



Issue # 46

Chairperson

Eleanor Grennan 902-425-7977
eleanorgrennan@eastlink.ca

Vice Chairperson:

Pearl MacDougal 902-469-3241
pearlwoman@hotmail.com

Members at Large:

Bob Cross 902-434-6998
ercross@dal.ca

Marlene LeJune
bearrivergarden@gmail.com

Ginny Phillips 902-423-3285
Ginny.p@ns.sympatico.ca

Caroline Scott 902-423-2782

Easter Seals Liaison:

Sam Parsons 902-453-6000x230
samparsons@easterseals.ns.ca

Provincial Support Group Contacts

Middleton:

Linda Haven 902-825-6190
lindahaven@av.eastlink.ca

Sydney:

Louise Gillis 902-564-4102
Louise.gillis@eastlink.ca

Yarmouth:

Linda Muise 902-648-3238
gerlyn@yar.eastlink.ca

Newsletter

Joan M. Walker,
Editor & Science Advisor
jmwalker@dal.ca

Samantha Parsons, Layout
Easter Seals NS
samparsons@easterseals.ns.ca
902-453-6000x230

**Would you like to assist with
the annual meeting?**

**Please contact Sam Parsons or
Eleanor Grennan. A recording
secretary is needed & assistance
with refreshments.**

The Editor's Comments

In this issue we sadly offer our thanks, bid farewell, and wish Faye Joudrey, our mainstay at Easter Seals over two decades, well in her retirement. As editor Faye's support has been invaluable. I have been amazed at how quickly she noticed and sent on obituaries of PNS members. A measure of her contribution is that she is being replaced by no less than 3 people! We welcome **Sam Parsons** as our new 'caretaker' at Easter Seals.

We recognise the passing of several individuals, notably the achievements of the great physicist Stephen Hawking, and a former member of the PNS executive, Rolie Boyd. Whether locally, provincially or internationally, these people show remarkable achievements and contributions to society despite disability.

In the last newsletter tips were given to prevent falling. In this issue a focus is given to balance exercises; especially for those who cannot do exercises in standing. There is an update on Chronic Fatigue Syndrome, Linda Haven describes the attractions of the Valley, and Linda Muise contributed pieces on accessibility and polio material. I hope you find something of interest in the newsletter and again encourage readers to send in material – anytime from now to next February! I thank all contributors, Sam and Faye at Easter Seals, without them this newsletter would not be produced.

To view and receive this newsletter electronically, please visit easterseals.ns.ca/news or email samparsons@easterseals.ns.ca. Additional articles are included!

Annual Meeting, May 12th, 2018

Our annual meeting will be held as usual on the second Saturday of May, between 2-4pm at Easter Seals on Kempt Road (#3670). *Come and say farewell to Faye!* Bring your stories, questions and solutions for discussion. If you can contribute to drinks and munchies please contact Eleanor. Do come!

Mark your calendar now for our next meeting, Saturday May 11th, 2019

Letter from the Chairperson

Greetings to all!

Here we are in April 2018 with another winter behind us. Hopefully, none of you suffered any mishaps. Sadly, we have lost two members of our group in early winter, namely, Rolie Boyd and Ralph Ferguson.

Also, many of you may know that Faye Joudrey has retired from Easter Seals Nova Scotia which is also a loss to us because she has contributed so much to our group over the years. We plan to show her our appreciation at our meeting on May 12th. We also want to welcome her replacement, Samantha Parsons, who I am sure will serve us well. I am hoping that many of you will be able to attend.

I am looking forward to seeing you all again this year and having a great discussion, not to mention the tasty refreshments! See you all on May 12th at 2pm.

Eleanor Grennan

Sam Parsons: Hailing from Dartmouth, Sam is a recent Saint Mary's University graduate with a BSc Biology and minors in Business and International Development. Drawing from experience as President of the Best Buddies society at DAL/SMU, time working in camp administration, and a life spent in sports and recreation, she is excited about working on a variety of programs at Easter Seals Nova Scotia.



Faye Joudrey: Throughout Faye's 30 year career at Easter Seals NS (formally The Abilities Foundation), she has worn many different hats. Faye worked on community promotion, fundraising, recreation, and was involved in a number of other departments, societies and boards. Faye has been instrumental in the equipment side of Easter Seals NS, helping individuals across the province to have access to wheelchairs and assistive devices.



Among Faye's many responsibilities she cared for the Polio Nova Scotia group. Faye maintained the survivors' register, organized the publication and distribution of the twice-annual newsletter and in the last 5 years or so also organized the layout and final production of the newsletter. She set up for the meetings giving up her Saturdays and sent out pamphlets and other information materials when requested. Without Faye's support the group would not have flourished as it has over many years. What Faye has achieved and been responsible for over the past 30 years is wide ranging and amazing; she will be missed by many people across the province.

