connections

colorado post-polio • since 1981

When was the last time you were on a horse?

Was it like here?

Our peppy staff helpers can get you started.

Do you fish too?

Well, hurry; hurry, because there are a few spaces left for our second Retreat AUGUST 14 to 19, 2016

For Information -----Anita Vedi (303) 587-8412

Summer, 2016

Having Fun, Making Friends, Mastering Skills, Expanding Knowledge and Independence is what We'll offer you.

SEVERAL OF OUR PREVIOUS PRESENTERS ARE COMING AGAIN!

WE'LL LEARN A LOT AND HAVE OODLES OF FUN TRYING SOMETHING YOU'VE NEVER DONE. YOU CAN CHOOSE TO ROUGH-IT WITH OLD FRIENDS OR STAY IN OUR NIFTY MODERN LODGE WITH NEW FRIENDS.

We've secured physical therapists for many exercise sessions. Soak in the hot tub, bask in the pool or take Pool Therapy in it. Dr. Maynard is returning for the "Body" session and "Ask a Doctor." Dee Ann Vick is coming again for "Ask a Physical Therapist". We'll offer Adaptive Yoga, Meditation, Acupuncture and Qigong, and if you want to try something new,

Sandy Stolar, a returnee, will cover the "Mind" session, cleverly giving us the latest news on Brain developments. Cindy Charlton, a widely known quadruple amputee who speaks with joy and enthusiasm will talk about "Spirit". If anyone is an inspiration, Cindy surely is! Don't miss her presentation! Talks on Caregiver and Emotional issues, fatigue, sexuality and End of Life decisions were a success last time and will be repeated. Don't miss sessions on breathing and durable medical devices.

If you believe the schedule is exhausting, you can take mini-hikes, rest, read or add your remembrance to the Memory Tree.

All Camp facilities and paths are handicap accessible. Savor the clean air as you meet new friends and fill up with the latest Post-Polio knowledge.

There still is space in each of the lodging options and the year-around camp helpers prepare three delicious meals a day! A flexible casual and fine dining menu allows for special dietary needs. Water and snacks are always available.

Call Nancy Hanson for a brochure: 303-233-1666 x237 – Nhanson@eastersealscolorado.org If you are computer savvy, here's how you can find more information and see pictures of the Camp itself: http://www.easterseals.com/co/shared-components/document-library/rocky-mountain-village.pdf

A long-term member recently received our $650 DME (durable medical equipment) grant. Her jubilant response was and still is, that it's "HEAVEN SENT".

Her old undependable power chair would develop problems as she got ready to go, leaving her with a fear of it's abandoning her in the middle of a trip. Service people were unable to diagnose the old chair's problems.

Her new chair has many upgrades, and the grant paid toward the cost of an elevating seat that Medicare wouldn't pay for. She is thankful that now she's able to reach higher without standing up and she won't be caught in the middle of an intersection!

***WE STILL HAVE ONE MORE $650 DME GRANT AVAILABLE*.**

The DME fund offers individuals who have a gap between their insurance coverage and their financial assets to cover durable medical equipment. The applicant must be a POLIO SURVIVOR who RESIDES IN COLORADO, with LIMITED FINANCIAL RESOURCES. The GRANT can be used IN ADDITION TO INSURANCE. The recipient PAYS SOME OF THE COST THEMSELVES and IF ABLE, may be asked TO VOLUNTEER IN SOME WAY TO SUPPORT POST-POLIO.
Nancy Hanson 303-233-1666 Ext. 237 has the application and will send it to the applicant.

LINDA GROTH - THE IDEAL VOLUNTEER!

Linda's mother died when she was 9, when she had both bulbar and spinal polio. At 10, her father tried to get other family members to take her to raise. She remembers feeling her fear, until one aunt and uncle stepped forward to give her a new home.

In school some kids gave her trouble and the name "Grasshopper." She found later her great-grandfather had been given the same nickname! After high school, she married and stayed home to raise 2 daughters. She was able to work until 1995, when Post-Polio began to settle in.

She cares for her husband, Neil, who uses a walker from a form of Parkinson's and peripheral neuropathy. Linda has diabetes and A-fib, both under control. Linda found an adjustable bar stool where the seat rises, helping her to cook, but she needs a power chair outside the house. For transportation, they have a big Ford van. She calls it their "Independence Mobile" because it takes her power chair. Linda and Neil have been blessed by 57 years of marriage!

