of the documentation that accompanies the prisoner. In the fact situation in this inquest, Mr. Topey's judgment and ability to communicate was getting worse the longer he was off his medication so he would have been less able to give a medical history as time passed. It was tragic that information collected early in his incarceration was not passed on to the correctional facility because the correctional officers did not know that such information would be in the documentation and could be important.

7. **The jury recommended** that in the event of an inmate being transferred to the hospital for the first time with a serious or unknown health issue, an urgent search of medical records based on information on file (family doctor, previous hospitalization, etc) be instigated by the Health Care Clinic of the Correctional Facility. Also, a notation of this request should be indicated on the Health Care Consultation Form for Correctional Facilities which accompanies an inmate when he/she is sent out of the Correctional Facility to a hospital for assessment.

   Coroner's Comment: When Mr. Topey was transferred to the Milton site of Halton Healthcare Services, the nurse wrote that he had been at HSC for a liver disease on the Consultation Form. The nurse did not contact HSC, expecting that the doctor in the emergency would do this.

8. **The jury recommended** that the Ministry of Community Safety and Correctional Services be encouraged to provide information about this death and inherited metabolic disorders to the health care staff and doctors in correctional facilities and detention centers in the Province of Ontario.

   Coroner's Comment: It was apparent that the doctors and nurses who provided care to Mr. Topey had never heard of OTC Deficiency and did not know that his odd behaviour was due to acute encephalopathy from hyperammonemia. The expert testified that this disease is rare and he was not surprised that they had not heard of it. Communication of the facts of this case to all doctors and nurses providing care in correctional facilities and detention centers would be an inexpensive and instructive way to ensure that they become aware of the rare metabolic disorders.

9. **Arising from this inquest, the jury recommended** that the Health Care Consultation Form be annotated to reference the fact that the information provided is a summary only and the Health Care Clinic of the institution should be contacted if further information be required.

   Coroner's Comment: This is another recommendation about a matter arising from the inquest that was not found to be a factor in the death. In this case, the doctor in the emergency department was called by the nurse and the neurologist had Maplehurst called so this annotation would have been unnecessary.

To Police Services:

10. **The jury recommended** that based upon the number of inconsistencies of all information in the records of arrest (family contact information, medical information etc), it is recommended that all records of arrest should contain all pertinent medical information and, in particular, the names of all medications for a detained person. In addition, all Police Services in Ontario are encouraged to provide Correctional Facilities with the record of arrest and/or any other documentation that lists observations and/or information about a detained person's medical condition.

    Coroner's Comment: Four records of arrest were completed for Mr. Topey on July 20th because of a number of charges. Only one of the four contained notations respecting Mr. Topey's health history and medications. The concern was expressed that if any charges were withdrawn, the only record of illness/medication/allergy would not accompany the prisoner to a correctional facility.

General:

11. **The jury recommended** that based upon medical evidence, that individuals with rare potentially life-threatening conditions should be encouraged by health care providers to wear medic alert bracelets and to carry a card summarizing the nature of their condition and where more information can be obtained.

    Coroner's Comment: Mr. Topey seemed unable to name his medical problem from the time of booking and as his encephalopathy got worse, his judgment and ability to communicate deteriorated. If he had been wearing a medic alert bracelet or chain or was carrying an information card in his wallet he would have received the care he needed in a timely manner.

12. **Arising from this inquest the jury recommended** that funding be put in place to cover the cost of registering for a medic alert bracelet, the cost of the bracelet and the annual fee for any patient with a rare metabolic disorder and demonstrable financial need.

    Coroner's Comment: Mr. Topey's mother testified that a medic alert bracelet was recommended for her son, but she could not afford it.

13. **The jury recommended** that a case summary regarding this death be published in "The Dialogue", a publication for the College of Physicians of Ontario.

    Coroner's Comment: OTC deficiency is a rare metabolic disease that produces acute encephalopathy from high levels of ammonium. A standard metabolic screen in most hospitals would not include ammonium level. A summary of this case printed in the publication of the CPSO could reach a large number of physicians and alert them to this possibility.

14. **Arising from this inquest the jury recommended** that publication of the various shelters, including their services be made available to all medical and correctional facilities.

    Coroner's Comment: The jury heard evidence that Mr. Topey lived at Covenant House before his arrest and that there are doctors and nurses that provide care to Covenant House residents. Mr. Topey's medical condition was known there and he had medication there. No one contacted the shelter for information. Doctors and nurses testified that they did not know Covenant House provided medical care**.**

Summary

Negus Topey was diagnosed at the age of eleven with Ornithine Transcarbamylase Deficiency (OTC Deficiency) of late onset, an extremely rare congenital metabolic disorder. OTC Deficiency is a disorder of the urea cycle that results in increasing levels of plasma ammonium in the blood and brain with associated irritability, vomiting, drowsiness and coma. As a result of this disorder, Mr. Topey required a low protein diet of 1.3 grams per kg of body weight per day and was required to take the following medication for the rest of his life:

1. Sodium benzoate 1435 mg, po, q6h
2. L-Citrulline 1000 mg po, q6h

Mr. Topey was living in a shelter in Toronto called Covenant House on April 7, 2004 when he told staff he was ill with fatigue, nausea and vomiting. They sent him to St Michael's Hospital where he was admitted, treated, and released on April 10, 2004.

