Making An Impact

The year 2012 marks the 25th Anniversary of the Ontario Brain Injury Association making a difference in the lives of those impacted by an acquired brain injury.

For many, OBIA has provided support and advocacy in such a way that it is a “guiding light” and has helped navigate the journey of rebuilding a life after brain injury.

As one mother of a survivor explains, it is not only about surviving a brain injury — it is about thriving with brain injury!
OBIA: A Snapshot of the past 25 Years

This year officially marks a milestone in OBIA’s history as we celebrate 25 years of supporting survivors and their families. The establishment of OBIA began when several determined families whose loved ones lives had been devastated by acquired brain injuries (ABI) came together to form what is now the Ontario Brain Injury Association (OBIA). In the early 1980’s there was little support in Ontario for those whose lives had been impacted by brain injury. Our founders personally experienced the gaps that existed in our health care, community and social services system and set out to bring this to the attention of the powers that be.

One of their main goals was to create a sense of awareness in the public and within the government of the need to provide services for those who have sustained a brain injury. That purpose remains at the heart of OBIA’s mission today. Over the years OBIA has grown and changed and this is due to the hard work and dedication of many involved. OBIA has been fortunate to have a number of dedicated staff that have been steadfastly committed to the founders’ vision of supporting survivors and family members. Some members of our staff were at OBIA for over 10 years, and some over 20 years. I would like to give special thanks to John Kumpf (who served as the Executive Director for twelve years), Dianne Radunsky, Jennifer Norquay, and the late Debbie Spaulding. When OBIA held public hearings on Bill 59 and when OBIA organized the highly successful 2011 conference attracted over 600 people – making it the largest ABI conference in Canada.

In addition, OBIA has partnered with local community association’s to host three major biennial provincial conferences. Most recently, the highly successful 2011 conference attracted over 600 participants – making it the largest ABI conference in Canada.

At the core of OBIA’s work is supporting ABI survivors and their families. The establishment of a support services department along with a 1-800 toll free line has been in operation since OBIA’s inception. In addition, the organization has been a leader in providing advocacy to survivors and family members with income support programs, discharge from hospitals, and finding appropriate placement for those with ABI. It also has worked with local associations in connecting survivors from across the province to them.

We could not have done it without you!

In recent years, OBIA created a staff role of Community Association Liaison, who works alongside the 21 affiliated local community associations across the province. OBIA collaborates on numerous projects with the affiliated community associations including a province-wide peer support mentoring program. While this only provides the highlights of the past 25 years with OBIA. It helps capture a snapshot of a successful quarter century. On behalf of OBIA I also want to thank our many partners who have supported us over the years.

We could not have done it without you!
It was a moment that changed his life forever.

That summer day in August 1980 started with Ray Rempel getting ready to celebrate his son’s birthday party. It quickly turned to tragedy when he turned onto Townline Road in rural Niagara-on-the-Lake and saw there had been a motor vehicle accident.

His young son, Jeremy, had been out riding his bicycle and was struck by a pick-up truck. “He was taken to the hospital and the next couple of weeks he was in coma. They actually induced him into a deeper coma and eventually had to remove a portion of his skull and forehead to allow the swelling to take its course.”

After Jeremy was finally released from the hospital, he spent time at home recovering. His eyes were open, his lower body was paralyzed, and he only showed minimal responses. The harsh realities that accompany brain injury were unexplored territory by the Rempel family, but something that would become all too familiar.

Over the next few years, Jeremy slowly began to recapture his movement and speech. He also spent time at the Niagara Peninsula Children’s Centre and eventually took up wheelchair road racing.

In those early years, Jeremy excelled at sports. He competed at the provincial, national and international levels, including the Paralympics, and went on to become a world record holder and wheelchair road racing champion.

Jeremy’s response was quite well. Lori Simpson, who has a brain injury, eventually got married. They now have two boys, ages 15 and 17, and the family lives happily in Niagara Falls.

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“Were we didn’t know what to do and neither did the healthcare professionals in the area,” explained Ray. “At that time nobody in Canada was talking about cognitive therapy.”

After getting together with half a dozen other families in the area, Ray and Elsie co-founded the Head Injury Association of Niagara. In the midst of their research the couple also came to learn that Beverley Mantell, a mother of a child with an ABI, had formed a group in Ottawa that provided support to parents who found themselves in similar situations. This discovery would be key as the Rempel’s and Mantell eventually co-founded, what is known today as, the Ontario Brain Injury Association.

As their network grew, associations began to spring up in other parts of the province.

Ray was even invited by doctors to speak at medical conferences to share his perspective on what it is like for the parents of a child who has a brain injury. It was at one of those conferences where he connected with experts like Dr. Peter Eames and Dr. Roger Wood, who were carrying out ABI research in England.

At the time, Ray was in the insurance business, but had to give it up. He wanted to devote more time toward the creation of a provincial head injury association because the harsh realities of what to do and neither did the healthcare professionals in the area, “explained Ray. “At that time nobody in Canada was talking about cognitive therapy.”

