

April – May 2007  
Southern Arizona  
Post-Polio Support Group  
Est. 1985  
P.O. Box 17556  
Tucson, AZ 85731-7556  
(520)-750-8608  
(Message)  
www.polioepic.org

# POLIO EPIC, INC.

## THE BEST THINGS IN LIFE ARE NOT THINGS

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**General  
Membership  
Meetings  
Every Second  
Saturday of the  
Month  
10:00 am.  
HealthSouth  
Rehabilitation  
Center  
2650 Wyatt  
Road**

**April 12<sup>th</sup>** - Sonia Weirich, who is with New York Life Financial Services. Her topic will be "Smart Financial Planning."

**May 12<sup>th</sup>** - Sandra Knight, with SILVER SNEAKERS- a group that encourages and teaches exercises for Seniors. Since Sandra's mother is one of us (A Polio Epic PPS'r), she really knows what we need and what we can do!

Start making plans now for our annual June meeting with by-laws, elections and planning for the new fiscal year of 2007-2008!

I read an article in a Florida newspaper last month about a woman who just had her 60<sup>th</sup> birthday. She had polio when she was 3 years old and has spent the last 57 years in an iron lung. During her youth she could spend some of her time outside the "machine", but when she reached her early 20's she had to stay in it fulltime. Because of the severity of her respiratory problems, she can not use more advanced machines that might allow her time to breathe on her own. She graduated from high school, attended college, wrote a children's book and gave a healthcare foundation the opportunity to pledge to provide for her care for the rest of her life. People in her community value her love and concern for others. She is a role model for her family and friends. She sets an example.

This article got me thinking about what it is that we value about each other. Is it about what we do or who we are? During an activity at the monthly polio epic general meeting on March 10, we wrote down what we appreciated, liked or valued about each other. Most of the words on our lists were adjectives and how we feel when we are around each other. Words like "loving, creative, happy, strong and funny" were listed, rather than things that we could do. I thought also about an older couple at my church that left for Minnesota last week. I miss their smiles and the way I felt safe when I was around them. They could easily lift my spirits!

This month, one of our earliest and well-loved polio epic members, Joanne Yager, celebrated her 70<sup>th</sup> birthday. There were friends and relatives from Tucson, Colorado and Kansas at her party. We took turns talking about how we knew Joanne. Besides an overwhelming number of remarks about her excellent cooking and baking, most people said she was "fun to be with, loving, helpful, a faithful member of her church and a good friend." Those comments speak to who she is and how others feel in her presence. Could something as simple as a smile, a friendly greeting or a gentle touch change a life for the better? Absolutely!

We do make a difference in each others' lives and we need to know that we are valued for who we are. Tell someone how important they are to you. You don't need a special occasion. Pick up the telephone, write a letter or send a card.....today!

**WITH LOVE,  
YOU'RE PRESIDENT,  
KARLA CARR**

*The opinions expressed in this publication are those of the individual writers and do not necessarily constitute an endorsement or approval by POLIO EPIC, INC. If you have personal medical problems, please consult your own physician*

## **CHANGES IN OUR BYLAWS**

The Board of Directors has been working hard in updating our bylaws. The following are the proposed changes. If you have any questions or suggestions, please contact a board member. Please make sure that you review the changes, and your opinion vote makes you an important part of this vital group and organization.

## **OPERATING POLICIES OF POLIO EPIC, INC.**

### **ARTICLE 1 – PURPOSE AND GOALS**

#### **NEW**

**SECTION 1:** Polio Epic, Inc., is a non-profit 501(c)(3) organization of polio survivors and their families, community professionals and other interested parties. It shall function as a support group to empower its members with tools necessary to make adjustments needed to continue a life of ***dignity, independence and interdependence.***

#### **OLD**

**SECTION 1:** Polio Epic, Inc., is a non-profit 501(c)(3) organization of polio survivors and their families, community professionals and other interested parties. It shall function as a support group to empower its members with tools necessary to make adjustments needed to continue a life of dignity and independence.

#### **NEW**

**SECTION 2:** The organization shall strive to further interests of people affected by polio and to support such activities, including educational ~~activities such as~~ seminars, classes of instruction and symposiums, conducive to the broader understanding of the impact of polio in the State of Arizona, including for such purposes, making distributions to organizations that qualify as exempt under Section 501(c)(3) and whose purposes are similar to the purposes of this organization; to further promote an understanding of the adjustments needed to continue a life of dignity and independence

#### **OLD**

**SECTION 2:** The organization shall strive to further interests of people affected by polio and to support such activities, including educational activities such as seminars, classes of instruction and symposiums, conducive to the broader understanding of the impact of polio in the State of Arizona, including for such purposes, making distributions to organizations that qualify as exempt under Section 501(c)(3) and whose purposes are similar to the purposes of this organization; to further promote an understanding of the adjustments needed to continue a life of dignity and independence.

