



### **OCTC-CHEO Amalgamation Brings Concept of “One Door, One Story, One Chart” Closer to Reality**

“It’s quite the medical journey when you have a kid like Griff,” says Jennifer Walker, the mom of Griffin Walker, who recently passed away at the age of 11 from complications related to cerebral palsy. “But just because our kids are complex, doesn’t mean the health-care system has to be.”

Simplifying the system is one of the major reasons she is such an advocate for the upcoming amalgamation of the Children’s Hospital of Eastern Ontario (CHEO) and the Ottawa Children’s Treatment Centre (OCTC) – two of the largest pediatric health care providers in the region. As a parent advisor on the OCTC-CHEO Strategic Alliance Task Force, which oversaw a due diligence process to ensure there were no major obstacles to amalgamating, she sees many benefits.

“The outcome for Griffin would have been the same, but I can see how much better coordinated all those appointments and scheduling and communications between doctors could have been,” says Jennifer. “Having one organization instead of two would also have made it possible to have a single, coordinated path of care, versus two.”

#### **Griffin’s Journey**

Griffin, the eldest of Jennifer and Dan Walker’s three children, was born on March 18, 2004 at the Ottawa Hospital (Civic Campus) by emergency Caesarean after what had been a normal pregnancy, and spent 14 days in the neo-natal intensive care unit before heading home.

“Griffin had brain damage at birth and we knew he would have issues, but we weren’t quite sure what those would be,” says Jennifer.

Griffin was ultimately diagnosed with Level 5 cerebral palsy (CP), the most severe form of CP. He was unable to sit or hold his head up on his own and spent most waking hours in a wheelchair. He took many medications throughout the day, was fed through a gastrointestinal tube, had various reflux and digestive issues, had challenges with his eyesight, and was diapered.

“Griff would laugh and cry and could show you by facial expressions – like a grimace – how he was feeling, but we had no idea what was behind the expression,” says Jennifer.

Throughout his life, Griffin was seen by 18 physicians and 14 therapists – the bulk of them from CHEO and OCTC. For Jennifer and Dan it was sometimes a blur as to which physician or therapist was from which organization.

The journey began at CHEO, through the neonatal follow-up clinic several months after Griffin's birth. Present for that appointment was a developmental pediatrician from OCTC, who had been invited for a consult, and a neurologist from CHEO (who also operated at clinic at OCTC).

"Because of Griff's seizures at birth, Neurology was one of the first groups involved, and Neurology straddled OCTC and CHEO," she explains. "So sometimes we'd go to CHEO to see the neurologist and sometimes to OCTC."

Feeding also highlighted for Jennifer the overlap of services provided by CHEO and OCTC.

"Feeding can be very complicated for kids like Griff. He could eat pureed foods orally – and he breastfed as an infant – but he was diagnosed as 'failure to thrive' because he couldn't put weight on. It took us so long to feed him that he just couldn't get enough calories into his body."

His occupational therapist and dietician at OCTC referred Griffin to CHEO to determine if he'd be a candidate for a gastrointestinal tube – a tube surgically inserted into the stomach so liquid nutrients could be fed directly into his body.

"So you have your regular occupational therapist and dietician from OCTC, who know Griff so well, but now we're in CHEO, and we are seeing different therapists and dieticians who are part of CHEO's medical feeding team – Griffin's new team. So you are straddling both worlds. And when you are released from CHEO, you continue to be followed through the outpatient clinic at CHEO, at the same time that you continue to see your OCTC people."

Jennifer is convinced that by amalgamating CHEO and OCTC, children, youth, and families will have clearer and easier access to services and more seamless and coordinated care. What she is particularly excited about is the concept of "one door, one story, one chart".

"When you have a child with complex needs, it can be very challenging to understand and navigate the health system and coordinate services for your child. It becomes even more confusing when some appointments are at CHEO and some are at OCTC, when CHEO physicians have clinics in OCTC, and when you get referred by OCTC to CHEO doctors and vice versa. It's great that they have such a strong relationship, but in reality they are still two separate organizations, with two different administrations and processes and each with a separate health record about your child. As the parent, you are trying to keep it all together, but you are never sure who might be missing what information about your child."

Throughout his life, Griffin continued to be supported by both organizations – CHEO predominantly for two surgeries and various clinics (including Neurology and Ophthalmology), and OCTC on the developmental side, for such things as physical therapy, occupational therapy, speech therapy, dietary needs, seating and mobility. He also attended the OCTC preschool and later a community school with a special needs program.

In addition to her role on the OCTC-CHEO Strategic Alliance Task Force, Jennifer is also the co-chair of the Joint Advisory Group, made up of family representatives from Roger's House, Rotary Home, OCTC and the Complex Care program at CHEO. She also sits as a parent advisor on a number of committees, including the Roger's House Family Advisory Committee, the Ontario Association of Children's Rehabilitation Centres (OACRS) Provincial Family Advisory Committee and the Ministry of Health and Long-Term Care's Patient and Family Advisory Table.