Remembering Faye's Contributions

By **Ginny Phillips**, the first President of *Polio Nova Scotia*.

When I first got interested in finding information about polio issues in aging people, I went to the Rehab Center and then to the Abilities Foundation. Here I met Faye Joudrey who took me under her guidance. She then put my name forward to travel to Toronto to attend a conference, in Sept. 1988, on post-polio. Dr. Arthur Shears also attended this conference. I met many polio survivors from every province and some of these people had already organized provincial groups. The presentations were very informative and I received good papers.

When I returned home Faye enthusiastically supported me in organizing an information sharing meeting in May, 1990, held at the Abilities Foundation. This, our first meeting, was well attended and several people offered help to begin a regular group. During this period Faye always was there to help pass on information to those who called, and to contact me with reminders and support.

Faye has endeared herself to all the members of Polio Nova Scotia and she has become a personal friend for me. During my years on the Easter Seals Board of Directors I saw Faye take on many new responsibilities but she always found time to be very welcoming to all who asked for help. She will be missed by all of us from Polio Nova Scotia, and I speak for all our members in wishing Faye a much deserved retirement.

Best Wishes Faye for many years of happiness in this new stage of your life.

By **Linda Muise, Yarmouth**, Editor of the PNS newsletter for several years

Faye Joudrey, what can I say? She is an amazing woman. I have known and worked with Faye for 27 years and there was nothing she wouldn't do to help me. All I had to do was give her a call or write an email and it was taken care of. I could go on and on but there is no need, everyone who knows her knows what she has done for all of us. The Abilities/Easter Seals of NS and Polio NS will surely miss her but she deserves to have a wonderful retirement. God Bless You Faye.

Donations can be indicated on the membership insert in this newsletter and can be sent by mail, or given in person.

Want to recognize Faye Joudrey's work for Polio Nova Scotia?

Consider contributing to the Polio Nova Scotia's donation to Easter Seals' Faye Joudrey Recreation Scholarship. Easter Seals, on Faye's retirement after 30 years established this scholarship in honour of her extraordinary commitment to supporting sporting activities for those living with disabilities.

The scholarship will support Nova Scotians who have been diagnosed or self-identify as living with a disability and will aim to defray the costs associated with participating in recreational activities.

New Funding for Polio Eradication 2017.06.13 WHO Director-General elect, Dr. Tedros welcomed contributions and pledges of US\$1.2 billion for the Global Polio Eradication Initiative (GPEI). The pledges were made at the Rotary Convention in Atlanta, USA which was attended by 32 000 Rotarians from around the world.

A proportion of the money pledged will help WHO fund disease surveillance in more than 70 countries and enable it to provide expertise to help countries vaccinate 450 million children per year against polio. The Organization will also provide guidance on vaccination policy and participate in research into vaccine delivery methods, operational tactics and other approaches that can help accelerate eradication

Thirty years ago, polio paralyzed more than 350,000 children each year in more than 125 countries around the world. Since then, the highly contagious virus has been reduced by more than 99.9%, and eliminated in all but three countries: Afghanistan, Nigeria and Pakistan. Serious challenges remain in the final steps to eradicate the virus: weak health systems struggle to vaccinate every child to ensure high enough protection within a community, compounded in some places by logistical impediments. These include remote locations, insecurity and even conflict.

The eradication effort has been spearheaded by the GPEI, a public-private partnership led by national governments with five partners – the World Health Organization (WHO), Rotary International, the US Centers for Disease Control and Prevention (CDC), the United Nations Children’s Fund (UNICEF) and the Bill & Melinda Gates Foundation. Since its formation in 1988, the partnership has prevented over 16 million cases of polio paralysis.

Support organizations that promote global polio eradication and safe water access

The Fight Continues Polio Eradication Update

Source: www.polioeradication.org/Data and Monitoring/Poliothisweek.aspx accessed 18.03.26

Cases of Wild poliovirus (WPV) type 1 & Circulating vaccine-derived poliovirus cases (cVDPV)

	Year-to-date 2018		Year-to-date 2017		Total in 2017	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Globally	3	3	5	0	22	96
In endemic countries	3	0	5	0	22	0
In non-endemic countries	0	3	0	0	0	96

	Year-to-date 2018		Year-to-date 2017		Total in 2017	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Afghanistan	3	0	3	0	14	0
Dem Rep Congo	0	3	0	0	0	22
Pakistan	0	0	2	0	8	0
Syrian Arab Rep.	0	0	0	0	0	94

All cVDPV are type2. cVDPV (vaccine derived polio virus).

A dangerous job – more deaths of polio workers

<http://www.who.int/dg/speeches/2018/142-executive-board/en/> [extract by Ed.]