### **ARTICLE II – ORGANIZATION**

#### **NEW**

**SECTION 3:** Original copies of all records, reports, correspondence, receipts, minutes and all prepared data initiated or received by any officer of the organization shall be the property of Polio Epic and shall be received and filed ***by the Recording Secretary*** and stored in a location determined by the Executive Board.

#### **OLD**

**SECTION 3:** Original copies of all records, reports, correspondence, receipts, minutes and all prepared data initiated or received by any officer of the organization shall be the property of Polio Epic and shall be received and filed by the Recording Secretary and stored in a location determined by the Executive Board.

### **ARTICLE III – MEMBERSHIP**

#### **NEW**

**SECTION 1:** Membership is open to all interested parties, ~~whether they are post polios or not, and is~~ contingent upon paid or approved waiver of annual dues

#### **OLD**

**SECTION 1:** Membership is open to all interested parties whether they are post polios or not, and is contingent upon paid or approved waiver of annual dues, if dues are being assessed per Article III, Section 2.

#### **NEW**

**SECTION 2:** The Board of Directors shall have the power to assess membership dues based on the review of outside financial assistance as compared to projected expenses of the organization. Dues shall be a minimum ***of \$10.00*** per member per year with a maximum not to exceed ***\$15.00 through 2010.*** Waiver of dues based on financial hardship and for networking exchanges of newsletters will be appropriate. Waivers are to be approved by the Board of Directors.

#### **OLD**

**SECTION 2:** The Board of Directors shall have the power to assess membership dues based on the review of outside financial assistance as compared to projected expenses of the organization. Dues shall be a minimum of \$5.00 per member per year with a maximum not to exceed \$10.00 through 2007. Waiver of dues based on financial hardship and for networking exchanges of newsletters will be appropriate. Waivers are to be approved by the Board of Directors

### **ARTICLE IV – OFFICERS**

**NEW (Deleted this section since it was just like SECTION 4)**

~~**SECTION 3:** An election of officers shall be implemented and in effect beginning May, 1987. A President-Elect, Secretary, and Treasurer will be elected each year. The President-Elect will assume the functions of President at the conclusion of the current President's term. A minimum of seven (7), additional Directors shall be nominated by the Board and presented to the general membership for a vote. These Board Members shall serve a one-year term.~~

**NEW (Change to SECTION 3)**

**SECTION 4:** An election of officers shall be implemented and in effect beginning May, 1987. A President-Elect, Recording Secretary, Correspondence Secretary, and Treasurer will be elected each year. The President-Elect will assume the functions of President at the conclusion of the current President's term. A minimum of seven (7), additional Directors shall be nominated by the Board and presented to the general membership for a vote. These Board Members shall serve a one-year term.

**ARTICLE V – MEETINGS**

**NEW**

**SECTION 6:** Any member of the Board of Directors who has failed to attend three (3) consecutive Board meetings, without notifying **the President** shall forfeit his/her position upon the Board of Directors discretion. The Board shall then fill the vacancy by appointment.

**OLD**

**SECTION 6:** Any member of the Board of Directors who has failed to attend three (3) consecutive Board meetings, without notifying at least one (1) Board member shall forfeit his/her position upon the Board of Directors discretion. The Board shall then fill the vacancy by appointment.

**ARTICLE VII – ORGANIZATIONAL FUNDING**

**NEW**

**SECTION 3:** An annual audit review shall be conducted of the financial records of the organization at the end of each fiscal year. An independent party shall review and insure accuracy of the **yearly** reconciliations. ~~or an audit committee, appointed by the President no later than October 31 shall conduct an audit review.~~ The Treasurer ~~cannot be part of the audit group but~~ is required to furnish all documents and records. ~~and to assist the group in every way possible.~~

**OLD**

**SECTION 3:** An annual audit review shall be conducted of the financial records of the organization at the end of each fiscal year. An independent party shall review and insure accuracy of the monthly reconciliation, or an audit committee, appointed by the President no later than October 31 shall conduct an audit review. The Treasurer cannot be part of the audit group but is required to furnish all documents and records and to assist the group in every way possible.



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**BOOKS IN POLIO EPIC'S LIBRARY**

We have a lending library that is housed at HealthSouth, where we have our monthly general meetings.

We will be listing a few books in our newsletter, periodically, with a brief synopsis.

If you are unable to attend the Saturday meetings, but are interested in checking out a book, please contact a board member.

