

NeuroMatters

Connecting YOU to the Research

The Best of Three

A study to find out which drug is most effective for people with an overactive bladder

The very first issue of NeuroMatters reported on the recommendations of an international panel of urological experts on gaps and future areas of research in urological care. Ontario Neurotrauma Foundation has now begun to follow up on some promising areas of research recommended by that panel.

The panel recommended more research into the safety and effectiveness of Muscarinic (M3) receptor drugs for those people with spinal cord injuries who have neurogenic detrusor overactivity, more commonly known as "overactive bladder". Many researchers believe that M3 receptors are responsible for contractions in the bladder muscle, and that M3 receptor-specific drugs could effectively treat people with this condition. So in 2007, work began on a comparative study of the effectiveness and safety of three drugs for overactive bladder management.

But first, a little background ...

What is a "receptor"?

A cell "receptor" is like a listening device that is waiting to hear nerve signals; it detects incoming signals in a cell. Sometimes injury or disease can confuse the signal: a receptor might receive an unnecessary or unwanted signal. For example, a contraction of the muscle in a bladder wall might make someone feel that they need to urinate.

Drugs can target the receptor and change what happens in the body. Some drugs are not specific and therefore change many different functions of the body – that is, they cause side effects. Other drugs target a specific area or function, and have few side effects. To use an analogy, you could communicate a message by opening your front door and yelling your message to the wide world; your message would get out, but not effectively. Or you could pick up your telephone, dial the correct number, and connect with a targeted individual.



IN THIS ISSUE

- 1 The Best of Three
- 2 Ontario Neurological Strategy
- 3 ERABI
- 4 ASIA Conference
- 5 No Flying Under the Radar
- 7 Upcoming Events
- 8 Harnessing the Power



What do we know about drug treatment?

Receptor have been targeted for the treatment of overactive bladders for several decades. Since the 1960s, the most commonly used drug to treat overactive bladders in people with spinal cord injuries is Oxybutynin Chloride, also known as Uromax®. This drug works on the bladder's muscle wall to lessen spasms and reduce pain. The drug also affects the muscle that eliminates urine from the bladder by making its contractions weaker. Side effects of this drug include: dry mouth, constipation, sleepiness, and blurred vision. This drug also affects the brain and therefore has cognitive risks.

New drugs have been developed in the last few years to help people with an overactive bladder including Darifenacin

...continued from page 1

Hydrobromide (Enablex®) and Trospium Chloride (Trosec®). These drugs target M3 receptors. Both appear to have fewer side effects than Oxybutynin Chloride.

Until now, no studies have been done with people with spinal cord injuries using these drugs.

About the study...

In a study funded by Ontario Neurotrauma Foundation and led by Dr. Magdy Hassouna, researchers are testing and comparing the safety and effectiveness of Darifenacin Hydrobromide, Trospium Chloride and Oxybutynin Chloride. Researchers hope to better understand which drug works best for people with spinal cord injuries.

The study is taking place at Lyndhurst Centre in Toronto and at Kingston General Hospital. Up to 84

adults with a spinal cord injury will be part of the study.

Each participant will get 105 capsules over 52 days. All capsules used will look the same and have a secret code. Participants will take a capsule in the morning and in the evening at approximately the same time of day. Neither the researchers nor the participants will know which of the three drugs each participant is getting. The codes for the drugs will be kept secret until the end of the trial.

During the four-month study, the participants will come to the study site once a month to have their health monitored (e.g. urodynamic test, blood test, urine culture test, and renal ultrasound). A research doctor will examine them. The participants will keep a urination diary, and they will complete a monthly survey about their health.

Evaluation

The evaluation of the effectiveness of the drug will be based on the number of bladder accidents and episodes of incontinence, and the extent to which participants need to urinate frequently.

The evaluation of the safety of the drugs will be based on:

- participants' reports of the effects they are experiencing from the drug
- a physical exam of participants
- lab tests

When the results are assessed, there will hopefully be a better picture as to which of the three drugs is best for those people with spinal cord injuries who are experiencing an overactive bladder. The study will continue until June, 2011.

