JANUARY 2011

POST POLIO MATTERS

The Polio Survivors Network Newsletter - Volume 7, Issue 3
n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk

It does exist!

World Health Organisation Code for

POST-POLIO SYNDROME is

G 14

and

WE'RE STILL HERE!
October 10-16, 2010
www.post-polio.org

SUPPORTING PHI'S YEARLY CAMPAIGN

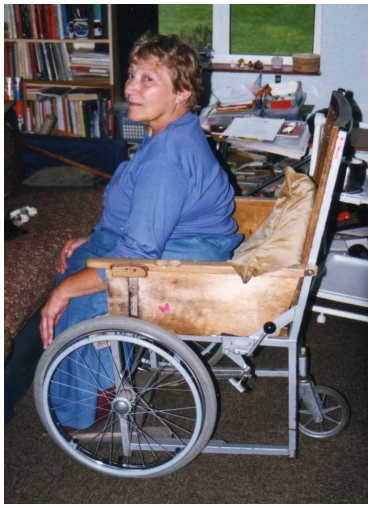
The Late Effects of Polio encompasses anything happening after having POLIO that is affecting how the polio survivor is managing.

Post Polio Newsletter
Dec 2010 Vol. 21 No. 4
Post Polio Network
of
Western Australia
www.upnaway.com/~poliowa

This issue is dedicated to the memory of Polio Survivor and former Trustee

Jean Tapper

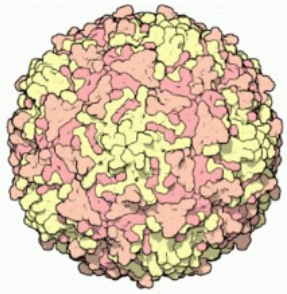
April 12th 1929 ~ January 8th 2011



The Polio vaccine was developed by Jonas Salk, and announced to the world by Salk on April 12th 1955.

Jean's 26th birthday.

I am only one,
but still I am one
I cannot do everything,
but still I can do something,
And because I cannot do everything
I will not refuse to do something I can do



Poliovirus, which is found in three similar forms, is designed to attack a given person only once. It makes its offspring and then is off to the next person. In most cases, poliovirus causes a simple flu-like disease as it attacks cells in the digestive system. This infection is rapidly cleared up by the immune system. But in about 1 in 100 cases, the virus spreads to the nerve cells that control muscle motion, causing paralysis--poliomyelitis--as the nerve cells are infected.

EUROPEAN CONFERENCE ON POLIO - Page 10

european polio union

ptu LIFE AFTER THE ACCIDENT

POST POLIO SYNDROME
– a challenge of today

COPENHAGEN // AUG 31 – SEP 2 2011

PSN AGM Saturday 18th June 2011

Venue:- The Pinsent Mason Suite 2,
The MAC Birmingham, Canon Hill Park,
Birmingham B12 9QH
1.p.m. To 5 p.m.

mac birmingham

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This issue of Post Polio Matters

AGM
Research
European Polio Conference
Anaesthesia Sharing Info

Hydrate for Health Sponsor Post Polio Matters

NAIDEX NEC BIRMINGHAM April 5, 6, 7 2011. Disability Equipment.
www.naidex.co.uk

MOBILITY ROADSHOW June 30th to July 2nd 2011 East of England Showground, Peterborough
www.mobility roadshow.co.uk

Contents

New Members and Donations received.

We welcome new members Janet Whitworth & Helen Brown

Thank you to the following for donations given towards our work.

Rose Fenton, Peter Button, Val Scrivener, Pat Stokes-Smith
Berenice Bowles, Joanne Curtis, Margaret Lamb, Nicholas Harvey,
J. Tavener, Steve Clynch, Tony Fuller, Winifred Hyam, B. Smith,
Vic Gabriel, Yvonne Grosse, Vivien Holland, Hilary Boone,
Richard Boone, Janet Whitworth and Bob Price

Donation from Cadbury of £500

Anonymous donation of £100.

Total since last newsletter is **£965.90**

We have no paid employees. We would like to recognise and thank the following for so generously donating their time. The Trustees, Dave Eate, Chris Salter, Barry & Olivia Branston, Bob Price and Anne Bennett.

Donations & offers of time towards our work are always welcome.

Editorial by Hilary Boone

Firstly I must apologise for the delay in providing this issue due to my laptop going in for repair for 12 days and having to take time out to deal with problems thrown at us by the complicated procedures Lincolnshire Social Services have in place for Personal Budgets. It is more than 8 months now since we started the assessment procedure and still we have unresolved issues to deal with. It has been a total nightmare but we are now into the fifth week of employing two support workers and at last we can see the tunnel!

Secondly, I am sorry to have to let you know the sad news of the passing of two or our members. Frank Knights who lived in the south of England and Jean Tapper from Lincolnshire. Jean was a Trustee of the Lincolnshire Post Polio Network in our early years. The poem was one she oft quoted and was read out at her funeral. I remember her as a very strong willed, determined, polio survivor and Lynn Hobday and I heard at her funeral that she had served on many Village committees and recently received a local award for her volunteering. About ten years ago I remember her telling me how disappointed she was that she could no longer call the numbers at Bingo because her voice was now too soft and she ran out of breath. Two months later she rang me to say, 'I now have a new gizmo that brings my whispers up to normal voice level so am back to calling the Bingo'. Did you notice the wheelchair she used in the late 90's had the large wheels at the front, one small wheel at the back with a cane seat? [see picture front page]

Sponsorship. Do you know any company or other organisation who would sponsor our newsletters by paying £50 for a year's mention? [4 issues] Hydrate for Health are our first sponsor. Two more members have let me know they have purchased one of these and how much easier it is to have a drink at night.