**The Upside of the Downside: Journeys with a Companion Called Polio**

by Kent, Kloeping –***Kent is a member of Polio Epic recently published his memoirs.***

He contracted polio in 1945, at the age of seven. Though he would never walk again, Kent refused to let this event define the rest of his life. Even though he is faced with a lifetime of challenges, Kent has the support of his family and many friends, He faces these challenges head-on. Through humor and unrelenting stamina, Kent tells about his life as a “gimp” and his accomplishments, starting with grade school, the college years, jobs, and many travels worldwide. Kent retired from the University of Arizona in 1998 as head of the Center for Disability Resources.

**A Nearly Normal Life: A Memoir**

by Charles L. Mee

In 1953, when he was a robust 14-year-old, Charles L. Mee was stricken with viral polio. This memoir describes his struggle with polio, and also comments on the treatments (sometimes horrific) that were tried to beat this virus that, in 1953 alone, struck over 50,000 people. His struggle was not an easy one, and his later life wasn't either, but he comes to terms with his limitations, becoming a successful historian and playwright. It's a real eye-opener, and he doesn't mince words, which makes for a compelling read.

**My Last Days as Roy Rogers**

by Pat Cunningham Devoto

It is the story of Tabitha “Tab” Rutland who lives in a small Alabama town. The 1954 polio scare is on, and all of the swimming pools are closed. So with her new friend, Maudie (who is the daughter of the neighbor's African-American maid)

they set about to build a fort in a kudzu vine thicket which they nickname Fort Polio. They then begin a summer spying on the local moonshine maker, taking a fishing trip to get money for school supplies for Maudie, and other adventures. Meanwhile, Tab's mother is blackballed by the venerable Ladies Help League. The summer ends and Tab and Maudie's friendship is changed forever.

This is fictional but the historical details are exceptionally real regarding the polio vaccine, segregation, and other parts of history which are portrayed in this book.

### **Polio: A Dose Of The Refiner's Fire: Surviving Polio**

by Jeane Currey L. Dille

In October 1952, a twenty-eight-year-old mother of two young children was diagnosed with bulbar polio which affected shoulders, arms and breathing. Soon the patient was placed in a chest respirator (which assisted breathing) and a tracheotomy was performed (which provided a clear airway for breathing). Early in the hospital stay, pregnancy was discovered. After a total of 8 months in the hospital, isolated from the children, she returned home with both arms still in arm slings. She had only minimum use of the left arm which made living at home and dealing with children difficult. But a year later, the challenge of losing her home catapulted her back into the world of work. And this transition proved more demanding and, ultimately, far more rewarding than she imagined.

### **Small Steps: The Year I Got Polio**

by Peg Kehret

In a riveting story of courage and hope, Peg Kehret tells of months spent in a hospital when she was twelve, first struggling to survive a severe case of polio, then slowly learning to walk again. Her powerful account is also full of the humor that she and four spunky roommates found in daily hospital life.

### **Walking Fingers: The Story of Polio and Those Who Lived With It**

by Helen D'Orazio

Thirty-six poignant stories of polio survivors and their caregivers are recounted in this history of the evolution of medical treatment in Canada since the first major polio epidemic of 1927. Canada's pivotal role in the production and mass distribution of vaccines to thousands of children reveals the determination of the people and organizations that raised funds for treatment and researched the disease.



## **A world-class conductor persevering through polio**

 **By Karen Meyer**

July 13, 2006 - **Itzhak Perlman** is considered one of the greatest violinists of the late 20th century. But shortly after he began to study violin, he became disabled from polio.

He performed Wednesday night at Ravinia and Thursday night he returns to conduct the Chicago Symphony Orchestra.

"I wanted to study the violin when I was three and half and everybody said you know a little bit too early," said Perlman. "So when I had polio I still wanted to pursue the violin." Itzhak Perlman brings joy to millions with his music. He has appeared with every major orchestra and says the biggest obstacle is getting on some stages.

"There's a very famous hall in Amsterdam called the Concertgebouw," said Perlman. "The Concertgebouw is a disaster because it has about eight steps on the sides of the stage, but usually people go from the back of the stage, which is up about thirty steps in the view of the audience." Even though he can walk, he prefers to use a wheelchair.

"I find it's a lot of fun and I like it very much because it gives me a lot of flexibility," Perlman said.

Perlman won numerous awards including the 2003 Kennedy Center Honors, five Grammy Awards and an Academy Award for the music in "Schindler's List". Twelve years ago, Perlman's wife encouraged him to start conducting. "I started a little bit and everybody said you know you should really do that because it's not bad," he said. "People thought it was pretty good and one thing led to another."