Ontario Neurological Strategy

Did you know that there are over one thousand different diseases and injuries that can affect the brain, the spinal cord and the nervous system? Today, over one million Ontarians live with one or more of these "neurological" conditions. It is likely that one in three Canadians will be affected by at least one of these conditions at some point in their lives. For this reason, it is important for leaders in the neurological field to determine the best way to help people with neurological conditions – now and in the future.

Neurological Health Charities Canada (NHCC) is an umbrella organization that started just over a year ago. It consists of 12 charities that serve people with some form of neurological condition. The charities believe that, by working together, they have a better chance of

improving the lives of the people they serve.

Eight months ago, NHCC and the Health System Strategy Division of the Ontario Ministry of Health and Long-Term Care developed a Joint Working Group chaired by Kent Bassett-Spiers, the CEO of Ontario Neurotrauma Foundation. The group is looking into issues (such as primary care, housing and transportation) that are common to all people with neurological conditions.

The goal of the Group is to provide recommendations that will improve the health and quality of life of the people they serve. In turn, by improving the way services are delivered, the hope is that these changes will also save tax dollars, improve the economy, and get people back to work as soon as possible.

The group is looking for creative



suggestions on how to:

- better utilize existing programmes and services
- develop new ways of reaching people
- find ways to better use scarce financial resources

The Joint Working Group is consulting with key stakeholders, including consumer representatives from the NHCC membership, to gain input and advice. The group will gather the information and then make recommendations to the Ministry in February and March 2010.

ERABI

A website of information on Rehabilitation for ABI healthcare professionals... and soon for people with ABI, too

Let's say you hear through the grapevine about some new kind of treatment for people with an acquired brain injury (ABI). You want to know a little more about the treatment before you talk to your doctor, so you try googling the name of the therapy. But the search results point to articles that are long, technical and pay-for-access. You sigh, and say to yourself: "Wouldn't it be great if I could get online access to brief, user-friendly information on this treatment?" Well, one day in the very near future, people with ABI will be able to get that kind of basic information – by pointing their browsers to www.abiebr.com and accessing the ERABI website.

What is ERABI?

ERABI stands for "Evidence-Based Review of Moderate to Severe Acquired Brain Injury". Created five years ago by ABI rehabilitation researchers and healthcare professionals in London, Toronto and Ottawa, ERABI is a comprehensive online collection of reviews of medical literature on ABI rehabilitation. Geared towards ABI healthcare professionals, ERABI is updated regularly; the latest version (the fifth!) has just been released on the website.

ERABI was designed to identify areas of research where there is a base of research evidence, so that it can be shared with healthcare professionals and be used to improve treatment for and care of people with ABI. But it was also designed to identify areas of research that had limited evidence-based information, so that researchers could focus on these areas and develop new knowledge. ERABI has grown because new studies have emerged as researchers focused on the gaps identified in earlier versions.

What's in ERABI?

The project team has looked at 25,000 titles in medical databases for evidence-based research on ABI for possible inclusion in ERABI. To date, 651 titles have been

reviewed, written up and summarized in ERABI. It is updated on an annual basis.

To be included in ERABI, an article had to be about rehabilitation therapy for moderate to severe ABI, and at least 50% of the study's participants (minimum of 3) had to have an ABI.

These reviews are organized into 18 modules or subject areas – community rehabilitation, communication, medication, challenging behaviour, and sleep disorders, to name a few.

ERABI provides:

- up-to-date reviews
- best practices
- specific conclusions

Each ERABI module offers:

- an introductory paragraph on the topic
- a summary of key points about a group of treatments
- guidelines and recommendations
- a listing and careful systematic review of individual studies with scientific quality ratings
- a discussion of these studies
- conclusion which provide levels of evidence for each treatment

Why ERABI?

While it is true that healthcare professionals look for the best possible treatment for people with ABI,



Evidence-Based Review of Moderate to Severe Acquired Brain Injury

5th Edition

Executive Summary

The ERABI Research Group

they do not always have the time to keep up with the latest research in rehabilitation treatment. The ERABI project team felt that there was a way to provide an easy solution to the time problem: make the information more accessible by collecting the reviews of the research and then putting them in one place. By bringing together the useful literature on ABI rehabilitation for front-line healthcare professionals, ERABI increases the knowledge transfer from research to clinical practice, thereby improving treatment and care for people with ABI.

