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NEWS RELEASE

Epilepsy Care in Ontario Reaching a Turning Point

Health Quality Ontario Commends the Province and Medical Community for Improving Access to Care

Toronto, ON, March 28, 2014 - Health Quality Ontario (HQO) welcomes the province's <u>March</u> <u>28 announcement</u> that it is taking action to increase services and reduce wait times for the people in Ontario who suffer from the debilitating effects of epilepsy.

"Children and adults with epilepsy and their loved ones experience a huge medical, social and economic burden," says Dr. Joshua Tepper, President and CEO of HQO. "We commend the province of Ontario for acting on the recommendations of our Ontario Health Technology Advisory Committee (OHTAC) Expert Panel on a Provincial Strategy for Epilepsy Care and improving access to the highly specialized medical interventions that are required to treat and manage epilepsy."

Research initiated by HQO led to the discovery that Ontario epilepsy patients faced significant gaps in care. In particular, many were missing out on a potentially life-changing surgery.

Michael Kennedy had successful epilepsy surgery in January, 2013, and has been living seizure-free since his operation. Kennedy's seizures were increasing in frequency and severity during the preceding years and his quality of life suffered drastically.

"Undergoing epilepsy surgery was one of the best decisions I've ever made," he says. "To date, my surgery has been a huge success. I feel like I'm regaining my identity and much of the confidence I lost when seizures dictated my activities and played such a significant role in everyday life."

Despite the potential benefits of surgery for a significant portion of patients with epilepsy, awareness of this treatment option is not widespread and is rarely initiated. In fact, HQO's research showed Ontario patients faced wait times of over a year to get the diagnostic testing to determine their eligibility for surgery, and only about two percent of surgical candidates received the procedure.

In response to this need, HQO took action on a number of fronts, including:

- Conducting further evidence-based analyses and commissioning a field evaluation by the <u>Programs for Assessment of Technology in Health (PATH) Research Institute</u> at St. Joseph's Healthcare Hamilton and the <u>Centre for Brain and Mental Health</u> at The Hospital for Sick Children (SickKids) in Toronto
- Forming a Provincial Epilepsy Strategy Working Group, co-Chaired by Dr. O. Carter Snead, a staff neurologist at SickKids and the late Dr. William Shragge, who was Chair of OHTAC at the time. The working group was a remarkable collaboration of child and adult medical services, with representatives of adult and pediatric neurology from all epilepsy centres in Ontario.

"This comprehensive, evidence-based work has allowed us to break down silos," says Dr. Snead. "This was the first time in my 40-year career that I have been privileged to be involved in a project that covers the entire life span. Epilepsy does not respect the traditional pediatric/adult medicine and surgery silos we all live in and, in our report, neither do we."

Based on the findings of the working group, HQO created the OHTAC Expert Panel on a Provincial Strategy for Epilepsy Care. The panel, also co-chaired by Drs. Shragge and Snead, produced a report on the current state of care for drug-refractory epilepsy in Ontario that included a series of comprehensive, short- and long-term recommendations, with an immediate focus on increasing access to potentially curative surgery. HQO endorsed the report and urged the government to use it as a guide in developing a Provincial Strategy for Epilepsy Care in Ontario.

"Today's announcement by the Ministry of Health and Long-Term Care offers great hope - to the tens of thousands of Ontarians, and their families who suffer from the burden of epilepsy - for a comprehensive, evidence-based system of care," says Dr. Snead.

<u>Click here</u> to access HQO's research, reports and recommendations related to epilepsy.

FAST FACTS

- Approximately 70,000 Ontarians (adults and children) suffer from epilepsy and approximately 30% (21,000) continue to have seizures even when taking anti-seizure drugs.
- HQO's research found the majority of people (13,200 patients) whose epilepsy does not adequately respond to medication may benefit from surgical intervention, including having an 80 percent chance of becoming seizure-free.

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About HQO

Health Quality Ontario (HQO) is an arms-length agency of the Ontario government, mandated to evaluate the effectiveness of new health care technologies and services, report to the public on the quality of the health care system, support quality improvement activities and make evidence-based recommendations on health care funding. Visit <u>www.hgontario.ca</u> for more information.

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