Membership. Members paying yearly can pay by Standing Order or by cheque. To save costs on printing and postage your renewal date appears on the address label of the newsletter and will be updated when payment received. Please send sae if you require a receipt. A renewal form will be included with the last newsletter of your current years membership. Life Members. We included another Contact Information Update Sheet with the last issue but only two more members returned them, 5 in total. It really would help us if you would write, ring or email me to ensure that our records are up to date.

Medical words used in articles. If you are unable to look up the definition of any term used and the article is relevant to issues you are experiencing then please get in touch and we will provide you with the definition. I will compile a list of the most used terms for the next newsletter.

'The Late Effects of Polio encompasses anything happening after having POLIO that is affecting how the polio survivor is managing' I saw this definition also printed on our front page in the Post Polio Network of Western Australia's Post Polio Newsletter, December 2010, V.21 No. 4. Do you think that this statement covers the symptoms and problems you raise that you are told are not Post Polio Syndrome?

Photo Cards by Member Val Scrivener [See back page] has added some more photos to the cards she is making and selling supporting our Network. Choose any five photos to make up packs of 5 and maybe you could sell a pack or two to your family and friends and help towards the costs of our work.

Medical Terms in articles. Some articles have a few medical terms that may make it difficult for you to understand all of the article. These are provided in case you have related issues so that you may share information with health professionals who may not be aware of the information.

Polio Survivors Network - Meeting information

The next Trustees Meeting is being held in Birmingham on
Saturday 7th May, 2011

Annual General Meeting is on Saturday 18th June 2011

At the MAC, Canon Hill Park, Birmingham, B12 9QH, from 1pm to 5pm.

www.macarts.co.uk/plan-your-visit/getting-here/

If you have any matters for our attention at our meetings please get in touch via
info@poliosurvivorsnetwork.org.uk
or Tel: 01522 888601 or write to us at Polio Survivors Network PO Box 954, Lincoln LN5 5ER

Cadbury donates £500 towards our work.

Member Gillian Bryan Co-opted to PSN Committee

PSN Survey Good response

Rare Disease UK [RDUK]

☎

020 7704 3141

Fax

020 7359 1447

Message from the Chair

I am hoping you all got through the snow on snow winter, enjoyed Christmas, New Year, Burn's Night, remembered all those old acquaintances, Chinese New Year of the Rabbit and, by the time you read this, Valentines' Day!

Since our last Newsletter we have a new Co-opted Committee Member, Gillian Bryan, who has attended her first Trustees' Meeting and she brings with her a life-time's experience and knowledge of business administration - her skills are much welcomed and much needed by our Polio Survivors Network.

We had a good response by members to our survey and the full report will be available at the AGM which, this year, will be held at the Midland Arts Centre in Birmingham. Early information indicates that of those who returned questionnaires Polio Survivors achieve quite a few years lived beyond three score years and ten! Well done PSN people.

The consultation for Reform of Disability Living Allowance (DLA) ends on the 14th February, 2011. Information about this has been posted on the Members Email List, including the petition to recall the Consultation and calling for the Minister for Disabled People, Maria Miller, to be sacked. We only really have two channels of communication with which to raise issues with you; Post Polio Matters and the Members' Email List. We do not have more resources to raise issues with you at the moment. The DLA Consultation began after the last newsletter and ends as this one goes out. We will obtain a copy of the Report of the Consultation and, if an opportunity arises, respond to it. We will do our utmost to keep you informed.

PSN is a member of Rare Disease UK and Rare Disease Day is on 28th February with events happening in England, Wales, Scotland and Northern Ireland.

For more information contact RDUK at www.raredisease.org.uk or

The Secretariat, Rare Disease UK,

Unit 4D, Leroy House, 436 Essex Road, N1 3QP, UK.

Email :- info@raredisease.org.uk

PSN has contributed to the RDUK's draft strategy for Rare Diseases and as soon as this is published we will let you all know.

Well, we're on our way to Spring and, fingers crossed, sunny days ahead. Oh and as well as the 1st March being my wedding anniversary it is also St. David's Day so to our Welsh Members:

Happy St. David's Day ..... DYDD DEWI SANT HAPUS IAWN

Sandra

sandra.paget@poliosurvivorsnetwork.org.uk

Tel: 01494 729373 Mob: 0777 294 0905

POLIO SURVIVORS NETWORK
ANNUAL GENERAL MEETING

SATURDAY JUNE 18TH 2011

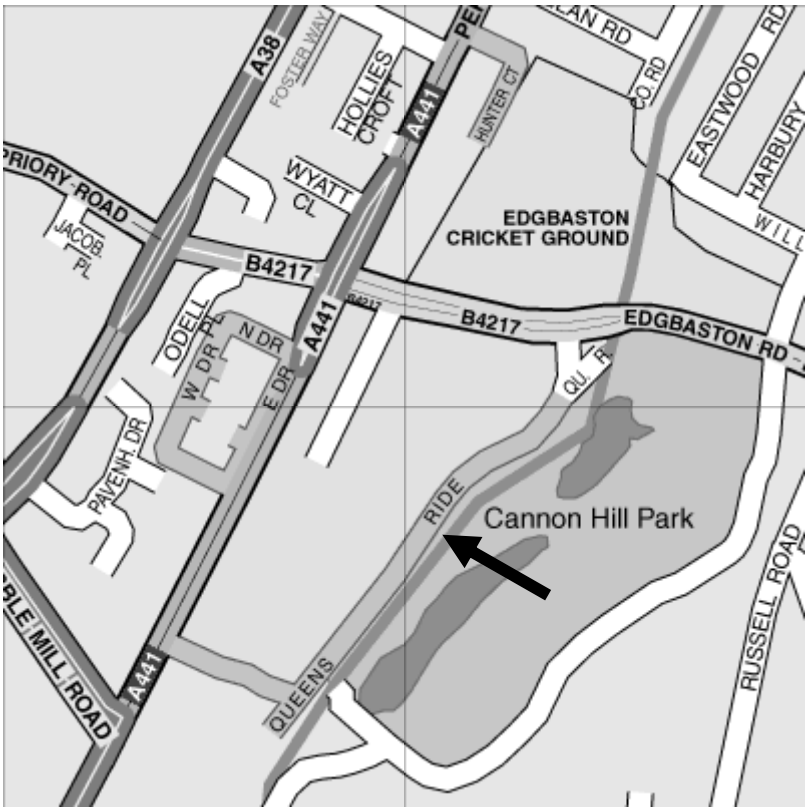
Pinsent Mason Suite 2,
The MAC Birmingham, [Midlands Arts Centre]
Canon Hill Park,
Birmingham B12 9QH

1.p.m. To 5 p.m.

Bridges Café Bar

Offer a tempting selection including daily specials,
breakfast: hot and cold sandwiches,
pastries, delicious cakes, main meals and jacket potatoes.
9am- 11pm (Hot Food available 9am - 8.30pm, snacks available until 11pm)

Arrive early and have a snack or lunch in the Cafe Bar
Room opens at 1.00 p.m. AGM commences at 1.10 p.m.
Followed by Speaker, Tea Break and Raffle, Speaker and Q&A session
To ensure the room chosen will accommodate all attendees
If you think you might come please return the enclosed slip. THANKYOU
More information in the next newsletter



MAC is located in
Cannon Hill Park,
Birmingham,
opposite the
County Cricket Ground
on Edgbaston Road,
off Pershore Road (A441)
and Bristol Road. (A38).
Buses
1, 35, 45, 47, 62 and 63.

Two articles by Member Edward Bollenbach, Professor Emeritus in Biology.

Article 1. Where Is The Research That Will Matter?

I have been wondering if we will have the time to see breakthroughs in research that will benefit polio survivors. It seems like there is nothing new to read. Does that mean we are adrift with nothing of value in the pipeline for us?

We know the cause of the damage we now suffer. Clearly, it is a loss of nerve contact with muscles. This came about because when we recovered from acute polio compensation from the damage came in the form of new growing connections between surviving nerve and muscle. This was called "Compensation". The loss of nerve muscle connections was compensated for by live fiber sprouting from surviving nerves. Now we have decompensated. Those connections are gone and more are going and the muscle targets are in big trouble or have atrophied.

Most people with old polio lament that there is a dearth of meaningful research in the direct area of post-polio syndrome to address this loss, and many believe that such targeted research is our only hope for future advances to improve our lives. I have a different take on this and feel that we may be lucky enough to enjoy new functionality in our future. History has shown that new understanding of specific medical problems, more often than not, comes from research targeted toward other problems, sometimes in areas not even related to the disease which is helped, but nonetheless apply and are beneficial even thought this was unforeseen in the original research.

Historically, one of the most famous instances of a new application from research which benefits something else unforeseen arose from an experiment by Louis Pasteur. In the last years of the 19th century everyone was trying to find the cause of various diseases in animals and man by isolating bacteria and proving that the isolate caused a particular disease. Robert Koch in Germany first isolated the anthrax bacterium and showed that when it was inoculated into healthy cattle they developed anthrax. A big problem in France at this time was chicken cholera, which could spread through chicken farms and decimate populations of chickens in these facilities.

Pasteur decided he would isolate the bacterium that caused chicken cholera by drawing blood and feces and separating bacterial isolates into single cultures of bacteria. Then, he would test each type by inoculating healthy chickens. He meticulously used Robert Koch's earlier published procedures for doing this and in a short time he came up with a candidate bacterium. Alone in his basement Pasteur would inoculate healthy chickens with his pure bacterial type and the chickens would develop cholera. He felt he had nailed down this problem and called other microbiologists and veterinarians to view his accomplishment. But he used older growths of his pure candidate bacterium and some of his chickens did not get sick. He went home and thought about it and decided he needed to use newer fresh bacterial growths to cause the disease. He called for another demonstration, the story goes, and this time he used all new growths of his candidate bacterium for chicken cholera. But another problem occurred. The problem this time was that some of the chickens he inoculated with his new growths he had also earlier inoculated with his old growths. Guess what happened? Some chickens didn't get sick and the one's that didn't were the ones inoculated earlier with old cultures. Pasteur didn't know why this happened at first but he soon found that the chickens that didn't get sick were previously inoculated with the old cultures. He had accidentally vaccinated them against a disease where he had isolated and grown the cause, and this step forward allowed for an explosion of vaccines that protect us today from a host of diseases from influenza to polio. Right now there are over 300 new vaccines pending to protect against things like Alzheimer's and certain cancers as well as other problems. This was an enormous advance in bio medicine but what started it was Pasteur looking for something else entirely: the cause of chicken cholera.