Before ERABI, a healthcare professional could spend a lot of time finding and reading articles on a topic. Because of ERABI, this exercise takes much less time.

ERABI ... in the near future

ERABI was originally designed – and written in – highly technical medical language, for front-line ABI healthcare professionals. It will continue to serve this audience. However, the ERABI project team is also going to make the information more user-friendly for a broader range of healthcare professionals, as well as for people with ABI – and their friends and family – who may also want to access this resource.

...continued on page 4

ERABI...

- is funded by the Ontario Neurotrauma Foundation (ONF)
- is a joint effort of researchers and healthcare professionals from the Departments of Physical Medicine and Rehabilitation at St. Joseph's Health Care (London), the Toronto Rehabilitation Institute (Toronto), and The Rehabilitation Centre (Ottawa)
- is a collection of current, evidence-based research in the field of rehabilitation for people with ABI
- facilitates best practices in rehabilitation for people with ABI
- helps healthcare professionals to direct the care of people with ABI

...continued from page 3

But a few changes have to take place first, in order to make it more accessible for the general public.

Many people with ABI and even some rehabilitation therapists, have found it challenging, time-consuming and frustrating to wade through the jargon used in ERABI. Therefore, the first change implemented will be to have three-page summaries of each module. "The language will be less technical," says Mark Gibson, a social worker specializing in ABI at Parkwood Hospital (London) and a member of the consulting group hired to work on the summaries. Gibson thinks that the summaries will offer a "higher level" of information on ABI than a general overview brochure does, and therefore they will be useful to people with ABI and to other rehabilitation professionals.

The second change will be the creation of a function that allows website visitors to search through all of the information in all of the modules. (Right now, searches can be done only on information within

a single module.)

The original plan was to write one summary for each of the 18 modules, but the consulting group is giving some thought to grouping related topics.

When the new summaries become available on the ERABI website (www.abiebr.com) by March, 2010, ERABI will then offer three distinct levels of information:

1. the summaries
2. the modules containing reviews of the research articles
3. a list of the research articles

ERABI will also be offering educational/teaching modules for each chapter as well as 15 case studies of simulated patients with brain injuries. Website visitors will be able to test their knowledge against best evidence in a "real-life" scenario.

The next time you want to look into the latest approaches to rehabilitation and ABI, point your browser to www.abiebr.com and give ERABI a try. Mention it to your health care professionals too.

Conference Notes 1

American Spinal Injury Association (ASIA) Conference

The joint conference of the American Spinal Injury Association, the American Association of Spinal Cord Injury Psychologists and Social Workers, the Paralyzed Veterans of America, and the American Paraplegic Society was held September 23-26, 2009 in Dallas, Texas. Almost 1,000 researchers, clinicians, consumers, and caregivers shared the current

status of research, clinical practices and management for spinal cord injury at this annual conference.

There were poster and podium presentations, workshops, and gala dinners where opportunities arose for informal exchange of ideas, for building relationships, and for future collaborative research, both nationally and internationally.

Tara Jeji, SCI Program Director

at ONF, did a presentation on 'Parenting Stories' – stories by parents with spinal cord injuries about the joys and challenges of raising children.

For future ASIA meetings and other SCI resources, see: <http://www.asia-spinalinjury.org/>

No Flying Under the Radar

Reporting on the evaluation of the Spinal Cord Injury Pilot Project

Some history:

When people sustain a spinal cord injury (SCI), receive rehabilitation for that injury, and eventually reintegrate into the community, they need someone who knows the “system”. They need someone who can wade through processes, policies and procedures to get them what they need – someone who can help communicate their health issues, work around or remove barriers, and assist them to get back to their life activities.