Linda says she's no longer "Wonder Woman". However for the last 16 years she's led the full-of-life Colorado Springs Support Group. The group, formed in 1989, includes mostly long timers, but is getting smaller because of deaths, accidents and moves. One couple in the group both had polio. Linda sends birthday, get well, holiday and sympathy cards to members. She subscribes to other Polio newsletters, reads, looks for and passes out suitable articles to her members. The group gives to the Ecumenical Social Ministry, a local nonprofit group for homeless people and families. Donating toiletries, clothing and food since 1998, is their way of giving back. They meet monthly and Linda documents everything they do! Thus she's THE IDEAL VOLUNTEER.

Despite pain, fatigue and weakness she reports she's still good to be the Springs' leader for awhile longer. For that, we are all mighty grateful!

"The friend who holds your hand and says the wrong thing
is made of dearer stuff than the one who stays away".
Barbara Kingsolver – Novelist, Essayist and Poet

Two on a barstool

By Duane Gentner

OK, how many polio survivors do you know who are grateful they contracted the disease? Well, I am one….Guess I'm a "glass is half-full" guy. Oh, I'm not proposing that people try to catch polio just to make their lives better.

I developed my particular attitude by retracing my life back to 1949, when I was knocked down by infantile paralysis (the popular term then). I was 15 and busy planning for what I hoped my future held for me. Boy, I was way off.

My 7-years-younger brother caught the disease also but he has no residual symptoms now. I had no respiratory involvement, but was in the hospital for 7 months. Fortunately the teaching-hospital had a pool and I could do exercise, helped by student nurses. Over the years, I would say I became about 90-95% recovered.

Instead of becoming a Michigan State Patrol officer or an Air Force pilot (a guy can dream, can't he?) Polio sent me in a different direction, as I know it did others.

After high school and a year of college, I took an office job at a machine shop close by. Four years of going nowhere followed. Seeking a change, I applied and was hired by United Airlines as a ticket agent. I didn't realize it then; there was exactly where I was meant to be. I retuned to college, while working, and earned my degree. I was moved into flight operations management in Michigan, Illinois and Colorado, and I retired from UAL after 44 years.

It was at an after-work airlines party that led to meeting my wonderful wife, Carole. Jam-packed with so many partiers, some from other airlines, the two of us had to share a barstool.

After 5 months we married and had two responsible kids which led to their caring spouses. They blessed us with our sweet, affectionate and lovable granddaughter and our imaginative and constantly moving grandson.

I am now 82 years old. Carole, my beautiful and faithful (she was both) wife of 55 years, passed away two years ago from Alzheimer's. About losing Carole, I told several people I was confused, because I didn't know how I was supposed to feel. My daughter told me to just feel the way I feel. Well, a huge sense of relief is what I felt - not for me – but for Carole. She was no longer in the grip of the terrible disease that had robbed her of her capacity to be herself.

I live within a few miles of my kids, their spouses and my full-of-life grandkids. Sure, post-polio syndrome has entered my life, but with my cane and my walker. I'm handling it, I still

drive! I'm happy; life is good. Can't ask for more. Our paths take interesting twists and turns, don't they? Occasionally, something really bad turns into something really good.

So, what might have befallen me had I not had polio? Who knows? What I do know is that polio pointed me in a new direction, and that direction was my "yellow brick road." Along the way I met many great people, which led to my happy, meaningful life. Had my original ideas come to fruition, it wouldn't have been the same.

Thanks for reading part of "my life story." I wish you continued success with your efforts to bring help and hope to people such as me.

* * * * *

Nothing has ever happened in the past
that can prevent you from being present now;
and if the past cannot prevent you from being present now,
what power does it have?
Eckhart Tolle – Spiritual Writer, Teacher and Guide

Colorado Post Polio has been distributing yellow billfold-size warning cards about anesthesia. We gave them for the Fall Conference, the Polio Medical Clinics and at our Support Groups. We'll have them at the Retreat, too. Obviously the article below provides more detailed information.

The LATE EFFECTS OF POLIO Surgical CONSIDERATIONS (LEoP)

This article appeared in newsletter of the Post Polio of Tennessee *Support Group* and referenced the December 2015 Support Group of South Australia and The Post Polio Awareness and Support Society of British Columbia and the Spring 2015 newsletters.