On January 22, 2018 Dr Tedros, Dir-Gen of WHO announced the shocking news that two polio workers, a mother and daughter, had been shot dead in Pakistan. He noted that unfortunately, it is not only them. In the first three quarters of last year, 44 health workers were killed while doing their jobs, trying to save and the lives of others.

New book! The Promise of Assistive Technology to Enhance Activity and Work Participation

502 pages | 6 x 9 | Paperback
 ISBN 978-0-309-45784-2 | DOI 10.17226/24740
 Alan M. Jette, Carol Mason Spicer, Jennifer Lalitha Flaubert, Editors; Committee on the Use of Selected Assistive Products and Technologies in Eliminating or Reducing the Effects of Impairments; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine

Accessibility Compliance by 2030

Submitted by Linda Muise from an article by Carla Allen in *The Vanguard* Feb.28, 2018, Yarmouth

Note: The Editor welcomes information from readers on improved accessibility in their area.

Under Nova Scotia's Accessibility Act the government will work with persons with disabilities, the public and private sectors to create 6 standards for an accessible Nova Scotia. "The standards will be in the areas of goods and services, information and communication, public transportation and transportation superstructure, employment, education and the built environment, which includes buildings, rights-of-way and outdoor spaces."

Yarmouth's Recreational director, Frank Grant noted that "this is a huge task for municipalities and towns to take on, as much of the infrastructure is not accessible to all citizens." The costs will be enormous. Mr. Grant noted that plans were to hire a consultant and to develop planning tools to make facilities more accessible for users. He said progress was made "in making fees less of a barrier to participation, the Count Me In summer program for children with disabilities or various struggles, sledge hockey gear and promotion, hippocampe free rental (for disabled persons to experience feeling of bike riding), etc." With funding obtained plans include improving accessibility to the Milo Boat club.

The article stated that the government has invested \$1.8 million in the 2017-2018 budget to increase provincial ACCESS-Ability grants for community buildings and to launch a new grant program for small businesses to become more accessible.

Cellphones power polio fight:

Rotary and its partners in the Global Polio Eradication Initiative are strengthening the lines of communication by giving cellphones to health workers in Pakistan and Nigeria.

In Pakistan, in partnership with a Telecommunications provider, Telenor, 800 phones have been distributed and 5,000 are planned for distribution by the end of 2018. Efforts in Pakistan aim to reach the nation's 35 million children under age five. Health workers can use the phones to send data via text message to a central server.

Messages include alerts for suspected cases of polio, tracking parental refusal of vaccination, recording successful immunizations, as well as monitoring other factors that affect maternal and child health.

Worldwide there are about 7 billion mobile phone subscriptions, 89% of them in developing countries (WHO). Cellphones are used more than any other technology in the developing world & increasingly play an important role in global polio eradication.

Source: *The Rotarian*, January 2018, *Insider*, Ryan Hyland, 55-57.

Support Rotary's efforts to eradicate polio worldwide



Polio on the Silver Screen: At the Toronto Film Festival in September, 2017 the film **Breathe** was debuted. *Breathe*, (118 minutes) tells the story of Robin Cavendish, born in Britain, who contracted polio in 1958, age 28. Paralyzed from the neck down and dependent on a respirator Robin defied gloomy prognoses and with the help of his wife left the hospital to live at home. He helped design a wheelchair with a respirator, and traveled with his family, living for 36 years. Quality of life mattered. Robin received an MBE, was a British advocate for disabled people, medical aid developer & one of the longest-lived responauts in Britain. (*Definition of responaut - A person permanently dependent upon a ventilator (artificial respirator) to maintain breathing. Oxford Dictionaries.*)

Robin's son Jonathan is the film's producer and "sees the film as a love story but he knows that is also has an important message about people with disabilities". He noted that people with disabilities want a level playing field and need help achieving that in terms of access and resources.



Responaut.com This is the home of *The Responaut*, a quarterly magazine in Britain that was by, for and about respirator-aided and other gadget-aided people. Published between 1963 and 1989, this site reproduces volumes of the 1960s and 1970s and gives a perspective on what it was like living with a disability towards the end of the 20th century.

Rare Roosevelt photo

By *Ellen Moynihan*

Source: New York Daily News – 9 January 2018

A rare photograph of President Franklin Roosevelt wearing the braces he needed to stabilize his polio-stricken legs was unveiled Monday at the Roosevelt House Public Policy Institute at Hunter College.

The image, shot by Daily News photographer Martin J. McEvilly in 1933, depicts the President as few ever saw him.

The photo was presented to Roosevelt House as a gift from the Daily News. Never published in *The News*, the picture was discovered during the digitalizing of the photo archives in the 1990s.

Roosevelt House is the former residence of the Roosevelts and the photograph was taken on the stairs outside the building.