For over 25 years, the Canadian Paraplegic Association (CPA) Ontario has been providing this navigation service through their Regional Services Coordinators. The demand for this service was high, and the service was not able to address some hospital-related issues. Therefore, several years ago, Hamilton Health Sciences (HHS) partnered with CPA Ontario on a project that would bring the role of the Regional Services Coordinator into the hospital setting so that people who are newly injured could better connect to this navigation service and other CPA Ontario services; these “navigators” would be integrated into the healthcare team. Through the determined work of both organizations and funding from Ontario Neurotrauma Foundation, and Rick Hansen SCI Solutions Network, the Spinal Cord Injury Pilot Project was born in September, 2007.

What is the SCI Pilot Project?

The Spinal Cord Injury Pilot Project has three components: the newly injured clients, the SCI Pilots, and the Regional SCI Solutions Alliance.

Like the Regional Services Coordinators, the SCI Pilots are navigators; additionally, the SCI Pilots are members of the health

care team in the hospital setting. They work with clients – from the time of injury, through rehabilitation to living in the community. They help their clients to recover by facilitating relationships and connections. They connect their clients to relevant resources in the hospital and the community, as well as to people who can help the clients achieve their individualized goals. The SCI Pilots have an SCI, so along with their professional expertise, they have personal insights into the needs of those who are newly injured and of those who have been living with SCI for years.

Funded by the Rick Hansen Spinal Cord Injury Solutions Network, the Regional SCI Solutions Alliance consists of local decision-makers representing a broad range of health and social service agencies, as well as researchers and funders. It is a resource for SCI Pilots to use when they run into barriers that they cannot deal with on their own. The Alliance also advocates for systemic change. The Alliance fits into a provincial and national network of community leaders dedicated to removing barriers for people with SCI.

The primary goal of the SCI Pilot Project is to support people with SCI and their families in order to overcome existing barriers and to gain the skills and knowledge needed to successfully manage their recovery. HHS and CPA Ontario want the project to enhance clients'

- independence
- empowerment
- satisfaction
- smooth transitions from hospital to community
- goal attainment

The Regional SCI Solutions Alliance, which addresses systemic barriers at the request of the SCI Pilots for their clients, has four specific target areas:

- access to timely and informed primary care doctors
- access to accessible regional transportation
- availability of adequate and trained attendant services
- affordable accessible housing

In February, 2008 HHS and CPA Ontario decided to have the SCI Pilot Project evaluated to ensure that the project's goals were being met and that the services were meeting the original expectations. The Ontario Neurotrauma Foundation (ONF) agreed to fund the evaluation.

Evaluation:

The purpose of the evaluation was to understand the SCI Pilot “navigator” process, and to inform HHS and CPA Ontario administrators, the SCI Pilots, and the Regional SCI Solutions Alliance how to:

- make project improvements
- achieve project goals
- identify unintended outcomes
- select and prioritize project outcomes

Led by P. Lina Santaguida and Jeff Jutai, an external evaluation team from McMaster University Evidence Based Practice Centre used a multi-pronged approach – such as online surveys, interviews and focus groups – to evaluate the project. They asked SCI Pilots, Regional SCI Solutions Alliance members, healthcare team members, and SCI clients about successes and gaps in expectations, services, efficiency, and effectiveness of the SCI Pilot Project.

...continued on page 6

...continued from page 5

Challenges faced by the evaluation team:

Researchers found it challenging to connect with clients willing to talk about the project for several reasons. They were recruiting during the summer months and had a fairly short turn-around time for the evaluation. In addition, ethics approval required that initial contact with clients come from the SCI Pilots or other members of the healthcare team.

In the end, the following people participated in the evaluation:

- Out of 20 potential client participants, 13 completed the survey, and four of them were interviewed.
- Out of 29 potential healthcare worker participants, 25 completed the survey, and four of them were interviewed.
- Out of 25 Regional SCI Solutions Alliance member participants, 8 completed the survey.

Research findings:

The evaluation report showed that clients who had actually received services from a SCI Pilot were not generally aware of the term “SCI Pilot” or “SCI Pilot Project”, and that some clients were unclear about the services that SCI Pilots provided. Some healthcare workers had the same uncertainty, even though half of them were familiar with the SCI Pilots – and worked with them occasionally. Add to this uncertainty the service overlap of several professions – such as Regional Services Coordinators, social workers and insurance case managers – and it is easy to see why the SCI Pilot’s role was unclear.