Some of you may have heard of Moore's law. It states that the number of transistors that can be placed in an integrated circuit has doubled every two years for the last half century. We don't know when this will stop although we are approaching limits. The rate of new knowledge

generated in biomedicine is even faster than that for computers . This is due in part to improvements in computer technology (Moore's Law) but it is also due to other scientific factors relating to increases in knowledge which feed even faster increases in meaningful research and technological applications.

The rate of progress we now see in bio medicine, as well as in computer science, have resulted in an exponential increase in biomedical research to the point that I see new things every day that may help us. Just think of Pasteur's fumbling around giving us decades more in life expectancy just by isolating disease bacteria and accidentally weakening them to produce vaccines. Then think about how many experiments are occurring today with our increased knowledge and how many of them can surprise us with real help as our research knowledge doubles in less than two years, faster than it does with Moore's law for computers.

Let me make this more concrete. In the 1970's gene sequencing was expensive and very slow. I remember sitting in a Genetics seminar at Cold Spring Harbor on Long Island, with my graduate school mentors, listening to scientists talk about a project to sequence and decode the human genome. That is, to find every letter in the code of life that makes us human. Many thought this would be an expensive and inordinately long process. But the speed at which sequencing genes increased, and the expense of doing it decreased over the years so rapidly that this rate of biomedical progress in genetics is today astounding.

Back when the human genome research project began, when geneticists were trying to unmask our entire human genetic map the cost was about 3 billion dollars. Today it is about $5000. In the next few years it will be under $1000 and we will be able to map our individual genes. This is astonishing and illustrates what is true in many areas of biomedicine today. We may even be able to replace defective genes soon.

According to a lecture in 2004 on the “Pace of Biotechnology” by Michio Kachu http:// www.physicspost.com/science-article-197.html , the rate at which we can now sequence genes doubles and decreases in cost by more than a half every year. Here are some of Kachu's other predictions: Soon we will be able to grow organs like the liver and pancreas in a lab. Producing a pancreas may cure diabetes. Replacing defective genes may cure diabetes too as well as many other genetic diseases. We expect advances in cloning, aging research, and neurology that will astound and surprise us in the next few years. Much of it will be applicable to the polio problems we now face. Neurons are now being produced from a person's own cells and we will be able to use them in spinal cord damage and brain damage. This will make possible the replacement of neurons where there is a deficit. These predictions point to the fact that we are at a time when miraculous cures for all kinds of disorders are at our doorstep.

Here are some recent advances in the science news:

A study of the blue green algae spirulina was shown, when used as a supplement, to delay motor neuron degeneration in ALS. This study was published in “The Open Tissue Engineering and Regenerative Medicine Journal” (3:36-41). At Stanford University, a study of zebra-fish showed that the number of synapses (nerve connections to muscle) varied between night and day. This article appeared in the October 2010 issue of the journal Neuron. It is clear, within the article, that chemical instigators can be isolated that will spur neuronal growth. A UC Irvine study is the first to demonstrate that human neural stem cells can restore mobility in cases of chronic spinal cord injury, suggesting the prospect of treating a much broader population of patients than traumatically injured spinal patients. (www.medicalnewstoday.com/articles/198573.php)

Microtubules within motor neurons generate the end fibers we have lost due to polio. In “Current Biology, 09 December 2010” a new biochemical named kinesin was discovered which can allow scientists to direct the growth of microtubules through damaged tissue to target muscles. This could result in directed growth of arrays of microtubules with the proper ends facing muscle surfaces to allow contact and connection to weakened or newly grown muscles.

In the Journal of Neuroscience, September 29, 2010 an article titled: “New Drug Treatment Triggers Sodium Ions To Regrow Nerves And Muscle; Could Extend Treatment Window For Acute Injuries” has obvious applications to old polio, since both muscle and nerve would need to be regrown. In another article entitled ‘Stem Cells to Treat Muscular Dystrophies – Where are we?’ Neuromuscular Disorders ,Volume 21, Issue 1 , January 2011, Pages 4 -12, as current as can be, the authors review criteria for using stem cells to replace damaged muscle in muscular dystrophy, but there is no reason why these techniques and therapeutic recommendations could not be used in old polio. And remember the fight over using embryonic stem cells? In the past year it has become possible to routinely coax human skin cells and transform them into neurons and other cell types. This makes the embryonic stem cell ethics moot.

The examples and discussion above is a prelude to some of the advances I see, that were targeted for different purposes within bio medicine, and in which important applications are likely to emerge for people with old polio.

In other words, it is not as depressing as is generally thought regarding biotechnological applications to old polio. If all the money allocated toward the research described above were allocated solely to polio I would be surprised if we found ourselves with as much application directly to old polio damage. We would run out of useful projects to try because our knowledge base would fall behind the amount of money we would have to spend. Many discoveries have proven to be accidental. The more research the more these serendipitous accidents will occur. It is the volume of biomedical research that matters, and the increasing pace of discoveries. The real question is how fast and safe is it going to be to do trials on humans and how expensive will these treatments be. And above all, will we just miss these rapidly developing bio-medically relevant applications because we were born just a tad too early. At the increasing rate of discovery and application it is not unrealistic to think positively.