Perlman's ability to perform has never been an issue for him but some have questioned it. "In the very beginning many people did not agree with my career," he said. "I did not feel that I could do it because there's so much traveling involved and so on -- I had to basically prove that I could do it." Karen Meyer, Feature Reporter on Disability Issues, ABC 7 News

**Make sure you talk to Linda Falzmeger (one of our board members) about her personal walk and talk with Mr. Perlman, himself. What a great meeting with a great Polio survivor. Linda used her meeting with Mr. Perlman in our meeting, where we gave an interesting little known fact about ourselves. I was so fascinated with Linda's fact, that I looked up this interview with the famous Itzhak Perlman.**

## DONATIONS

Ed Boyles  
BUILDERS \$100 & OVER  
Carol Anderson  
Billy Campbell  
Nick Candito  
Bill Craven  
Jean Haugrud  
Noel Matkin  
Carol Young  
FRIENDS \$99 & UNDER

Ed Boyles gave a generous donation to Polio Epic, in the memory of his beloved wife, Ann.



## NEW MEMBERS

Glada Mae Sprenger – Coolidge, AZ

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**One of our special members (Joanne Yager) found this great article in the Fall 2006 issue of “Special Living Magazine” in the “View from a wheelchair” regular series by Joni Eareckson Tada.**

### Stem cells:

Every night around 8:00 pm, my paralysis forces me out of my wheelchair and into my bed. My body is wearing out after almost 40 years of living as a spinal cord-injured quadriplegic, It's a good time to watch some TV. Not long ago, I flicked on a PBS special called “innovation: Miracle Cell.” When I learned it was about new therapies using stem cells, I asked my husband to turn up the volume.

Paralyzed after a car accident, pretty 19-year-old Laura Dominguez looked up from her wheelchair and into my room through the camera, and smiled. She had reason to. Recently she traveled to Portugal for an extraordinary operation that changed her life. First, Dr. Carlos Lima drew stem cells – her body's own “repair cells” – from the lining in her nose, and then gently packed the cells into the damaged portion of her spine. After three months of therapy, Laura was able to move her foot and regain feeling in her back and legs. Said Dr. Lima, “I will be able to say to somebody with a spinal cord injury, “yes, you will walk again,” as opposed to telling them life is good from a wheelchair.” The same week Dr. Lima published his research in the Journal of Spinal Cord Medicine, I picked up the July 24<sup>th</sup> issue of TIME and read “What a Bush Veto Would Mean for Stem Cells.” Rather than read the same line about embryonic stem cells being the Holy Grail of miracle cures, I read how “Adult Cells, such as those found in bone marrow, were though to be less valuable than embryonic cells. But adult cells may be more elastic than scientists thought, and could offer shortcuts to treatment that embryonic cells can't match.”

I and others with disabilities have been closely monitoring the debate between adult and embryonic cells, and we know there isn't an embryonic cell treatment that heals even a rat – there are tumors, tissue rejection, genetic abnormalities and death; there are no miracle cures. Yet, right now over 70 medical conditions are being successfully addressed by adult stem cell therapies either in human clinical trials or human treatments. Laura Dominguez knows first hand; she can now even walk a bit with crutches!

No wonder people like me are excited. True, many adult stem cell therapies are not yet bona fide cures, but so far, they have proven substantially more successful than embryonic stem cell approaches. Still, some people say we should wait and see what happens with stem cells gleaned from human embryos. Pardon me, I'd rather not wait. Besides, there's something deeply unsettling about tearing into a human embryo for it's spare parts. Is it really nothing more than a mindless clump of cells? I shiver when I hear politicians and so-called experts talk that way.

People like me are vulnerable in a society that disregards the rights of the weak, the infirmed, the unseen, and the very, very small. When we tamper with the essence of our human genesis – certain only of the uncertainty of our outcomes – we mock the God whose imprint we each bear, and we provide false hope to those whose hope sustains them.

I stand with countless Americans with disabilities who believe our cause is not advanced when human life is sacrificed in hopes of finding a cure. Our cause is uplifted when we take the commonsense and ethical course to hope and hearing. And if you don't elieve me, ask Laura Dominguez.

--By Joni Eareckson Tada

*Joni, who has been a quadriplegic since 1967 from a diving accident is president of JAF Ministries which she founded in 1979. If you would like to learn about one of JAF's national retreats, visit their website: [www.joniandfriends.org](http://www.joniandfriends.org).*

## Study Investigates Potential for Adult Stem Cells to Repair Heart Damage

*Clinical research trial involves injecting patients' own stem cells into areas of heart with poor blood flow* Columbia University Medical Center and NewYork-Presbyterian Hospital is one of the first medical centers in the country participating in a novel clinical trial investigating if a patient's own stem cells can treat a form of severe coronary artery disease. The Autologous Cellular Therapy CD34-Chronic Myocardial Ischemia (ACT34-CMI) trial is the first Phase II adult stem cell therapy study in the United States designed to investigate the efficacy, tolerability and safety of blood-derived selected CD34+ stem cells to improve symptoms and clinical outcomes in patients with chronic myocardial ischemia (CMI), a severe form of coronary artery disease. "This promising stem cell therapy may be an alternative for patients without any other means to treat their chest pain," says Warren Sherman, site principal investigator, interventional cardiologist at NewYork-Presbyterian/Columbia and associate professor of medicine at Columbia University College of Physicians and Surgeons.

