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ACCESS TO APPROVED THERAPIES

I would like to take this opportunity to provide you with some information about a very important project that our Foundation is engaged in with other groups across Canada.

A coalition of patient groups has been brought together to help ensure patients who are suffering from pain are given a voice to help convince governments, hospitals and civil servants that there is a strong desire for increased access to approved neurological therapies.

The coalition which is named; Consumer Coalition for Neurological Therapies ("CCNT") has a vision and a mission. The vision is "to create an environment where every Canadian who has a neurological disease or impairment and who would benefit from an approved therapy would be able to receive one – when they need it." The vision goes on to "ensure neurological therapies are accepted and funded intentionally and systematically by Provincial Ministries of Health, hospitals, insurance companies, and employers."

The mission is to ensure that approved neurological therapies get the necessary funding so that patients can have access to these therapies in order for them to go on and enjoy life without the pain and discomfort they were experiencing.

You may be wondering "why is The Canadian Continence Foundation involved?" Well, simply because many individuals suffering from neurological disease also experience incontinence. Implants have also been a benefit for consumers suffering from atonic bladder when constant infections and pelvic pain had become the norm and was restricting normal activities and in some cases had caused the consumer to cease working. The Canadian Continence Foundation continues to be concerned about "quality of life" issues for consumers.

Members of the CCNT consist of the following organizations: The Canadian Pain Society,

NEUROCARE Canada, Canadian Paraplegic Association, Parkinson Society Canada, Multiple Sclerosis Society of Canada, Understanding Disabilities Creating Opportunities and The Canadian Continence Foundation.

It is the commitment of the CCNT that has allowed this project to move forward in such a positive and constructive way. The idea of having a number of patient associations working together, and with one voice, to fight for this very worthwhile endeavour has impressed many within the government. It is the collective orientation and determination of the CCNT that will allow our "vision" to be fulfilled.

The initial meetings with various government officials we have had over the last few months have given us hope that there is an understanding and, more importantly, an acknowledgement that something has to be done for those who are suffering such horrific obstacles. We need to continue to dialogue on behalf of our patients with governments, hospitals and insurance companies to provide them with information and facts about the suffering that is part of everyday life for these individuals.

This needs to end. We need to continue our efforts on behalf of the coalition's members to ensure they receive all the possible care they and their loved ones need to enjoy life. This can only happen if we continue to speak with one voice and we continue to educate those in society that make the decisions regarding healthcare in the country.

We will continue to keep you posted on developments.

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The informer

New Possibilities For Consumers

With every new opportunity for consumers to have a better quality -of - life and become continent, we applaud the efforts by industry and Government. The FDA has just approved more conclusive screening for InterStim Therapy for Urinary Control

Here is some background on InterStim Therapy.

The FDA approved a more accurate screening test that identifies people who can benefit from InterStim Therapy, allowing more people with bladder control problems to benefit from the therapy.

- InterStim is an implantable device that provides electrical stimulation to the sacral nerves - nerves in the lower back that control the bladder.
- 20 million Americans suffer from bladder control problems and the vast majority - about 85 percent - are women between the ages of 30 and 59. Treatments for bladder control problems include medication, biofeedback, and pelvic floor exercises . Prior to the InterStim therapy, options available to patients when these treatments failed were limited to irreversible bladder surgery, a life time of absorbent pads or self-catheterization.

The newly approved test uses a surgically placed lead - a thin, insulated wire with electrodes at one end - that can remain implanted if the test is positive. This test is for patients who have had false negatives using an earlier test, a percutaneous testing technique. Researchers have determined the earlier screening test may lead to false negatives because the lead is not anchored, resulting in movement.

InterStim is approved for refractory cases of urinary urge incontinence, significant symptoms of urgency frequency and nonobstructive urinary retention.

Non-Invasive Treatment and Prevention

Non-invasive treatment for urinary incontinence are the different approaches of treatment that do not require surgery or medication. They are often called behavioural treatment as they imply the active participation of the person with the symptoms or the care giver. Their goals are to change or maximize certain behaviors or habits to improve bladder function and bladder control. They are accessible to people with a diagnosis of stress incontinence, mixed incontinence, frequency or urgency. The techniques used include the teaching of how the bladder works to be able to understand the problem. Bladder habits and dietary habits are therefore very important, they are the start of the behavioural changes the person can start with when they have the problem or they can even help prevent it . Depending of the type of incontinence, the health professional will guide the person to suppress urges with inhibition techniques, to control stress incontinence using the pelvic floor muscles, to train the bladder to fill and empty more efficiently. Certain tools are used to train the pelvic floor muscles: manual therapy, biofeedback and electrostimulation. These non-invasive treatments are simple and accessible for the majority of people, they do not cause side effects. They can help in decreasing the symptoms of urinary incontinence. These are the first steps in regaining bladder control.