“It shows Franklin Roosevelt in a way he never wanted to be seen,” said News editorial writer Michael Aronson.

“It shows him completely determined but completely disabled. He was very careful to hide that fact.”

Source: Polio Oz News Autumn 2017, p15

Come Visit The Annapolis Valley, Wineries, Fruits and Veggies

From Linda Haven

Greetings to everyone from the beautiful Annapolis Valley, and yes, I am prejudiced as I live here - by choice, and really enjoy the Valley!

As you know, during the Summer and Fall, there are many, locations to either "pick your own" or purchase farm fresh fruits and veggies, throughout the Annapolis Valley. The Valley now also offers many excellent wineries - and after contacting most of them on this website: valleytourism.ca/listing-category/wineries, all that I could reach (not three) assured me that they do have fully accessible tasting rooms/areas, as well as accessible washrooms.



There are twelve wineries listed on this website. The closest one, coming from the Halifax/Dartmouth area, is Sainte-Famille Wines in Falmouth, the furthest being the two in Bear River: Bear River Vineyards and Annapolis Highland Vineyards. Most are within a 30 min drive surrounding the Wolfville area. To my knowledge, the Beaver Creek Winery in Lawrencetown, Annapolis Co, is the only winery that produces wines using fruits other than grapes (also honey)! None of their wines is from grapes...quite interesting; some are very tasty.

Certainly not all, but some of these wineries do offer restaurants or cafes on site along with the wines...or, if you'd prefer to eat elsewhere, here are three accessible locations that I enjoy in various parts of the Valley:

- (1) The Port Pub and Bistro in Port Williams (this also has a lovely outdoor patio... and the upper deck of the patio also is wheelchair accessible). Opens daily at 11:00am
- (2) The Restaurant Pasta Jax in Middleton. Opens 11:30 am, closed Sundays
- (3) Bistro East in Annapolis Royal. Opens 11:00am daily (only the side entrance is wheelchair accessible, 2 steps at the front entrance) For those who are able to manoeuvre the steps of a bus, there is also the

Wolfville Magic Winery Bus (<https://wolfvillemagicwinerybus.ca>), that visits five different wineries. The bus is a classic British double-decker, and people can hop on/off during the day at the various wineries. Note: tickets (\$40.00 ea) must be purchased in advance. This runs Thursdays through Sundays, June 1st through Oct 15th this year.

Enjoy your visits to our beautiful Valley!!

Remembering

Stephen Hawking, (1942.01.08 -2018.03.14) *Abstracted from the Guardian Weekly Vol 198, no 16, 23-29 March, 2018)*

Stephen Hawking who died recently is recognized as the most famous scientist of our time. He shook up the world of cosmology and aimed at a complete understanding of the universe. A physicist, his book "A Brief History of Time" put physics in the hands of millions. He also, in a motorized wheelchair and speaking with a synthetic voice, showed triumph of the mind over disability. Stephen was diagnosed with ALS in his early 20's and died aged 76. In 2010 he wrote:

"Remember to look up at the stars and not down at your feet. Try to make sense of what you see and wonder about what makes the universe exist. Be curious. And however difficult life may seem, there is always something you can do and succeed at. It matters that you don't just give up."

Frances Ryan grew up disabled in Britain and she noted that Hawking contributed "perhaps unknowingly-to many disabled people: a sense of pride, encouragement and hope...all can reach for the stars" (Guardian Weekly 23.03.18, p19)

Mrs. Margaret (Peggy) Bellemore, Eastern Passage NS. Died June 27, 2016

Rolie Boyd* of Dykeland, born 1933, died 2018.01.28. Rolie contracted polio aged 6 months and despite considerable disability that required use of crutches all his life he rose above his advertise. He worked in construction, and was a well-known teamster having his own from 1977 to 1999. He travelled the exhibitions with them for 22 years, and also enjoyed traveling and camping. He served on the executive of Polio Nova Scotia for many years. The editor recalls Rolie describing how, driving his car or truck, he moved his paralyzed right foot from the brake to the accelerator pedal by pulling on a rope to lift the leg! Rolie is survived by his wife Joan. (*Abstracted from Obituary in www.demontfamilyfuneralhome.ca*)

Allison Coleman, AI, of Mount Uniacke, died 2017.11.13. AI had a passion for the Montreal Canadiens, was a keen gardener and frequent volunteer in his community

John Connell, died 2018.01.19, a banker, in his post-retirement he volunteered for 11 years on the airport Tartan Team; he was a keen golfer and walker.