### A Novel Clinical Trial

ACT34-CMI is a prospective, randomized, double-blind, placebo-controlled study that involves adults with CMI who are currently on maximal medical therapy and are not suitable candidates for conventional procedures such as angioplasty, stents or coronary artery bypass surgery. Patients in the study are randomly selected to receive either one of two dosing levels of CD34+ stem cells, or placebo.

The first step in the trial is to establish the baseline frequency and severity of anginal episodes for study participants. Next, all patients receive a series of subcutaneous injections of a commercially produced protein that helps release blood-forming CD34+ cells from bone marrow into the bloodstream. Investigators then use a cell separation system to collect from the bloodstream an enriched preparation of cells containing CD34+ stem cells. When this process is complete, technologists further process the collected stem cells with Baxter's ISOLEX 300i Magnetic Cell Selection System to select the CD34+ stem cells for use in this investigational therapy.

Excerpted from: Columbia News University Website. Press Release Updated: Mar 19, 2007  
Last modified: Mar 19, 2007

### May 2006 -- Adult stem cell implant first in orthopaedic patient

The Royal Melbourne Hospital has performed the world's first implant of cultured specialist stem cells into an orthopaedic patient.

Nine months ago, Jamie Stevens, 21 of Ivanhoe, suffered a broken femur which failed to heal.

Hospital Director of Orthopaedics Richard de Steiger performed the operation as an alternative to the standard bone graft which requires a separate incision and is potentially associated with other complications.

'If successful, this procedure may significantly reduce or eliminate long-term patient complications—while decreasing length of stay in hospital—and costs associated with the treatment of long bone fractures,' said Mr. de Steiger.

The operation is part of a groundbreaking Royal Melbourne Hospital clinical trial involving the use of adult stem cells in the treatment of patients suffering non-healing of bone fractures.

The trial is a world-first use of technology developed by Australian company Mesoblast Limited in an orthopaedic environment.

This technology is used to select and expand extremely rare adult stem cells and is a very promising area of regenerative medicine.

Millions of people worldwide suffer from non-healing of long bone fractures—a painful condition mainly associated with accident victims



*Editor's note:* This research may be used for Coronary Disease and Orthopedic issues, but the implications of using ADULT stem cells can benefit many different diseases and conditions, like Post Polio. Joanne Yager's question attached to the article in Special Living Magazine, was; is anyone doing research into using Adult Stem Cells? To answer her question, I found these pieces of information. I also found ADULT stem cell research into Cancer and cornea transplants. Way to go, Joanne!

## ACUTE, POSTOPERATIVE PAIN

Selma Harrison Calmes, MD  
Sylmar, California

Why try to prevent and treat postoperative pain? After all, you had an operation — it's supposed to hurt! This old attitude is changing today as the result of numerous influences. The new attitude evolving is that we are not supposed to have any pain at all. In reality, it is very difficult to achieve this new goal of no pain at all, which may not even be realistic — or good for you. But post-op pain can usually be made much better with some relatively easy techniques.

This talk will review briefly why postoperative pain (abbreviated as “post-op” from now on) should be treated, what can be done for acute post-op pain and the role of post-polio changes in possible management. Chronic pain in polio patients will be discussed by Dr. Julian Lo, and then there will be time for audience questions and discussion. Pain management is a very complex area, polio issues are a small part of a big picture, and it may not be possible to cover all issues, given the time allocated for the session,

In the past, cultural factors determined who got pain relief for operations. When anesthesia was first introduced in 1846, men having operations often did not receive anesthesia. Undergoing the pain of an operation was thought to help in achieving “manliness.” Similarly, poor people did not deserve pain relief. Women and children, thought then to be “weaker” than men, needed protection from pain during an operation, as did wealthy people and these groups always received anesthesia, if it was available. It took until the last quarter of the 19th century before most patients had pain relief during surgery.

Such cultural factors still play a role today in the area of post-op pain. The most common example is nurses from other countries not realizing a patient has pain or not treating it if the patient requests pain medication. A more difficult example is surgeons. Throughout the U.S., they are the main treaters of post-op pain. Unless they have had an operation themselves, they have little concept of the severity of post-op pain, how to treat it and the importance of treating it.