A summary of presentation made by Louise Perrin at the CANUP/TCCF Conference.

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Recently on CJAD Radio in Montreal, I heard Dr. Steven Soifer on an open about Shy Bladder Syndrome. I found the subject fascinating and in order to assist those who may be suffering in silence, I asked Dr. Soifer to write up a small article, which is below.

Paruresis or Shy Bladder Syndrome: The Little Known Urinary Problem

By: Steven Soifer, M.S.W., Ph.D.

Paruresis, better known as shy or bashful bladder syndrome, afflicts about 7 percent of the population in the United States and Canada, or about 20 million people. While widely recognized as a social phobia, there also appears to be a strong physiological component to this disorder.

Shy bladder is easily treatable through cognitive-behavioral therapy and/or certain medications. However, it is VERY important for those suffering from these symptoms to see their general doctor or urologist to make sure there is nothing physically wrong.

The most common symptom is the difficulty or inability to urinate in the presence of others, whether in public lavatories or even in your own home if there is company.

For more information, [Shy Bladder Syndrome: Your Step-by-Step Guide to Overcoming Paruresis](#) (available at amazon.com), or contact www.shybladder.org for more information.

People who suffer from paruresis are constantly worried if people might hear or see them urinating, or possibly be waiting for them to finish. In severe cases, paruretics can become highly anxious, depressed, or even have panic attacks.

Steven Soifer, M.S.W., Ph.D. is an Associate Professor at the University of Maryland School of Social Work in Baltimore, MD USA and is President of the International Paruresis Association

Membership Form

The Canadian Continence Foundation

Please complete this form and return to the address listed below.

- Professional Membership - \$60. (yearly membership fee)
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**I would like to
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- Events Planning
- Montreal Helpline
- Toronto Helpline
- Data Entry
- Other, please specify: _____

Please return to:

**The Canadian
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Volunteers Needed

The Canadian Continence Foundation, a national non-profit organization is looking for volunteers who are in a position to donate 4 hours a week to respond to calls received on our Toronto and Montreal Help Lines.

The Foundation responds to inquiries for assistance from the general public as well as healthcare professionals on urinary incontinence.

Volunteers have to be extremely understanding as most of the consumers calling are experiencing severe isolation and embarrassment.

Volunteers fill out a client profile form and send out a general information package to each caller.

There are occasions when volunteers would be asked to staff a booth and distribute documentation at conferences.

Volunteers will receive training but must be capable of working with little supervision.

Must be reliable and willing to ensure ample supply of documentation and maintain the office in a professional manner.

If interested please contact Ruth Pelletier- Executive Director by calling 514-488-8379 or e-mailing help@continence-fdn.ca

THANK YOU

On behalf of the Board of Directors, I would like to thank all the Professional Members who renewed their membership during our recent campaign. Your continued support is invaluable to the Foundation.

The Canadian Continence Foundation wishes to thank our corporate sponsors for their continued support. It is with their financial contributions the Foundation is able to continue its work on behalf of the consumer. They are listed on our website home page.

Consumer Report: TCCF/CANUP Joint Conference

End of October, 2001. I'm at the first TCCF/CANUP joint conference. Greeting old friends, meeting new people, this is not my first conference and although I'm excited, I'm not expecting anything to be very different from the others.

Friday's program is consumer focused – the medical terms are almost non-existent, or explained, making it so much easier on us non-medics. And all the activities are truly for the consumers: surgical procedures, physiotherapy, products to use... everything you need to know about incontinence is explained with a clarity that's almost surprising.

During breaks, I visit the exhibitor's booths and again I am surprised. Not only are the representatives anxious to answer questions, they encourage it. From biofeedback therapy to special undergarments to catheters, every service or product is explained in layman's terms. They even offer to send you additional information, should you need it.

Friday night, the end of a long day. I sit in my room, going over the notes I took and the pamphlets I picked up during the day. And I am amazed. The passion, the devotion, everyone has put into this very special day is almost overwhelming. The urologists, nurses, therapists and the exhibitors really put their heart and soul to help us, the consumers, to understand our condition. To guide us through the ins and outs, to help us have a better quality of life.

My only regret is that there weren't more consumers there to profit from all of this. To those of you who did come, I thank you. To those of you who didn't, whatever your reason, I send a heartfelt plea to reconsider when we have our next conference in 2003. I know of no other medical branch whose caregivers and supporters take a day out of their busy lives for their patients and consumers, all the while searching for new ways to make our lives better.

So come and see it for yourselves. You will not be disappointed, I guarantee it.

This article was submitted by Bonny Brunet, TCCF Consumer Advisor.

Note to our Members

Please notify us should you move or if there is a change in your family situation. This will help us keep our records up to date and will provide us with all the necessary information to ensure our members are well served.

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