That being said, clients felt that their SCI Pilots provided more information than other professionals did. They felt that the

SCI Pilots made themselves readily available, and took the necessary time to explain the issues. Because the SCI Pilots had an SCI, the clients felt they had an emotional connection to them. Clients also noted that the SCI Pilots were easier to access than other healthcare providers. And the majority of the healthcare team respondents also noted that it would be helpful to have SCI Pilots assist them in activities such as discharge planning, information provision, translating medical reports, and assisting with communication between the family and the healthcare team.

In terms of outcomes, the SCI Pilots, the healthcare professionals and the clients indicated that they were unclear about the goals of the project. They had different views on the meaning of independence, empowerment and goal attainment. For example, SCI Pilots thought that independence meant successfully navigating the healthcare system; clients felt independence was related to the activities of daily living. Clients felt that having access to a SCI Pilot to provide resources and resolve issues was empowering; SCI Pilots felt they were empowering clients

by increasing self-sufficiency, by being an example, and by providing opportunities to improve problem solving for specific goals and tasks. And some healthcare team members described the SCI Pilots as advocates; they thought that the role of the SCI Pilots was to empower their clients through advocacy initiatives.

On goal setting, SCI Pilots were clear that client safety goals were the most important. However, prioritizing other goals was complicated and challenging. Developing client-centred goals, and realistic stages to reach them, was identified as a next step in project development. Clients did not realize that they could work with their SCI Pilots to develop a strategy to reach their own goals.

The evaluators found that the Regional SCI Solutions Alliance may not have yet met its full potential as it is still in the initial phase of development. They found that the Regional SCI Solutions Alliance members were sometimes confused about their role, and how to move forward to resolve barriers. As well, the evaluators found that the Alliance members were not always strategically positioned in the community to be able to effect change.

...continued on page 7

**TELL
a
FRIEND**

**each issue
is free**

* E-mail subscribers get special updates!

**Sign up online for your copy of the
NeuroMatters e-zine at:**
www.onf.org

Or if you are a consumer living in Ontario, contact ONF at: (416) 422-2228 to receive your copy by mail.

...continued from page 6

Recommendations:

The research team made the following recommendations for the project:

1. Each new client should receive an orientation package that contains a description of the role of the SCI Pilot, a list of answers to frequently asked questions, and contact information.
2. New Regional SCI Solutions Alliance members should receive an orientation package on the nature of their role and the SCI Pilot's role, as well as a list of answers to frequently asked questions.
3. Support staff should be hired to maintain client records, keep contact information up to date, and monitor changes in client status (whether the client is active or inactive).
4. Project goals should be better defined so that all stakeholders know what they are trying to achieve, and so that appropriate baseline and time intervals for measuring success are clear.
5. Goal expectations need to be discussed between the SCI Pilot and the client, and the client needs to be made aware of how to manage and obtain those expectations.
6. SCI Pilots should receive more training on setting, measuring and attaining goals. They should design goal attainment forms. Computer software for reviewing goal progress and for reporting results into the goal attainment forms would help the process.
7. The intake form should identify other healthcare professionals working with the client – especially in the area of goal setting – so that all professionals can offer the client the best possible service.

...clients felt
that their
SCI Pilots
provided
more information
than other
professionals did.

8. The Regional SCI Solutions Alliance should be made up of people who are in a position to make decisions that will enable system change; all Alliance members should know each other's skill-sets.
9. SCI Pilots and Regional SCI Solutions Alliance members should find better ways to share information about clients so that the right people attend the right meetings to effect meaningful change.
10. The Regional SCI Solutions Alliance members should let other key stakeholders know about their actions to remove barriers for clients. They should keep a record of successful and unsuccessful attempts for change so that there is case-based learning for current and future members.

With these recommendations and new insights, administrators would be in a better position to drive the SCI Pilot Project forward and maintain funding. Already, administrators have moved ahead and determined that the SCI Pilot role and Regional Service Coordinator role share similarities and should be integrated into a combined job description. These two jobs will be further clarified. By defining roles, improving communication and being specific about goal attainment, the project will continue to grow – and, ultimately, assist people with SCI to make decisions about their own lives.