As I was writing this a new paper appeared on my computer screen: The Breast cancer drug Taxol helps regeneration of neurons through scar tissue. http://www.medicalnewstoday.com/articles/215049.php The pace just blows me away.

Article 2. Biomedical Research Is Accelerating. Why Don't We See An Acceleration of Cures?

In the previous article I argued that the pace of biomedical research is so rapid that specific research on PPS might be too narrow and that we are likely to discover new treatments of value from the expansive research happening right now. And, the pace is accelerating at more than double the rate of discoveries every two years. So, the cry for more PPS centered research, especially in this time of austerity, may not be productive for us after all. If these arguments are sound most readers should breathe a sigh of relief that there will be new drugs and new medical devices and new procedures that can help us. If we take stem cell research, for example, experts in this field say that for the first time cures for diabetes, paralysis, and blindness are in sight. Two of the aforementioned maladies have a large impact on the health of those of us with PPS. So what is the problem? If all this is in sight why can't we see them coming? I think our advocacy for research may be misplaced because the research, no matter how fast it proceeds, still entails waiting for 10 to 15 years to see marketing and application. This is too slow and , surprisingly, the pace of bringing treatments to market hasn't changed much in a century according to “Biomedical Research and Health Advances” by Moses and Martin in the January 10th 2011 edition of the “New England Journal of Medicine”(1). This is a big problem for us. What exactly is the problem and why can't cures and treatments make it to the patient faster?

I want to concentrate on one of the problems we have in the United States (which has enjoyed a history of biomedical research and discovery that made it the world's primary source of new drugs and treatments). Now, however, Europe, Israel, and Indonesia are on a pace that will outstrip the US in discovery and treatment if changes in the US are not made. Later, I will add

other problems we share in all countries that stifle the provision of new medicine to patients. One of the big problems here are patents on scientific research findings, shown in an article in Red Orbit news on January 10, 2011. (2)

Patents on intellectual property interfere directly with the way science works to correct itself and move on to more complete understanding. Earlier work must be available for scientists to test and improve upon. But patents by scientists, or the companies they work for, hoping to “cash in big” restricts others, and sometimes even themselves, to use known information and build on successful precedent.

Bob Lanza worked for a biotech firm called Geron for several years coaxing stem cells to produce beta cells that produce insulin. He was using them to cure animals with diabetes. He currently works for Advanced Cell Technology (ACT) but since Geron holds patents on the intellectual property he amassed on stem cell treatment for diabetes, during his work for the company, he is unable to use the results of his life's work because Geron holds the intellectual property rights to it and now he works not for Geron but for ACT. Unless he can secure that information he will be stymied in using his knowledge base to advance work toward curing diabetes in human beings. Geron is currently starting trials with stem cells on spinal cord injury and Advanced Cell technology is starting work on the blinding eye disease of macular degeneration with stem cell intervention. Both of those ongoing projects are likely to suffer setbacks because other entities hold intellectual property rights that may benefit these current programs. Even though both companies secure intellectual property rights and have to jump through hoops to get information to give them a better chance of success. Yet this practice continues.

We are at a point in scientific biomedical research where we have to find new ways about how intellectual property is patented and how improved sharing of information between the public sector, the private sector, and foundations can be done. If we don't prioritize this, we, the patients, will be the ones who will suffer.

The New England Journal of Medicine suggests that patenting be deferred in return for “new funding and greater latitude to conduct high risk research”. The research entities would immediately put new discoveries into the public domain to be built upon by new research. This would also allow new laboratories to hire new talent as researchers will not fear that by changing companies they will lose their life's work due to patents on intellectual property (1). This problem has been sidestepped in Europe and other countries conducting stem cell research. In Europe scientists are not allowed to file patents on scientific research because of a 2008 ruling which declared such patents would upset public order. Currently, the Hinxton Group, a joint US-British team that works to address these problems has recommended that two open databases be created. The first database would be for stem cell lines that are in use worldwide, the second would keep intellectual property rights so that scientists could openly access them. Right now, it is interesting to note that more research in these fields is occurring in private companies than governmental entities and this is going to continue through this austerity period. Government has a role in helping private companies change to better serve the public good.

There are several other problems that gum up the speed and delivery of medicine of high clinical value. Companies often do research and expound on discoveries through “rose colored glasses” exaggerating the effectiveness or safety of a discovery. We need better information on the effectiveness of new drugs and new treatments so that comparative studies can be done, preferably by uninterested parties like private foundations or academic laboratories.

Teaching hospitals, which do clinical trials, should have those trials done by freestanding institutes or unconnected academic centers so that the trials will have more clinical value and be more easily shared with other researchers. Governments and Foundations should develop priority financing of new scientific approaches to problems and also for models of collaboration between entities in the creation of new biomedical knowledge.

The establishment of Biomedical Trusts that individuals or companies can donate to for high priority diseases, and get tax credits for doing so, could promote more open research. States and governments could issue bonds for such research. We must put the "Care" back in healthcare at the discovery stage so that commercial issues do not slow progress by prioritizing profit interests above patient interests.

Biomedical Research produces new jobs, enhances trade between countries, and improves the Gross National Product of countries. However, as discussed above, it will take years, probably even decades to get our biomedical house in order so that effective discoveries can be expedited and provided to human beings who suffer from real diseases. When this aspect of the biomedical/commercial intellectual property rights/ social order can be effectively restructured, we will see good treatments get to market in a shorter period than the 10 to 15 years we have been stuck with for much too long. There is a lot of work ahead. Instead of advocating for specific research on specific diseases we should advocate to government and industry to work out better processes and procedures to get us where we want to be faster.