These old concepts are slowly changing in the U.S. These changes have been stimulated by patients' families, who have experienced the long, painful death of a loved one and asked why can't we do a better job of treating pain; scientific documentation of the harmful physiologic effects of pain; and the attention of hospital accrediting agencies, such as the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO), to this problem. New organizations interested in pain management, training programs in pain management and the ability to become Board-certified in this area, and validated measuring tools for pain also contribute to this transition in thinking. As an anesthesiologist working daily with recovering post-op patients, I can tell you we are still not where we need to be in all staff accepting that pain, especially post-op pain, needs to be relieved if possible.

Competing factors working against this new concept, in addition to cultural issues, include lack of adequate numbers of pain-trained physicians and RNs, a nation-wide shortage of anesthesiologists, the high cost of providing an acute pain service, lack of interest (this is not a flashy, techie area!), and reimbursement issues. Pain providers are financially rewarded for invasive procedures and not for drug management, which would often be adequate, and less risky than invasive procedures, at times.

What about post-polio's role in post-op pain? It does seem that post-polios often have more pain than other patients. Many of us have experienced, for example, very severe pain with a simple stub of a toe. See the pain pathway illustration and illustration of a spinal cord on the next page. Pain signals travel up (and down) the spinal cord and I postulate that pain signals are modified (probably enhanced, or “wound-up”) because of inflammatory changes in the spinal cord from the original polio infection of the cord. There is no experimental evidence (as far as I am aware) to support this concept; it is a theoretical idea only. But, we do know in other patients that pain signals are often modified (usually increased by “wind-up”) in the spinal cord.

*What is available for acute, post-op pain management?* Planning for a particular patient should be done at the initial pre-anesthesia visit. Multiple interventions should be planned, as a mix of approaches generally leads to greater efficacy and fewer side effects.

**1. IV OPIATES:** This is what most post-op patients get, because they are effective. These are drugs like morphine, and they work directly on the pain receptors in the brain and spinal cord to relieve pain. They have some side effects such as nausea, urinary retention and depressed respiration.

Typically, they are given only when a patient requests pain relief. The RN then has to get a key to the narcotic box, sign out and prepare the medicine and then go to the patient to administer it. This process often takes a long time, and it also results in an “up and down” blood level of the drug, not a constant therapeutic level. High blood levels (reached soon after the medicine is given) can cause side effects such as airway obstruction and low blood levels (as the medicine is wearing off)

give inadequate pain relief Patient Controlled Analgesia (PCA) systems, which were developed by anesthesiologists in the late 1960s, can deliver a constant blood level, and boluses are possible when the patient determines they need more pain relief. These machines solve the “up and down” problem and the RN time problem. PCA can be started in the recovery room, soon after surgery is over.

Morphine or Demerol are typical drugs used for PCA. (Demerol is used less and less because it has more side effects.) Other long-acting narcotics can be delivered in this system. Many hospitals today have PCA available, floor RNs are pretty well trained on it and, in general, PCA is very safe and effective. Intramuscular (IM) opioids should not be used because onset of pain relief is too long, and they are often ineffective. An anti-inflammatory drug Toradol (ketorolac) is popular for its additive effects to opioids for pain relief but has many contraindications. It is an anti-inflammatory drug (a NSAID like Vioxx) and is given IM or IV. It acts on the initiation of the pain signals at the site of the painful stimulus, in this case a surgical incision.

## **2. TECHNIQUES THAT ARE PART OF THE ANESTHESIA PLAN:**

a. Injection of local anesthesia at the surgical site(s): This is done by the surgeon, usually before the surgery begins, so it helps decrease the pain stimulus from the incision site during surgery and thus decreases the amount of other anesthesia needed. If a long-acting local anesthetic (usually bupivacaine or marcaine) is used, pain relief can be as long as 48 hrs. This forms the background, or basal, pain relief technique. It is not always possible to inject local anesthesia at a surgical site, usually because of infection. Because the injection takes time to do, it is often difficult to convince surgeons to take this simple but important step.

b. IV injection of a long-acting *narcotic* toward the end of surgery: This is done to cover the initial pain as a patient wakes up from general anesthesia. The usual drug is morphine; some use longer-acting drugs. A possible problem is that this would delay awakening, but cautious dosing, with additional small doses as it becomes clear where the patient is in the awakening process, can solve this problem. For short operations, the long-acting narcotic can be given even before anesthesia starts, as a pre-medication, planning on a post-op effect also.

c. Regional anesthesia, with additional drugs/techniques to prolong its pain relief: Regional anesthesia includes spinal, epidural and various blocks of the arms, hands, legs, feet and peripheral nerves. Not all operations can be done with regional anesthesia; but if this is possible, it can serve as a background technique for post-op pain relief. First, a long-acting local anesthetic could be used, to give pain relief for 24 to even 48 hrs. A good example of this would be an axillary block or supraclavicular block of the arm done with the long-acting local anesthetic marcaine (bupivacaine, mentioned previously).