Ralph Douglas Ferguson of Pictou, aged 76, died 2018.01.30. Ralph contracted polio aged 2 years and until the age of 16 spend many months in hospitals in Halifax, Montreal and Boston. He spend 30 years in Canada's public service and held in Pictou positions of councilor, deputy mayor and mayor. He was a tireless worker in the disabled community serving on NS League of Equal Opportunities, Central Highlands Assoc., of the Disabled, Let Abilities Work Partnership Society, and the Disabled Persons Commission. Amongst many awards he received the Mel Hebb Hourglass Action award in 2006 for his work in the disabled community, most notably his online newsletter which gave his community greater voice within Eastern Canada. His contributions will be missed. (*Abstracted from www.mclarenfuneral.ca*)

Murray Kerr* (1941-2017.09.01, of Baddeck, Cape Breton. In the last number of his working years Murray worked for the Cape Breton Regional Library Bookmobile bringing the enjoyment of books to many people. He was predeceased by his wife Joan (MacDonald).

** Obituaries include statement that donations could be given to Easter Seals-Polio Nova Scotia.*

One of the Last Using an Iron Lung Writes a Book

Paul Alexander went to law school in an iron lung. He travelled the world in it. And now he's writing a memoir about it.

Polio survivor Paul Alexander has been using an iron lung for 65 years -- and now he's writing the story of his incredible life. The memoir, titled "Three Minutes for a Dog" will hopefully be hitting shelves this Spring. He was inspired to write it, in part, due to a recent resurgence of polio.

Source: CBC Radio, Published Nov 23 2017



Nova Scotia Rehab. Center Update March 2018

Submitted by Susan McLeod, physiotherapist NSRC

Polio survivors are always welcome to attend one of our neuromuscular clinics here at the Rehab which has a team representing various areas of health care. People with specific problems who want to see a physiotherapist are welcome to refer themselves to out-patient physiotherapy. We have 4-5 physiotherapists in out-patients at the Rehab Centre who only see people with neurological diagnosis.

Our pool is available Monday through Friday for use with a physiotherapist if this agreed to be the best place for that person to exercise. Sometimes we show people what they can do in a pool, and then they do that in their Community pool. The **YMCA** runs a program in our Rehab gym and pool called "AIM". The contact person for the Y programs is Cathy Beirsto at 902 422-9622, ext. 225.

Available on the Web at: www.cdha.nshealth.ca. Go to internal departments at bottom of the page and click on Physiotherapy. You can then print the form you need, such as 'Self-Referral for Out-patient Physiotherapy'.

We also send some of our patients to the **Community Health Teams**. A physiotherapist runs a free 10 week low intensity exercise class. The phone number for a Community Navigator is 902 460-4560

Lastly, the **Canada Games Centre** in HRM just started an exercise class for people with mobility impairments and the contact is Amber at 902 490-3893.

For more detail, see the Spring 2017 newsletter, p2

Weight control for Chair-bound or Wheelchair Users

Adapted from: <https://www.nhs.uk/Livewell/Disability/Pages/weight-loss-wheelchairs.aspx>

Adults who use wheelchairs can find it harder to lose weight because they tend to use fewer calories through physical activity. But there are still changes you can make to achieve a healthy weight. Being overweight or obese puts you at higher risk of a range of serious health conditions, including type 2 diabetes, heart disease and certain cancers.

How to check your weight

Body mass index (BMI) is a useful measure of whether someone is a healthy weight for their height. You can check your BMI by using a BMI healthy weight calculator. However, it's sometimes not enough to use BMI to check the weight of someone in a wheelchair, as this may not give the full picture.

To work out your BMI

Divide your weight in kilograms (kg) by your height in metres (m) then divide the answer by your height again to get your BMI. If you're uncertain about your weight, talk to your Family physician (FP). They will be able to tell you whether BMI is suitable for you and whether you're currently a healthy weight. Your FP can also help if you're not able to weigh yourself.

Losing weight in a wheelchair

The average man needs around 2,500 calories a day to maintain his bodyweight. The average woman needs around 2,000 calories a day. If you're a wheelchair user and a senior, it's likely you'll need fewer calories than these guideline amounts. This is partly because you tend not to use the large leg muscles; having less muscle means fewer calories are needed to maintain a healthy weight.

A FP or dietitian can help you to work out your daily calorie needs.

Tips for losing weight

Aim to lose between 0.5lb (0.25kg) and 2lb (1kg) a week until you reach your target weight. A healthy, balanced diet and regular physical activity will help you to maintain a healthy weight in the long term.

It's important to eat a balanced diet from across the food groups shown in Eatwell Guides because, when you eat fewer calories, it can become more challenging to get enough nutrients, especially vitamins and minerals, from your diet.