Sources

1. "Biomedical Research and Health Advances" by Moses and Martin in the January 10th 2011 edition of the "New England Journal of Medicine"
2. www.redorbit.com/news/health/1984948/ us_patents_on_stem_cell_research_hindering_progress/index.html

Post Polio Syndrome - a challenge of today
European Conference, Copenhagen, Denmark, August 31st to September 2nd, 2011
European Polio Union [EPU} and the Danish Society of Polio and Accident Victims [PTU]

AIM
After the large polio epidemics in the last century around 700,000 people in Europe are now suffering from polio sequelae. Many survivors have a decreasing functional level because of paralysis, fatigue and pain, and this is a big challenge for polio survivors and the professionals, who are treating them.

The European Polio Union wishes with this conference:

- To give medical and social professionals a possibility to exchange new research results and to debate relevant topics on a professional level
- To give polio survivors a possibility to achieve and exchange new knowledge on assessment, treatment and coping
- To achieve awareness on post-polio issues in the health sector and social services

Congress language will be English. Online registration.www.polioconference.com

REGISTRATION FEE

	Before April 1st 2011	**After April 1st 2011**
Professionals	3000DKK / 400 Euro	3500 DKK / 470 Euro
Polio Survivors	1465 DKK / 195 Euro [£165.09]	1950 DKK / 260 Euro [£220.13]

Registration fee includes participation of the sessions and catering during the conference & free admission for the Welcome reception. Conference Dinner must be paid separately.

VENUE
Hotel Crowne Plaza Copenhagen Towers
Ørestads Boulevard 114—188
DK 2300 København S, Denmark
+45 88 77 66 55
www.cpcopenhagentowers.dk [rooms from £104 a night]

CONFERENCE SECRETARIAT
Merete Bertelsen
PTU, Fjeldhammervej 8
2610 Rødovre, Denmark
+45 3673 9044
mbe@ptu.dk

BEWARE UNCARING DOCTORS IF YOU NEED AN ANAESTHETIC

By Life Member Verité Reilly-Collins, Travel and Health Writer.

If anyone was a patient at the Royal National Orthopaedic, Stanmore, in the 1956, they might remember I was the 14 year old nuisance who was in the swimming pool all afternoon. J.I.P. James was my surgeon, and Sister used to freak out as I bantered with him. He would pull my plait as it hung through the bars of my bed – I often faced 'wrong way' so I could see more of what was going on in the ward.

We would have long conversations, when all other patients treated him with awe. I seriously believe that this helped me walk out of the hospital, when I had been told "you will never walk again". But a combination of my sheer blxxxdy mindedness and his interest in this appalling patient got me back on my feet.

So I left Stanmore, and got on with life. I couldn't swing from a trapeze any longer, nor climb trees, but apart from that I had few problems – until years later I developed breast cancer.

So it was back to hospital, where I learnt that many doctors don't know how to look after us. It's not funny – in fact it could be very dangerous.

So anyone reading this, you MUST tell your doctors and other health professionals that you had polio, especially if you have to have an anaesthetic. Not many British doctors have any idea how to treat us (is this familiar?), but having an anaesthetic is fraught with potential problems. Add post-polio to the equation, and I found out this is a recipe for potential disaster.

When I talked over my options with my cancer surgeon, I did mention that I had had polio, but didn't make a big fuss about this. I also told the anaesthetist – but as she was not the slightest bit interested, I assumed polio was no great problem. She was one of the team from the Royal Marsden; I thought they had a good reputation anyway, so she would know what to do.

Waking up after my op, there was no-one in the room with me. "Bother" I thought, "I didn't have the op", and started to get up off the trolley to find out what was happening. The trolley shot across the room, crashed into spare trolleys, and I was left hanging off the edge.

In burst a nurse, "you are meant to be asleep" she shouted. No apology, it was me that apologised to them – fool that I was. Back upstairs, I felt awful. Convinced this was what cancer was all about, I tried to stay in for longer – but you know the health service: I was sent home and spent a week in bed, too weak to move.

Gradually things improved, and it wasn't until two years later I happened to read Dr. Spencer's paper on anaesthesia for polio patients, and I realised how badly I had been treated. Every problem I had had – from taking days to get warm again (in the middle of July) and stop shivering, to being unable to move from my bed – all were mentioned in the paper as problems if polio patients had the wrong anaesthesia.

So ever since I have tried to ensure that hospitals take note and treat me properly – not easy, in the NHS culture.

Next problem happened with an MRI scan. By this time I was wary, asked how long it would take, and was airily told, "about 90 minutes". I asked what I would have to lie on, and was told the usual metal base. So I politely sent an email saying that I would need some form of pain relief to be able to lie that long on such an uncomfortable surface. The department confirmed they had received my email, so all was OK.

Until the day of the procedure, when a doctor swept in to tell me I didn't need pain relief. I said I did. She said I didn't, and we see-sawed back and forth for 20 minutes.

You know what we are like – at least what I am like – stubborn. Eventually doctor gives in, I am given something I assume is for pain relief, and we start the MRI scan.

Ten minutes later the red hot pokers are blasting up my spine, and I tell them I am coming out. Doctor is furious, meets me as I crawl out, arms akimbo; “I gave you something for claustrophobia” she told me!