Upcoming Events

Feb 4: CPA Ontario's KMS Series: *Secondary Health Complications – Aging with an SCI*. Wellness and health promotion to minimize the incidence of health complications. Toronto, ON. Info: <http://www.cpaont.org/event/toronto/secondary-health-complications-aging-sci>

February 5: Toronto Rehab presents *Mild Traumatic Brain Injury: Challenges and Controversy in Treatment*. Keynote presentation of ONF's Guidelines for the Care of MTBI and Associated Persistent Symptoms by Dr. Shawn Marshall. Toronto, ON. Info: <http://www.torontorehab.on.ca/education/mildbraininjury2010.html>

March 10-14: The International Brain Injury Assn's *Eighth World Congress on Brain Injury*. ONF will be attending and co-hosting a networking session. Washington, DC Info: <http://www.internationalbrain.org/?q=node/16>

March 29: CPA Ontario's KMS Series: *Topic to be determined*. Ottawa, ON. Info: 416-422-5644.

October 20-23: *The American Congress of Rehabilitative Medicine and the American Society of Neurorehabilitation's 2010 Annual Conference*. Focus on ABI and SCI. Montreal, QC. Info: <http://www.acrm.org/>.

October 28-30: Toronto Rehab presents: *Fourth National Spinal Injury Conference*. Niagara Falls, ON. Info: <http://www.torontorehab.on.ca/education/scic10/index.html>.

Conference Notes 2

by Debby Vigoda

Harnessing the Power After Brain Injury Conference



John Kumpf, Executive Director – OBIA
Ruth Wilcock, Assistant Executive Director – OBIA
Rob Burns, Board President – BIA of Niagara

What could compare with the awesome spectacle of Niagara Falls? The Provincial Acquired Brain Injury Conference, Harnessing the Power After Brain Injury, held in October, 2009 in Niagara Falls, was equal to the glory of the Falls. The conference was co-sponsored by the Ontario Brain Injury Association, the Brain Injury Association of Niagara, and the Community Support Network. The Ontario Neurotrauma Foundation was the Presenting Sponsor, and the “sold-out” sponsorships and exhibits provided support and information to the more than 550 people who registered.

Both keynote speakers, Abraham Sniderman, MD and Bryan Kolb, Ph. D., presented realistic but encouraging views to the audience. In his presentation “Whose life is it now? Cognitive and Emotional Issues after Brain Injury”, Dr. Sniderman dealt with the cognitive, behavioural and emotional consequences of brain injury from a neuropsychiatric point of view. In his presentation on “Harnessing the Power of Brain Plasticity to Stimulate Recovery

from Brain Injury”, Dr. Kolb offered many views on neuroplasticity (the brain’s way of figuring out new ways to send messages after injury), and his personal experience with a stroke.

The two featured speakers, Valerie Loughheed and Greg Golberg, were inspiring. Both sustained brain injuries, and both were role models in how to overcome a brain injury.

The 30 sessions of this two-day conference offered something for all attendees – brain injury survivors, caregivers, attendants, family members, healthcare professionals from all relevant fields, agency staff, faculty from universities and colleges, volunteers, exhibitors, and sponsors.

The sessions addressed:

- quality of life issues for survivors
- ways to promote self-awareness, self-esteem, empowerment, and connectedness
- the increasing awareness of the plasticity of the brain
- mental health issues
- substance use
- strategies to harness the power

within survivors to help the rehabilitation process

I attended the conference as a presenter, and also as the wife of an ABI survivor who sustained his injury almost seven years ago when he was 85. As a person who teaches people who are old, my topic was “You Can Teach an Old Dog...”. The audience consisted of survivors, caregivers, therapists, educators, nurses, and agency staff. I shared “our story”, focussed on older adults in general, and then spoke to strategies that help older adults learn. I felt that I had reassured those in attendance that, with encouragement, older adults are able to continue to learn and grow, although at a slower pace.

Personally, I found value in all of the sessions I attended: I learned, I made connections, and I found out about the many available resources.

Links to many of the presentations can be found online at the Ontario Brain Injury Association website, www.obia.ca (click “Prov. Conference Presentations” at the top of the homepage).