Continued on page 8

Continued from page 7

A healthy, balanced diet means:

- Eat at least 5 portions of a variety of fruit and vegetables every day
- Base meals on potatoes, bread, rice, pasta or other starchy carbohydrates
- Choosing wholegrain with less added sugar or fat, where possible
- Have some dairy or dairy alternatives (such as soya drinks and yoghurts) – choose lower-fat and lower-sugar options
- Eat some beans, pulses, fish, eggs, meat and other protein – aim for 2 portions of fish every week, 1 of which should be oily, such as salmon or mackerel
- Choose unsaturated oils and spreads, such as sunflower or rapeseed, and eating them in small amounts
- Drink enough fluids – the old recommendation of 6 to 8 cups/glasses a day has been disproved. Try not to have drinks just before meals to avoid feeling too full to eat

If you're having foods and drinks that are high in fat, salt and sugar, have these less often and in small amounts. It's important to remember that the Eatwell guides are aimed at the general population. Your dietitian or weight management adviser may have specific advice about portion sizes that are adapted for your particular disability. But this will still be based on a healthy, balanced diet. If you don't eat meat, find out how to have a [healthy vegetarian diet](#).

Get active in a wheelchair

Regular physical activity helps to maintain a healthy weight, and it's also important for your general health and wellbeing. Whatever your level of physical ability, there will be an activity or sport for you. Try to choose activities that improve your heart health and muscle strength.

If you can, try to do:

- At least 150 minutes of aerobic activity every week – use of a *Fitbit* can greatly help you record your activity and awareness of how active or inactive you may be.
- Strength exercises on 2 or more days a week. Therband© bands & cords can be obtained in different strengths and are easy to use at home.

Aerobic activity is particularly important when it comes to losing weight. This is activity that raises your heart rate, gets you slightly out of breath and causes you to break a sweat.

If the gym appeals to you, there's a range of good options for wheelchair users. These can include rowing machines adapted for wheelchair use, and weight machines for resistance exercises. Check out local availability and encourage fitness centers to have appropriate equipment.

Arm Ergometers

These machines allow you to get aerobic exercise in sitting & improve your cardiac fitness. There are several designs available from free standing ones as shown, to others with adjustable tables and or chairs attached. A Google search reveals a price range from \$140 to \$3,600. If you have a good handyman/woman, he/she could construct a simple version using bicycle pedals and chain. Your local physiotherapist would be happy to advise you on purchase and use.



**There is virtue in work/exercise and there is
virtue in rest. Use both and overload neither.**

Adapted from Alan Cohen, motivational speaker

Chronic Fatigue Syndrome – an update

Sources: PTinMOTIONmag.org/September 2017, pp16-25; www.cdc.gov/cfs/general; www.nap.edu/read/19012

Chronic Fatigue Syndrome (CFS) is recognized as a devastating and complex disease. CFS affects between 800,000 to 2.5 million Americans and it is considered that some 84 to 91% of people have not been diagnosed. CFS affects more women than men and has an average age of onset of 33, range: 10 -70.

Causes of CFS are not yet identified and there are no specific tests for diagnosis. Other conditions that may cause fatigue must be ruled out.

Diagnostic Criteria: A patient must have 1 of the following 3 symptoms:

1. A substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social or personal activities that persists for more than 6 months and is accompanied by fatigue, which is often profound, is of new or definite onset (not lifelong), or the result of ongoing excessive exertion, and is not substantially relieved by rest
2. Post exertional malaise
3. Unrefreshing sleep

At least 1 of the following also is required: Cognitive impairment or Orthostatic intolerance (symptoms that develop in standing and are relieved by lying down). Seeking and receiving a diagnosis can be a frustrating process for a number of reasons that include skepticism of health care providers. CFS is often seen as a diagnosis of exclusion.

What's in the name?

In a 2015 report from the Health & Medicine Division of the National Academies of Science, Engineering, and Medicine (formerly the Institute of Medicine) the name CFS was described as “Trivializing” “Stigmatizing” “A disservice to patients” “Does not accurately describe the major features of the disease”. CFS is sometimes called myalgic encephalomyelitis (ME) however the report noted that this term is inappropriate as there is a lack of evidence for encephalomyelitis (brain inflammation) and myalgia (muscle pain) is not a core symptom of the disease.

The new term the panel selected was **SEID**: systemic exertional intolerance disease, however SEID has not yet been widely adopted.

CFS Management overview

The 2015 report recognized CFS as a physiological disease with a central characteristic “that exertion of any sort – physical, cognitive, or emotional –can adversely affect patients in many organ systems and in many aspects of their lives”. Physical therapists therefore have changed their approach in assisting patients to manage their disease and include the following principles:

- That it is important to listen with good faith what the patient has to say, and to go from there.
- Encourage activity pacing within the limits of the individual. “Look at the peaks and valleys of daily activities, saw off the peaks and use that energy to help fill the valleys”.
- Advise exercise in lower-level anaerobic activities that doesn't cause any breathlessness (aerobic activity) and takes less than 2 minutes. Focus on stretching and gentle exercise. Use of a heartrate monitor may assist in keeping exercise under the level that will require rest.
- “Take a “go slow” approach. Gradually include longer duration activities by building on the anaerobic training and help the patient recognize that the prognosis for full functional recovery is very guarded and limited.”
- Education is important to overcome the fear of movement that can develop in response to the effect of over-exercise.
- Socialization can help combat the often present depression.
- Therapy for symptoms such as low back pain must be given within the context of chronic fatigue.
- Research into the etiology of aerobic-system dysfunction, pain science, and drug therapy should further the understanding and management of this complex disease.