After that, one would think my reputation would have spread around the hospital, and other technicians would be making sure I didn’t muck up expensive procedures. I am told I have to have an angiogram – but no-one told me I would have to lie with my arm above my head for half an hour. Of course I can’t raise it, so have to ask the doctor – who very bad tempered lifts it up and places it in some restraint.

Of course, you guessed it – this time they had to carry me upstairs to a bed and give me some very heavy pain relief. Then a wonderful surgeon, Mario Petrou, was given the task of telling me I had to have a seven hour heart operation. Poor man !

But – he bothered to get hold of the anaesthetist who contacted not only me before my op, but spoke to my polio doctor (Dr. Zilka at that time), and bothered to read the paper from the Polio Fellowship about what we needed. I woke up in Intensive Care feeling fantastic, and didn’t have a twinge or a problem afterwards.

So if you have to have an MRI Scan , Long CT scan, Long X-ray, Radiotherapy, Operation etc., make certain the team looking after you know you have polio, and if they don’t know how to deal with your condition, get papers that tell them what they must do.

It is counter-productive to have pain. If you have had a difficult procedure the last thing you need is to have to put up with the red hot pokers playing tunes on your spine – or wherever they entertain you.

Make a fuss. Be a nuisance. YOU are the patient, and medical staff should make quite sure you are comfortable. They are always harping on about ‘dignity’. Well, what’s dignified about being in pain?

Abroad patients are often used as Advocates, and introduced to nurses on training courses. I have tried to get this organised in Britain, but as I was told at The Marsden, “you are only a patient”.

However, if anyone has the ear of an MP, or better still someone from the Dept. Of Health, try if you can get them to introduce a half hour talk about “how to treat polio patients”. It can only be to our advantage, and surprisingly enough I bet the nurses and doctors will learn a thing or two.

Prof. Guiloff is now ‘my’ polio specialist and tells his students (bless him) “never ask a polio patient IF they can get up stairs. Always ask them HOW they get up stairs – it might be shuffling on their bottom”.

Verité Reily Collins <verite@greenbee.net>
Editor: www.after-cancer.com; www.healthspanews.com
Member Chartered Institute Journalists; the Sports' Journalists' Association., and the Association. Guild Health Writers

Mr. Hornby admitted to his wife that he was feeling much better since his operation, but couldn't account for the enormous bump on the back of his head.

"Oh, that," chuckled Mrs. Hornby.

"Just before your operation they suddenly ran out of ether!"

A man is in a hospital bed completely wrapped up in a body cast. One of the nurses gave him a rectal thermometer and told him not to move she would be right back. When she returned the thermometer was in his mouth. She asked in amazement,

"How did you get that in your mouth, you can't even move?"

He replied ‘I hiccoughed’.

Summary of Anesthesia Issues for the Post-Polio Patient

Selma H. Calmes, Chairman and Professor, (retired) Department of Anesthesiology, Olive View-UCLA Medical Center, Sylmar, California. Selma is also a fellow Polio Survivor.

Polio results in widespread neural changes, not just destruction of the spinal cord anterior horn (motor nerve) cells, and these changes get worse as patients age. These anatomic changes affect many aspects of anesthesia care. No study of polio patients having anesthesia has been done. These recommendations are based on extensive review of the current literature and clinical experience with these patients. They may need to be adjusted for a particular patient.

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 a longer period 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 poliovirus 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 intraop helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.

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

4. Postop 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 scarring 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 ventilatory function postop, and some patients who did not need ventilation have had to go onto a ventilator (including long-term use) postop. It's useful to get at least a VC preop, and full pulmonary function studies may be helpful. One group that should all have preop 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 preop and a plan for postop ventilatory support. Another ventilation risk is obstructive sleep apnea in the postop period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.

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 postop, after intubation or upper extremity blocks. ENT evaluation of the upper airway in suspicious patients would be 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.

For more info: Review "Postpolio Syndrome and Anesthesia" by David A. Lambert, MD; Elenis Giannouli, MD; & Brian J. Schmidt, MD, The University of Manitoba, Winnipeg, Canada, in the September 2005 issue of *Anesthesiology* (Vol. 103, No. 3, pp 638-644). This article reviews polio, postpolio syndrome and anesthetic considerations for this patient population. [See overleaf]

Postpolio Syndrome and Anesthesia

David A. Lambert, M.D.,* Eleni Giannouli, M.D.,† Brian J. Schmidt, M.D.‡

Anesthesiology 2005; 103:638–44

[Editors Note:- This article contains very important information to add to the previous two in this newsletter. This article is FREE to download at http://journals.lww.com/anesthesiology/Fulltext/2005/09000/Postpolio_Syndrome_and_Anesthesia.29.aspx#

We do not have enough room in this newsletter for the whole article which covers Poliomyelitis: Acute Illness and Recovery and then moves onto Post Polio Syndrome. To supplement the previous articles we start our reproduction at the sub-heading Respiratory Function. We urge anyone reading this who does not have basic knowledge of Polio and Post-Polio Syndrome to read the full article.

N.B. Page 13, the third line under the heading Preoperative Assessment, marked with an * - absence of known polio damage to the upper body should not preclude a full respiratory assessment as more and more polio survivors are now reporting and having symptoms confirmed when tests ask for a few repeats of actions.]