Ray served as executive director of the organization from 1986 until September of 1993. While significant advances have been made since those early years, Ray said much still needs to be done to protect the interests of those whose lives have been impacted by an acquired brain injury. And, for many OBIA will continue to be that unifying voice.
Initiated Status of Wellness Public Hearings which led to a dramatic increase in funding for people with traumatic brain injury in Ontario.

Get This Through Your Thin Skull poster developed.

ABI Directory of Services developed.

Selected by the Ministry of Community and Social Services to conduct the North Eastern Research Project.

Building a Lifetime of Growth Conference co-sponsored with Chedoke McMaster Hospital.

Participated in prevention projects Drive Sober, Wear Helmets and Wear Seatbelts.

Influenced the drafting of Bill 68 No Fault Auto Insurance Plan.

Developed Procite database of brain injury related articles.

Project Head Gear was developed including the Heads Up activity booklet.

5 Years

Darryl Sittler and Jeremy Rempel
Participated in ComaCon 92 - a conference examining research and innovations in coma treatment

Assisted in the development of the Canadian Head Injury Coalition

Actively worked to influence legislation on: Bicycle Helmet Private Members Bill, Bill 108-Substitute Decisions Act, Bill 109-Consent to Treatment Act, Bill 74-Advocacy Act

Bonehead awareness campaign developed

Co-chair and facilitator by appointment of the Minister of Health of the Task Force on the Continuum of Opportunity to develop a model system for services in Ontario

Established Resource Library
  • Shaken Baby Syndrome Awareness Program

Hearings held and Report Card on the 1989 Status of Wellness Hearings published

Jeremy Rempel inducted into the Terry Fox Hall of Fame

Brain Injury - the Perspective from the Other Side of the Looking Glass was published

Worked towards the repatriation of ABI survivors from treatment facilities in the US.
Guidelines for Return to Play after Concussion developed

Publication of research papers and articles based on OBIA Training Programs

Research Organization to form the Ontario Neurotrauma Foundation (ONF) Partnered with Rick Hansen Institute, Ontario Neurotrauma Initiative, Canadian Paraplegic Association and the Spinal

Received ONF Grant to develop educational materials to promote Return to Play Guidelines

Partnered with the Canadian Hockey Association to refine Return to Play Guidelines

Held public hearing on Bill 59 and published the report entitled Adding Insult to Injury

Participated in Ministry of Health ABI Committees

Received approval for ONF Educating Educators Project

Return to Play guidelines adopted by International Ice Hockey Federation and International Olympic Committee

Participated in revisions to Form 1 for Attendant Care and redefinition of the term catastrophic

Remember Me awareness campaign conceived, developed and successfully launched during June, Brain Injury Awareness Month

Received a Trillium Grant for $109,500 to develop the strategic Plan and the fund development plan

Responded to a request from the Ministry of Finance for recommendations for modifications to Bill 59, the legislation that governs automobile insurance in Ontario Brain Injury Association
The Fund Development Committee hosted a fundraising event at the Famous PEOPLE Players theatre in Toronto which netted over $14,000.

Was awarded a grant by the Ontario Neurotrauma Foundation (ONF) to research Best Practices in the delivery of programs and services in acquired brain injury. This will provide feedback on structure, governance, programs, services, and resource development for not-for-profit brain injury associations, as well as investigating potential models and relationships between local, provincial, and national levels of organization.

Approved a revised mission statement for OBIA, to enhance the lives of Ontarians living with the effects of acquired brain injury through education, awareness, and support.

Received approval of funding through the Ontario Trillium Foundation for $360,000 over two years. Outcomes of this funding will be: the design and implementation of a new membership program; updated sustainability plan for OBIA; development of 4 new community associations (Toronto, Thunder Bay, North Bay and Kingston).

Ms. Hayman left a $375,000 legacy to OBIA to be used to provide training and education in the assessment and treatment of persons with acquired brain injury.

The manual for teachers entitled Educating Educators about ABI, co-authored by Drs. Dawn Good and Sheila Bennett from Brock University and OBIA’s Executive Director, John Kumpf was published. The book has raised the profile of ABI in schools and resulted in the writing team putting on numerous workshops for regional special education conferences, individual boards and individual school staffs.

The Ministry of Health and Long Term Care granted $266,000 to fund the first year of the Peer Mentoring Support Program.

The Ontario Neurotrauma Foundation offered to fund an independent evaluation of the Peer Mentoring Support Program.
The Canadian Association of Occupational Therapists awarded OBIA with the Provincial Territorial Citation Award.

October saw the launch of the biennial Provincial Acquired Brain Injury Conference which was a project of OBIA, the Brain Injury Association of Waterloo-Wellington (BIAWW) and the CSN. The conference was sold out with 368 delegates in attendance. The conference netted over $68,000. These monies were divided between OBIA, BIAWW and 9 participating community associations.

OBIA became an intricate part of the Alliance for Action on Brain Injury which was funded by ONF. The Alliance’s mandate was to create public awareness as well as gaining the attention of the Government. Leadership and expertise was provided by a public relations firm, PR Post which did an excellent job of articulating the key messages and putting them in front of the public in four public service announcements and a website. PR Post then orchestrated a provincial media tour which included members of the Alliance accompanied by a local person living with the effects of ABI. In each city the media bought into the message and in some cases did follow up pieces.