Another possibility is to add narcotics to the local anesthetics injected into the spinal canal or epidural space. These narcotic drugs migrate into the spinal cord and actually enter it to “sit” on narcotic receptors in the spinal cord, giving long-acting pain relief. If many days of pain are expected, a small plastic catheter can be placed in the epidural space and a continuous infusion, or bolus injection, of either local anesthetics, narcotics or a mixture of both, can be given. This gives excellent pain relief and is how “labor epidurals” are given for obstetric patients. This is a manpower-Intensive technique, however, and many hospitals don’t have adequate manpower to manage these — you can’t just walk away from them and think the technique will work perfectly.

No matter which pain relief technique is used for a post-op patient, certain “system” pieces must be in place: The RNs should ask you frequently how much pain you’re having and what the pain is like. The timing of questioning varies from the recovery room to the floor. If you report significant pain, you should expect that the RN will give additional pain medicine, and then re-assess the pain to see how effective that medicine in that dose was. (Other techniques such as ice packs can be tried in certain circumstances.) These two requirements are from the JCAHO and MUST be met by every hospital that is accredited. The RN is also to record your pain (eve), the intervention used and the response to the intervention. Unfortunately, there are many difficulties getting these requirements established consistently, especially the re-assessment part.

Unusual circumstances may interfere with efforts to get good post-op pain relief For example; low blood pressure (hypotension) or breathing (ventilation) problems may occur postoperatively for various reasons and interfere with our ability to “push” narcotics to the needed level. Finally, surgical misadventures can lead to new pain post-op. The most common example I see is unrecognized post-op bleeding in a laparotomy patient, and blood is accumulating inside the abdomen. This is typically painful, if the usual pain relief techniques don’t seem to be working well, the patient needs to be reevaluated to determine all possible causes of pain. Return to the OR might be needed instead of additional morphine.

**3. POLIO AND POSTOP PAIN MANAGEMENT:** Post-op pain management depends greatly on narcotics such as morphine. Many post polio patients have obstructive sleep apnea. Narcotics may increase the apnea episodes and increase the risk of death. (Deaths have occurred in “normal” post-op patients with sleep apnea.) The solution is, first, try to rely on other pain relief techniques — generous local anesthesia, Toradol, etc — and, second, to put the patient where they can be directly observed (an ICU) for 24-48 hours post-op.

Ventilation is often marginal in post polio patients also, and the respiratory depression from narcotics can cause further problems. The solutions are to, first, identify ahead of time post-polio patients with limited respiratory reserve; next, make an appropriate plan (try to use local or regional anesthesia and avoid narcotics, if possible), admit the patient to an ICU post-op and be ready to support ventilation as needed. Artificial ventilation might be done for several days, and pain management could then be adequate since the risk of respiratory depression is taken away. During weaning from ventilation, if that is possible, pain medication would have to be cut back, of course.

Finally, technical issues can be prominent for post-polio patients. For example, we might want to place an epidural catheter for several days of post-op pain relief after a major operation, but the patient's severe scoliosis makes this very difficult or even impossible. New technology (ultrasound identification of the epidural space) may help with this problem.

In summary, with proper planning, good and safe post-op pain relief can usually be achieved in post-polio patients. However, many systems issues still make this difficult for some patients.

**Strategies for Living Well**      June 2-4, 2005      Saint Louis, Missouri  
Post-Polio Health International including International Ventilator Users Network    [www.post-polio.org](http://www.post-polio.org)

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## **EXERCISE: WHAT STEPS TO TAKE**

### **Exercise and Post-Polio Syndrome**

Mary Klein, PhD  
Philadelphia, Pennsylvania

- “Advising all polio survivors not to exercise is as irresponsible as advising all polio survivors to exercise.” (*Post-Polio Health*, Spring 2003, Vol. 19, No.2, part A).
- The benefits of exercise are endless. It can make you feel better physically and emotionally. These benefits can be achieved by performing as little as 30 minutes of exercise 3 times a week.
- Exercise can give you more energy, help strengthen your muscles and bones, decrease pain, increase flexibility, balance, coordination, and stability. Exercise can also help you lose weight, reduce stress, and help you maintain your independence with activity. If it is performed consistently it can be empowering, because it can leave you feeling like you are taking control of your body instead of fearing the negative changes.
- There are many conflicting articles that have been published regarding exercise and polio survivors. Some are in favor of exercise and others are against exercise. As a researcher, I cannot provide the answer for everyone of whether they should exercise or not. For polio survivors, exercise needs to be prescribed individually, just like medication.
- Individual. That is the most important word to remember when considering participation in an exercise program, especially as a polio survivor.
- Each polio survivor was affected in a unique way by the virus, both physically and mentally. When you are seeking treatment or being evaluated, your provider needs to be aware of what you have endured or overcome through your lifetime. That is why it is helpful for the provider to get a complete background of when you had polio, what areas were affected, what was the course of treatment, and how you recovered so that he or she can determine whether your body can tolerate exercise.
- Exercise must be done with planning and common sense and under the supervision of an experienced professional educated in exercise and knowledgeable in the effects of polio on the body. The professional will monitor your tolerance to the program and adjust it as needed. It may be helpful to keep an exercise journal to monitor your progress and reaction to the program.
- In general, a proper exercise program should involve three key components: a warm-up, exercise program, and a cool-down. The warm-up and cool-down are very important. The warm-up allows your muscles to stretch, your blood to start flowing, and your heart to pump a little harder. The cool-down slows your body down after the exercise and prepares it for rest. It allows you to slow your heart down gradually after the exercise.
- When we talk about stretching, we mean moving your body part to the point of feeling a pull in the muscles. If you feel pain, back off of the stretch and always avoid pain. In some cases, muscle tightness may be the body's way of compensating for muscle weakness. Stretching can undo this benefit and you could end up with less function than