Improve your balance, exercises in sitting and in a wheelchair.

There are many exercises that can be done in a wheelchair. Local physiotherapist, *Sue Ehler*, has posted videos of various types of exercise on a website (www.strokeclass.com). The website has a sitting balance exercise video. Her exercises are generally very good for all neurological conditions.

Sue also runs an exercise class for people with neurological conditions called “Chairability” in Dartmouth. Her clinic contact number is 902 462-8589

For readers without access to a computer here are some exercises to do. You don't have to do them all! Try doing a few in the morning, a few in the afternoon. Make doing these exercises part of your daily routine, like cleaning your teeth!

Sitting balance exercises

All exercises can be done sitting in a chair with or without arm support. Try to maintain tall posture as you are completing the exercises. Make sure your feet are shoulder width apart and flat on the floor. You should try to have good footwear on to help support your balance. You can take a break in between exercises so that you are always working with good quality of movement.

In sitting with your arms by your side, reach down to the floor beside you. Return to the upright position. Then reach to the other side. Repeat 5-10x each side.

In sitting, reach around to one side as far as you can and then reach around to the other side as far as you can. Repeat 5-10x.

In sitting, squeeze your buttocks together and hold for 5 sec. Repeat 5-10x.

In sitting, slouch down and then sit tall and hold x 5 sec. Repeat 5-10 x.

In sitting, clasp your hands together and reach forward as far as you can, then sit back up tall. Repeat 5-10x.

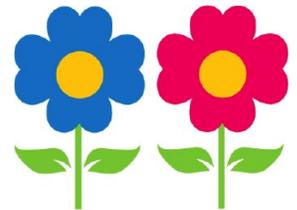
In sitting, clasp your hands together and then reach forward and complete a big circle – like you are stirring a pot. Complete 5x in one direction and then 5x in the other direction.

In sitting with your hands clasped together. Reach down to the floor and then reach up toward the ceiling. Repeat 5-10x.

Sitting forward on the seat of your chair. Clasp your hands on your stomach. Then lean back slightly, but do not touch the back of your chair. Then sit up again. Repeat 5-10x.

In sitting, away from the back of your chair. Place your hands on your hips. Complete a trunk circle. Complete 5x in one direction and then 5x in the other direction.

In sitting, wiggle forward to the front edge of your seat by shifting weight side to side and then wiggle back to the back of your seat.



Susan Ehler PT, BSc PT

Atlantic Balance & Dizziness Center

One in Standing

Stand facing the kitchen counter, wear non-slippery shoes. Stand with your feet at least hip width apart and your fingers tips resting lightly on the counter top. Practice moving all your weight from one foot to the other, returning to the center each time.

Then transfer your weight to one foot and lift the other slowly off the ground, still standing upright and not leaning forward over the counter. Practice this with both feet.

As you feel more stable standing on one foot try to lessen the support you have through your fingers tips until you can stand on one leg without any fingertip support at all. Try and look straight ahead!

Remember, practice makes perfect & your confidence in standing will improve!

Should you have the Shingles vaccine?

Shingles is a painful skin rash with blisters. The rash may last 2-4 weeks. Occasionally affected persons have severe pain that can last years after the rash has cleared (postherpetic neuralgia). Shingles is caused by the varicella zoster virus, the same virus that causes chickenpox. In some people who have had chickenpox, the virus becomes active again later in life and causes shingles. About 1 out of 3 people will get shingles in their lifetime. Shingles is more common in people over 50 years of age or in those with immune systems weakened by medication or disease.



You cannot get shingles from someone who has shingles. However, Dr J Wheeler of the Mayo clinic noted that “a person with shingles can pass the varicella-zoster virus to anyone who isn't immune to chickenpox. This usually occurs through direct contact with the open sores of the shingles rash. Once infected, the person will develop chickenpox, however, not shingles. Chickenpox can be dangerous for some groups of people (https://newsnetwork.mayoclinic.org; 042015).

Shingles vaccination:

Shingles, often a very debilitating disease, can be prevented by vaccination. The vaccine Zostavax contains a weakened form of the virus that does not cause disease, and is approved by Health Canada. It has been recommended for people over 60 years, and only one dose is needed for protection. The vaccine reduces the risk of getting shingles by 50%, and should shingles develop after being vaccination, the symptoms are usually less severe. However, protection lessens with increasing age.