When a polio survivor presents for surgery, special precautions are necessary as these patients may suffer complications during and post-surgery as a consequence of LEoP. The choice of anesthesia requires special consideration and lower doses are generally recommended for general anesthesia but higher doses (eg, twice the dose) are required to control pain for local anesthesia in dental surgery. Intensive monitoring may be required in the post-operative period and recovery may be prolonged.

PRE-OP ASSESSMENT - The following are important factors for health care providers to take into account when a patient suffering the **L**ate **E**ffects **of P**olio **(LEoP)** undergoes surgery:

- Regional anesthesia is preferable to general anesthesia in LEoP patients as it is associated with fewer side effects.
- The choice of general anesthetics requires special consideration. Generally, selection of shorter acting agents with titration to desired effects is preferred in patents with the LEoP
- Patients with LEoP may have an **increased** sensitivity to the effects of injection drugs, maintenance drugs, muscle relaxants and opioids. Consequently, a lower dose of any such medication is generally recommended in this patient population.
- Baseline twitch response to peripheral nerve stimulation should be measured before administration of neuromuscular blocking agent, as this response may be abnormally small in some muscles in post-Polio patients.
- Patients should be comfortably positioned with consideration given to limbs with contractures.
- Blankets or warming devices may be needed during surgery for LEoP patients with intolerance to cold
- Prophylactic anti-emetic medication may be required as some LEoP patients have bulbar dysfunction and an increased risk of aspiration. It is also crucial to carefully suction the laryngopharynx area prior to emergence from anesthesia.

POST-OP ASSESSMENT- Important considerations for health care providers during the Convalescent period include:

- Recovery from surgery in LEoP patients may be prolonged by 2 or 3 times beyond the expected duration for the general population.
- It should be recognized that being outside of one's comfort zone may lead to the need for more assistance (a need which may not be identified by staff unaware of post-polio limitations).
- Some patients may require intensive monitoring in the postoperative period, particularly in order to monitor their pulmonary function.
- LEoP patients with sleep apnea may experience a worsening of their symptoms following general anesthesia.
- Polio affected muscles may be temporarily weaker after general anesthesia and patients may require mobility aids.
- Paralyzed limbs may have delayed wound healing due to decreased blood supply.

DENTAL SURGERY: Although polio survivors with LEoP are more sensitive to general anesthesia, they seem to require about **twice** the typical dose of **local anesthetic** for **dental surgery** because of their increased sensitivity to pain. A problem is that the increased dosage may cause paralysis of facial, tongue and pharyngeal (throat) muscles and impair the ability to swallow saliva or breathe. **Swallowing and breathing may be further compromised** in those who had bulbar polio or paralysis of the respiratory muscles simply by reclining in a dental chair. A safe and comfortable reclined position should be identified before any dental procedure begins. Polio survivors need to communicate their polio histories and any requirement for physical assistance in transferring to and from the dental chair in the pre-operative period. Their medical history should include swallowing difficulties and the need to use ventilator support. They should

also inform the dentist of all medicines taken since **high doses of painkillers such as aspirin can cause excessive bleeding of the gums and anti-cholesterol drugs can further weaken muscles.**

GLOSSARY

titration - ti-trey-shun - A measured amount of a solution of unknown concentration is added to a known volume of a second solution until the reaction between them is just complete; the concentration of the unknown solution (the titer) can then be calculated.

laryngopharynx - la·ryn·go·phar·ynx/ (-far´inks) - The portion of the pharynx (throat) below the upper edge of the epiglottis opening into the larynx (voice box) and esophagus.

epiglottis - e-pu- glo-tus - a flap of cartilage that covers the windpipe while swallowing

Excerpt from ANESTHESIA ISSUES FOR POST-POLIO PATIENTS

By DR. Selma Calmes, MD.
Retired Clinical Professor of Anesthesiology, UCLA School of Medicine

The full article appears in our Resource Book of Articles Related to Post Polio and Post Polio Syndrome
(For words in RED, see Glossary at the end)

1. Post-polio patients are nearly always very sensitive to sedative meds and emergence can be prolonged. This is probably due to central neuronal changes, especially in the Reticular Activating System, from the original disease.