The Dual Membership Program and the Online Directory of Services were launched. Gluckstein & Associates, Henderson Structured Settlements and James Wegg & Associates were the exclusive development sponsors of the projects.

The new level one program Neurorehabilitation: Assisting Recovery and Function in Everyday Life Following Brain Injury was launched in St. Catharines with 125 in attendance. A second program was held in Winnipeg, Manitoba with another 105 attending.

Two more community associations were added to the Community Support Network. 12+ community associations are now involved with the Peer Support Mentoring Program.
Jeremy Rempel is a thankful man. He has a wife, two children, a good job and a close group of family and friends who really care about him.

Speaking to him on the telephone, one has no idea he has a disability. He is well spoken, articulate and has no problems getting across his thoughts or points of view.

When Jeremy was nine, he was riding his bicycle and was involved in a motor vehicle accident that left him with a brain injury.

“I wasn’t wearing a bike helmet,” recalled Jeremy, who is now 41 and lives in Niagara Falls with his wife, Lori, and their two teenage boys ages 15 and 17.

“Back then no one really knew the importance of helmets and how they can really change your life if you wear one.”

After coming out of coma, it was a slow road to recovery spending months in hospital. There was a time he could not speak and was paralyzed from the neck down. He was bedridden for months.

“After an accident like that, your brain and your body have gone through so much trauma you don’t remember very much and you are just lucky to be alive. I don’t remember any details and only know what people have told me over the years.”

Slowly, Jeremy was able to relearn and recapture much of what he knew and could do before his accident.

“I was athletic even before I was injured so I had that base to work on. My parents thought it would be a good idea if I got involved in sports as part of my rehabilitation,” said Jeremy.

When he was in high school sports and athletics became an important part of his life. He started with wheelchair basketball and swimming, but his interest was more in track and field.

Lori Simpson became his trainer and coach and soon he was on his way to becoming an elite athlete and a wheelchair sprinter. He represented Canada in Europe and throughout North America.

“Athletics really played an important role in my life because that’s how I got all my world records and met a lot of people that became close to me and good friends, but most of all that’s how I met my wife Lori. Everything I have in my life I owe to sports.”

Jeremy said they started dating and finally he got the courage to go out and buy a ring.

“I asked her to marry me and she said yes.” They were married on Aug. 8, 1992.

“We have two lovely boys, one is 17 and the other is 15, and my life is great. I work for a company called Anagram Rehabilitation Community on Line 1 in Virgil that my father used to own and I work in one of the houses as a rehab educator. I’ve been working there since our second son, Jacob, was born about 15 years ago.”

On a typical day, Jeremy gets up about 8 a.m., showers and gets ready for work. He works from 10 a.m. to 4 p.m. and then returns home to spend time with his family.

Lori said the one thing that stands out about her husband is that he never gives up.

“When he used to train and I would push him to do stuff, he would never say no and he would just keep trying and that’s why he did as well as he did. He had an attitude that he would get the job done.”

Lori said the two of them have had a good life, and while they’ve had ups and downs like any other relationship, they’ve always been able to get through the more difficult times and work as a team.

“I have always worked with disabled people so I know we could manage it and that we would be OK.”

In his work with disabled individuals who all have brain injuries, Jeremy said he knows what they are going through because he has been there himself. He tries to keep them motivated and show them by example that things can get better.

“I know it can be frustrating for them at times because they don’t know what to do or how to do it. It can be really difficult and very depressing at times and I try and tell them what they have to do to get through it.

“As you keep taking those steps forward, hopefully it starts to get easier and you can keep moving forward and make improvements,” said Jeremy.
Many thanks to all of our community partners, legal professionals, and service providers across Ontario who have helped us over the years.

Your tremendous support has been invaluable.

With special Thanks to

Ontario Brain Injury Association
Belleville
BIA of Quinte District
Branford & District
Brantford & District BIA
Chatham
BIA of Chatham Kent
Dufferin County
Headwaters ABI Group (HABI)
Durham Region
BIA of Durham Region
Fort Erie
HIA of Fort Erie and District
Hamilton-Wentworth
Hamilton BIA
London and Region
BIA of London and Region
Niagara Area
BIA of Niagara
North Bay Area
BIA of North Bay and Area
Ottawa Area
BIA of Ottawa Valley

Peel-Halton
BIA of Peel & Halton
Peterborough Area
Four Counties BIA
Sarnia-Lambton
BIA of Sarnia-Lambton
Sault Ste. Marie
BIA of Sault Ste. Marie & District
Sudbury and District
BIA of Sudbury & District Branch
Thunder Bay
BIA Thunder Bay & Area
Timmins
Brain and Seizure Association
Toronto (GTA)
Brain Injury Society of Toronto
Waterloo-Wellington
BIA of Waterloo-Wellington
Windsor-Essex
BIA of Windsor and Essex County
York Region
York Region Brain Injury Support Group