A new vaccine, Shingrix, has been approved by Health Canada (Nov. 2017) and has been shown in clinical trials to be more than 90 per cent effective at preventing the nerve pain of shingles in people over age 50, when compared with a placebo. Shingrix, by GlaxoSmithKline, is not made with live attenuated zoster virus, but was created from a protein taken from an inactivated form of the virus, which triggers an immune response in the body, boosted by what's called an adjuvant. Dr. Susie Barnes, vice-president and country medical director at GSK Canada, said that Shingrix is indicated for adults aged 50 and older and requires two doses given by injection in the arm, two to six months apart.

CARP (formerly Can.Assoc. Retired Persons) is pushing for Shingrix to be paid for by provincial health plans. <http://www.cbc.ca/news/health/shingles-vaccine-cost-1.4470406>, M.Fitzpatrick. Accessed 180402

Should everyone be vaccinated? No, you should speak with a health care provider if you:

- have had a life-threatening reaction to any component of the vaccine including gelatin or neomycin;
- have an immune system weakened by disease or medical treatment;
- have active, untreated tuberculosis; or

if you are ill and have a fever greater than 38.5°C (101.3°F) you should wait until you have recovered before getting the shingles vaccine.

Dr Bruno advises “*always get vaccines from your Doctor who knows your history, not the guy in the pharmacy at Walmart*”. (<https://www.papolionetwork.org/bruno-bytes.html>). Is it safe for persons with postpolio syndrome to be vaccinated? This was discussed in the literature between 2008 and 2016 -the consensus was it is safe for persons with PPS to have the vaccination. (Ed.)

More information on shingles and its vaccination is available on the net but use a reliable site.

Sources: <https://www.healthlinkbc.ca/healthlinkbc-files/shingles-vaccine>, accessed 180401

News from Easter Seals Nova Scotia

Thank you for the opportunity to contribute to the Polio Nova Scotia newsletter, and for your continued collaboration with Easter Seals Nova Scotia!

It has been my pleasure to take on the role of President and CEO of Easter Seals Nova Scotia last July. During that time, I have witnessed the amazing work of this organization resulting in improved mobility and inclusion for persons with disabilities.

Camp Tidnish is on track to be sold out again this summer with over 270 folks enjoying a weeks' vacation at Nova Scotia's only barrier free and fully accessible camp. The past year has been extraordinarily busy for New Leaf Enterprises with catering and Christmas Baking outperforming previous years. This past Christmas, our trainees had the opportunity to operate their own Pop-Up Shoppe in Scotia Square, selling our home décor products and this pilot project was a tremendous success!

Last month, we said good bye to Faye Joudrey as she embarked on her journey into retirement. Heidi Wallace has taken over the role in our Wheelchair Recycling Program and is now joined by technician Dale McNamara as we move in a new direction for that program and Assistive Devices. This year has also seen the addition of Multi Program Coordinator, Sam Parsons who has been amazing in role of stewarding and growing Take Part Programs, Camp Tidnish and our social enterprise points of sale.

The coming months will be full of change and expansion as Easter Seals Nova Scotia moves to a new Centre in Summer, 2018 in Burnside. This new and much bigger space will allow us to grow our programs to serve more people with disabilities. We look forward to opening our own Café in our new space, offering a retail area for our products, a much larger kitchen, program space, business hub and woodshop.

This is an exciting time for Easter Seals Nova Scotia and we thank Polio Nova Scotia for being part of our journey.

Joanne Bernard, President & CEO

Legacy Giving

Considering a planned or legacy gift is an emotional experience. These gifts can range from the relatively simple bequests made in a will, to gifts like charitable gift annuities and charitable remainder trusts that provide major gifts to a non-profit while at the same time returning income to the donor. Legacy or planned giving helps provide you with a unique tax advantage that eases the tax burden on your loved ones. With effective planning, they will not lose your hard-earned income or assets to fees and taxes.

Have you considered giving a planned or legacy gift to Easter Seals Nova Scotia?

Each year, Easter Seals Nova Scotia helps thousands of Nova Scotians living with a disability. Remembering us in your Last Will and Testament ensures that you leave a legacy that will make an impact on their lives beyond your lifetime. For more information please contact John MacDonald, Director of Development at 902-453-6000 ext. 224 or email at john.macdonald@easterseals.ns.ca

Mission Statement of Polio Nova Scotia

To enhance the lives of Nova Scotians who are Polio Survivors, through support, education, advocacy and networking.



Newsletter

c/o Easter Seals Nova Scotia

3670 Kempt Road, Halifax NS B3K 4X8

Tel: (902) 453-6000; Fax: (902) 454-6121

www.easterseals.ns.ca email: easterseals@easterseals.ns.ca