2. Non-depolarizing muscle relaxants cause a greater degree of block for longer periods of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the polio virus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater sensitivity to relaxants. Also many patients have a significant decrease in total muscle mass. Neuromuscular monitoring intra-op helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.

3. Succinylcholine often causes severe, generalized muscle pain post-op. It's useful if this can be avoided, if possible.

4. Post-op pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to "spill-over" of the inflammatory response. Spinal cord "wind-up" of pain signals seems to occur. Proactive, Multi-modal post-op pain control (local anesthesia at the incision plus PCA etc.) helps.

5. The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarcina in the anterior horn "spills over" to the intermediolateral column, where sympathetic nerves travel}. This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anesthetics are given.

6. Patients who use ventilators often have worsening of ventilator function post-op, and some patients who did not need ventilation have had to go onto a ventilator (including long-term

use) post-op. It's useful to get at least a vital capacity (VC) pre-op, and full pulmonary function studies may be helpful. One group that should all have pre-op PFTs is those who were in iron lungs. The marker for real difficulty is thought to be a VC <1.0 liter. Such a patient needs good pulmonary preparation pre-op and a plan for post-op ventilator support. Another ventilation risk is an obstructive sleep apnea, often a problem in the post-op period. Many Post-Polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.

COMMENT: post-op respiratory failure in these patients can be difficult to manage. The patient's pulmonary physician could help by doing a pre-op evaluation and being involved in post-op ventilator management. This situation might call for the resources of an ICU in a major medical center.

7. Laryngeal and swallowing problems due to muscle weakness are being recognized more often. Many patients have at least one paralyzed cord, and several cases of bilateral cord paralysis have occurred post-op, after intubation or upper extremity blocks. ENT evaluation of the upper airway in suspicious patients is useful.

8. Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fractured during positioning for surgery. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass or tendons.

9. NEW IDEAS/THOUGHTS: Spinals: Recent studies demonstrating the presence of cytokines in the CNS of PPS patients lead me to be less enthusiastic about using spinal/epidural anesthesia. There is no data on this situation, and there are so many benefits to this regional anesthesia, and it might be suitable in some situations. Lidocaine would not be a suitable drug choice for PPS patients. It has been shown to cause nerve damage when used for a spinal.

Regional anesthesia: Should the peripheral nerves of PPS patients be exposed to local anesthetics, especially for long periods post-op? There is no data, but many PPS patients have atrophied peripheral nerves. Perhaps smaller doses of local anesthetics and avoiding continuous post-op infusions would be safer.

Above-the-clavicle blocks (supraclavicular and interscalene) approaches have a high risk for diaphragmatic paralysis and should probably not be used in PPS patients, unless the patient can tolerate a 30% decrease in pulmonary function.

SUMMARY: PPS patients can have anesthesia and surgery safely, with careful preparation. Anesthesia and surgery is a process that involves anesthesia, surgery, and hospital care. For an optimal outcome, all must be at high levels of performance and achievement! You, the patient, must work to be sure you get these. Remember, few surgeries are truly urgent and you usually have time to get data from the web, the state's hospital licensing department, the state's medical board, and other resources. You should also research the operation and its consequences to be sure you can deal with them. Don't rush into anything until you're satisfied you'll get the best. You deserve it.

GLOSSARY

(1) The Reticular (netlike) Activating System (RAS) a set of connected nuclei in the brains of vertebrates that is responsible for regulating wakefulness and sleep-wake transitions. As its name implies, its most influential component is the reticular formation.
(3) Succinylcholine - a muscle relaxant
Glossary continued:
(4)(PCA - Patient-controlled analgesia, any method of allowing a person in pain to administer their own
(5) autonomic - involuntary
(5) scarcina - A genus of bacteria found in various organic fluids associated with certain diseases.
(5) tachyarrhythmia - a heart rate that exceeds the normal resting rate
(5) BP – blood pressure
(6) PFTs – Pulmonary Function Testing, testing of the respiratory system
(6) ICU – intensive care unit
(7) ENT – ear, nose and throat
(8) osteopenic - Osteopenia is a condition in which bone mineral density is lower than normal.

* * * * *

Already hundreds of women suffer from Zika, arriving at our shores, mostly from traveling to other countries where the Zika virus exists. The Center for Disease Control hasn't an idea yet for how to cure or treat them. Imagine having a new baby with a less than normal size head!