you had before the exercise. This is one reason why it is critical that polio survivors have a clinical evaluation from their physician or physical therapist prior to beginning any exercise program, including stretching exercises.

- For polio survivors it is very important to avoid pain and fatigue. If you experience either symptom, you need to stop the exercise immediately. Pain in this instance is a sharp pain that may affect your everyday movements. Fatigue is an overwhelming tiredness that requires you to stop what you are doing and rest. These two symptoms could predict if the exercise program is too easy or too difficult. These symptoms may also occur up to two days after the exercise is performed. It is important to respect these symptoms in order to avoid doing irreversible harm to your muscles.
- The majority of the recent studies that have been published about exercise and polio survivors recommend exercising every other day. If you are fatigued prior to your workout, do not exercise that day and try to do a less intense workout on your next session. It means that your last workout was too strenuous for your body and should be decreased until you build up your tolerance.
- Another very important aspect of an exercise program for polio survivors is test breaks. Pace yourself. Frequent rest breaks should be incorporated into your program. This needs to be done, even though you may not feel tired when exercising. You need to listen and respect your body and the signals of fatigue.
- Review of Important Exercise Tips:
  - Start with a one-on-one, in-person evaluation and testing by a trained healthcare professional in order to determine what will work and what will not work for you.
  - Start slowly, recognize limitations and be willing to make adjustments along the way.
  - Do not hold your breath while exercising (count out loud to promote proper breathing).
  - Exercise slowly and build rest breaks into your program.
  - Alternate exercises regularly so that no one muscle group becomes overused.
  - If the program increases your pain, stop the exercise, or perform the exercise in a pain-free range of motion.
  - Do not push to perform the extreme of the motion or exercise.
  - Stop exercising if you have muscle twitching, muscle cramping, or muscle fatigue that does not subside after a 2 minute rest break.
  - Do not exercise to the point of fatigue. You could do irreversible harm to your muscles.
  - Try to figure out whether you feel better when you exercise in the morning, afternoon, or evening. Some individuals prefer to exercise in the morning because they have the most energy. Others exercise later, so that they make sure they can tolerate their daily activities prior to the exercise session, and they can rest afterwards. Lastly, others may divide their exercise program into two sessions to pace themselves.
  - Remember, you are unique and only you can tell how you really feel and what works best for you. Figure out what works best for you and stick with it. There are no specific formulas that will work for everyone.
- As polio survivors, you must remember that all of the recommendations for healthy living are even more important for you.
  - Don't forget to eat a healthy, well-balanced diet, which could help control your weight. It is very important for you stay fairly slim so you do not have greater difficulty with your mobility.
  - Get the proper amount of sleep, because fatigue may be decreased with rest.
  - Do your most strenuous activities during your greatest period of energy and take rest breaks throughout the day. It is very important to pace yourself and rest when you are getting fatigued.
  - Take a nap during the day if you need it, and it may give you the regeneration that you need to finish your daily activities
  - Remember to exercise under the care of a specialist trained to prescribe and monitor your progress. Do not exercise to the point of fatigue.
  - Those of you who use assistive devices and have weak legs are prone to overuse injuries of your arms. You have to be protective of your arms and shoulders, and sit on higher surfaces and in chairs with arms.
  - It is also very important to keep moving. If you can tolerate exercising, studies have shown that you can maintain or improve your strength when properly supervised and performed.
- "Beware of Inactivity I" (The National Center on Physical Activity and Disability). The statement counteracts the old advice that warned against having polio survivors exercise. The thought is now that no matter what level of disability you are dealing with, you can participate in an individualized exercise program that is monitored by a professional.

**Mary Klein, PhD**  
Director, Post-Polio Project  
Moss Rehab Research Institute

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