Mr. Topey was arrested by the Toronto Police Service on July 18, 2004. At that time he gave a false name and date of birth. He was held in custody as a youth and spent the night of July 19 at the Hamilton Wentworth Detention Centre. At the time of his arrest, he told police he had a liver disease and had to take sodium benzoate and citrulline every 6 hours. He told the nurse at the detention centre that he had a liver disease but was not taking medication. She booked him to see the doctor in a week's time.

It was discovered that Mr. Topey was not in fact a youth and on July 20 in addition to other charges, Mr. Topey was charged with Attempt to Obstruct Justice and remanded to Maplehurst Correctional Facility. At the time he was booked, Mr. Topey told the booking sergeant that he took medication for a liver problem every 6 hours and that he would go into a coma without it. He also said that he had seen a doctor in Hamilton and that no medications were ordered for him. The nurse from Hamilton Wentworth Detention Centre testified that Mr. Topey had not seen a doctor, but she thought it was possible that Mr. Topey may have thought the nurse was a doctor because she wore a white coat and carried a stethoscope.

Four records of arrest were completed on July 20. Only one of these contained information about Mr. Topey's medical condition. At the admitting and discharge area at Maplehurst, a correctional officer gathered information from Mr. Topey for the Offender Tracking Information System (OTIS). Mr. Topey then saw a nurse who took a brief medical history. She did not receive any information about OTC Deficiency from Mr. Topey. Mr. Topey also saw a nurse for a Health Assessment and another nurse for a Mantoux test on July 28. He made no complaints to them about his health.

On or about Sunday August 1 2004, Mr. Topey's fellow inmates brought him to the attention of the correctional officers stating that he was always sleeping during the day and was very lethargic. Correctional staff took Mr. Topey to see the nurse.

Mr. Topey told the nurse that he had been diagnosed with a liver disease since childhood, but he could not remember the name of the disease. He told the nurse that he currently lived at Covenant House and was on a medication called sodium benz but was no longer taking it. He said he had been in a coma in the past related to this disease and had been treated at Sick Kids Hospital. He gave the nurse his stepmother's phone number. The nurse called his stepmother but unfortunately she did not know what disease he had and could not give a phone number for Mr. Topey's mother.

Mr. Topey was then transferred to the emergency department of the Milton site of Halton Healthcare Services. The doctor read the Health Care Consult note sent by the nurse, although he was not able to get any information from Mr. Topey. The doctor found Mr. Topey to be alert, with a non-tender abdomen and liver. Blood test results were normal, except for amylase and bilirubin, both of which were elevated. He sent Mr. Topey back to Maplehurst with directions for an abdominal ultrasound and an appointment to see the doctor in the morning.

Summary continued

Later on the day on August 2, Mr. Topey was brought to the nurse because his eyes were yellow and he was acting strangely on the unit. There were no reports of assault but the correctional officers wondered if he had been beaten. The nurse thought he was confused and she had difficulty getting any information from him. She could find no evidence of an assualt. She sent Mr. Topey to the emergency department at the Milton site of Halton Healthcare Services. While he was waiting to be taken to hospital he involuntarily wet himself and had jerky twitching movements.

He was seen by the same doctor who found him uncooperative and in no acute distress. The doctor concluded that Mr. Topey had a psychiatric disorder and sent him back to Maplehurst to be seen by the psychiatrist. It was his testimony that he ordered that Mr. Topey be put on suicide watch because this was a form of close observation.

The nurse at Maplehurst and the supervisor of the unit testified that they were worried about Mr. Topey's condition and it was their decision to place him on a suicide watch in the segregation unit to ensure that his condition would be monitored overnight. The nurse left instructions that Mr. Topey be transferred to hospital if his condition deteriorated. At that time the nursing staff went home at 11pm.

During the suicide watch early on August 3, a correctional officer found Mr. Topey on the floor of his cell naked and curled up in a fetal position, visibly shaking with his eyes rolled back. Officers entered the cell to check on Mr. Topey and found that he had forehead injuries. Mr. Topey was placed on his mattress and covered with a blanket. The supervisor arrived and called for the assistance of another correctional officer who had been an RPN.

An ambulance was called and the paramedics arrived at about 0145. Although it is policy for a patient to be taken to the closest hospital, in this case, the Milton site, Mr. Topey was taken to the Oakville Trafalgar site of Halton Healthcare Services, where he could receive a CT scan.

Mr. Topey was admitted to hospital at the Oakville Trafalgar site. He was seen by an emergency physician and a neurologist and admitted under a family physician. The neurologist asked for records from Maplehurst to be faxed to Oakville Trafalgar. She reviewed these records on August 5 when she came to read the EEG that she had ordered. She then made a request for old records from the Hospital for Sick Children (HSC) and St. Michael's Hospital. These records arrived on August 6. On August 7, Mr. Topey was started on emergency dialysis and arrangements were made to have sodium benzoate and citrulline sent from HSC to Oakville Trafalgar Hospital.

Despite dialysis with reduction in ammonium levels, Mr. Topey's neurological status did not improve so he was transferred to McMaster University Medical Centre (MUMC) on August 8. He was treated aggressively at MUMC but did not respond and was found to be brain dead. With the agreement of the family, life support was withdrawn and Mr. Topey died.

Contact

The "Coroner's Jury Verdict & Recommendations" highlights inquests of interest to hospitals. These inquests either relate to deaths in hospital or the coroner's jury, in these inquests, have made recommendations directed at hospitals. Although coroner's jury recommendations are not legally binding, hospitals may wish to review and consider them, as may be appropriate. For further details or a full copy of the verdict, please contact Cyrelle Muskat at (416) 205-1378 or cmuskat@oha.com.