This all reminds the Editor about the need for vaccinations. Since Polio is a life-long danger, thank heaven for vaccinations for it. Only three countries are still in danger because of not enough vaccinations there yet.

Vaccinations are an important part of childhood and adult health. The Colorado Board of Health requires certain immunizations for school entry, but waivers are available. Mumps and Measles are back in this country again. Even adults are getting some of these old diseases.

We hope mothers will seriously consider the importance of having their new ones vaccinated!

OUR EXECUTIVE COMMITTEE MEMBERS

Sandy Abbott	303-646-7346	Sandya65@outlook.com
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Pat Jenni	303-880-3581	patjenni@gmail.com
Janet Thompson	303-937-5052	janetandjere@SoftHome.net

Colorado Post-Polio Support Group Schedules

Support groups usually have a plan, an activity or program for each meeting. In bad weather, call the contact person to make sure the meeting will be held.

Aurora - Meets 4th Thursday of each month, 11:00am to Noon
Contact: Sandy Abbott – 303-646-7346 - sandya65@outlook.com

Colorado Springs - Meets 2nd Saturday of each month, 10:00am to Noon
Contact: Linda Groth - 719-633-1497 – (Call for location)

Grand Junction – Please call either of these members for date, time and place.
Contact: Loran Dake - **970-241-7825** - **lorandake@msn.com** or **Chuck Langan - 970-270-0654**

Lakewood - Meets the 2nd Tuesday of each month, 11:00am to 1:00pm in Golden, bring a brown bag lunch.
Contact: - Annette Beck - 303-427-1789 - annette.beck@hotmail.com

Northern Colorado (Fort Collins) - Meets 4th Saturday of each month, 10:00am to Noon **-**
Contact: Peter Way - NOCOPolio@gmail.com – 870-460-6164

Pueblo – Looking for new time and meeting place. Call for details.
Contact: Maureen Sullivan - 719- 561-3182 - **msmosul2005@yahoo.com** – or **Mary Agnes Leonard – 719-544-4789 – maryagnesleonard@gmail.com**

Survivors South – Due to health reasons, this group is regrouping. Contact **Sue Brandon** for more information. **763-377-2287**

Thornton – (now North-Metro) this group is reorganizing. Contact **Sue Brandon** for more information. **763-377-2287**

Because of vaccination efforts in the US since the 50's, we no longer have new polio cases here. However, many immigrants in their 30's to 60's who contracted the disease abroad travel here or become residents. Native-born survivors are now in their 70's - 80's. Support for the new survivors will be needed for the next 4 decades!

We are blessed, and with the help of some serious major donors; we are building reserves for the future. Our valued regular donors support our overhead, and special programs. Volunteers like Linda Groth are the icing on our cake.

Please complete this form, detach it, and mail it to Nancy Hanson at Easter Seals Colorado.

To insure that we receive 100% of your donation, any contributions should be payable to Easter Seals Colorado and PLEASE WRITE "POST-POLIO" IN THE MEMO LINE. Your contribution will be gratefully acknowledged.

Thank you!

Name:_____

A**ddress:**_____

City, State,
Zip:_____

Phone:_____

Mail_____

Mail to: Easter Seals Colorado, 5755 West Alameda Ave, Lakewood, CO 80226

Colorado Post-Polio Connections
c/o Easter Seals Colorado
5755 W. Alameda Avenue
Lakewood, CO 80226

FREE MATTER FOR THE BLIND OR DISABLED

This Is YOUR Newsletter-----

"Connections" is the official news publication of the Colorado Post-Polio Program. The opinions are those of the individual contributors, and do not necessarily constitute an endorsement or approval by either the Colorado Post-Polio Council or Easter Seals Colorado. **(Always check with your personal physician for all medical questions and concerns.)**

We invite not only your comments about this newsletter, but your personal stories, other story ideas, and contributions. Tell us what topics you want to read about in future issues. If you have article ideas or suggestions, are willing to write a short article, tell your personal story or you'd like to review a book, please call **Janet Thompson at 303-937-5052** or send an e-mail to her at janetandjere@SoftHome.net, or write to:

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If you prefer to receive this newsletter online or change your mailing label information, please notify Nancy Hanson at Easter Seals Colorado, at 303-233-1666, ext. 237 or email her at: Nhanson@eastersealscolorado.org