Respiratory Dysfunction. One of the hallmarks of the treatment of acute poliomyelitis was the negative pressure ventilator, or iron lung. Respiratory failure secondary to polio, when present, was the major cause of morbidity and mortality. Respiratory symptoms occur in up to 40% of PPS patients. **[37]** Symptoms range from mildly decreased pulmonary function to frank respiratory failure and the need for assisted ventilation. Contributing to these symptoms are restrictive chest wall changes (scoliosis, kyphosis), altered chest wall strength (decreased maximum inspiratory/expiratory pressures), recurrent infections, and sleep-related disordered breathing (SRDB).

Anesthesiologists are familiar with caring for patients with respiratory problems. However, patients with SRDB, including obstructive and central sleep apnea as well as hypoventilation syndromes, can be particularly challenging. Theoretically, PPS patients are at higher risk of SRDB because of previous damage to the reticular activating system, decreased strength and tone in upper airway musculature, and increased rates of obesity due to decreased mobility. whether PPS patients have an increased incidence of SRDB relative to healthy individuals is not clear. However, in one study of 155 Postpolio patients by Fischer, [**38]** the symptoms of frequent waking, snoring, and daytime fatigue were reported at least five times more often than in healthy controls. Daytime sleepiness, tiredness, morning headache, and restless leg symptoms were reported more often in PPS subjects than in healthy controls. **[39]** Another study retrospectively examined 35 subjects who fit the criteria for PPS and had symptoms of SRDB. **[40]** These investigators found three patterns of sleep disturbance: obstructive sleep apnea (n = 19), hypoventilation (n = 7), and a combination of both (n = 9). Interestingly, compared with non-PPS patients evaluated for obstructive sleep apnea by the same laboratory, PPS patients were of similar age (55 *vs.*56 yr) but weighed less (176% *vs.* 144% ideal body weight).

Laryngeal function was examined in nine subjects with PPS. **[41]** Subjects who reported severe swallowing problems were the same individuals who had impaired voice and laryngeal function, based on videostroboscopic evaluation, acoustical analysis, and, in three patients, laryngeal electromyography. Half of these patients were found to have unilateral vocal chord paralysis. These same patients gave a history of bulbar symptoms with their initial polio illness.

Cold Intolerance. Cold intolerance is not uncommonly reported in PPS patients. One 5-yr follow-up study of 68 PPS patients found that 65% of patients reported symptoms of cold intolerance. **[24]** Whether this is the result of altered perfusion to limbs secondary to vascular changes in atrophied muscles or from changes in vasoconstrictor tone due to damaged sympathetic pathways is not clear. **[42]** Treatment is symptomatic.

Dysphagia. [difficulties with swallowing] Dysphagia is reported by 10–20% of PPS patients. **[43]** Symptoms range from mild "sticking" of food in the esophagus to frequent choking and symptoms of

reflux disease. In one study, ultrasound and videofluoroscopy were used to evaluate swallowing function of 32 PPS patients. **[44]** Fourteen had symptoms of dysphagia, and 12 had a history of bulbar involvement. Interestingly, swallowing abnormalities were revealed in 31 patients, regardless of the presence or absence of dysphagia. These studies suggest that PPS patients, even if asymptomatic, may be at increased risk of both overt and silent aspiration**. [40,41,43,44]**

Anesthesia and Postpolio Syndrome

Only four case reports discuss anesthesia and PPS. **[45–48]** Two of these describe complications. The first report describes a 79-yr-old patient with unanticipated ventilator failure postoperatively, which, on investigation, was thought to be the result of undiagnosed PPS. **[48**] The second and most recent report is that of a 51-yr-old patient presenting for foot surgery related to her previous childhood polio illness. **[46]** The patient experienced acute cardiopulmonary arrest in her hospital room approximately 1 hour postoperatively and did not recover from the resulting cerebral injury. The arrest was presumed to be the result of oversedation secondary to opioid administration in the presence of possible obstructive sleep apnea. The other reports describe PPS patients who underwent anesthesia without incident (spinal anesthesia in one patient and anesthesia for electroconvulsive therapy in the other patient). **[45,47]**

Preoperative Assessment

Preanesthetic evaluation of a PPS patient should begin with an assessment of the history of the patient's previous poliomyelitis illness. The patient's age at the time of illness, severity (including the presence or absence of bulbar symptoms*), and amount of recovery are all helpful in anticipating the likelihood of developing PPS. Documenting the extent of residual deficits is important to understand the patient's baseline function. If the patient reports symptoms suggesting PPS, one should consider referral to a specialist with experience with PPS patients, such as a neurologist, if this has not already been done. In some cases, the surgical service may be unaware of the fact that their patient has PPS. Communication of this information should enhance overall patient management.

Often, chronic pain syndromes are present in these patients. Evaluation of contractures or spinal deformities is important to establish a baseline and anticipate positioning issues that might arise intraoperatively. Although patients may already be taking oral opioid medications, many are "opioid naive." Some patients may report excessive sedation with opioid or sedative hypnotic drugs, as prescribed for dental procedures, for example.

A detailed respiratory evaluation is very important in this patient population. Anesthesiologists may encounter PPS patients with no respiratory symptoms at all, or conversely, the PPS patient may have a mature tracheostomy site and may be dependent on overnight positive pressure ventilation. Any symptoms suggestive of decreased respiratory reserve should be thoroughly evaluated with a baseline chest radiograph and spirometry. Vital capacity of less than 50% of the predicted value, or 1,500 ml, warrants complete pulmonary function testing, including maximum inspiratory/expiratory pressures. Special attention should be made not to overlook a history consistent with sleep apnea or hypoventilation syndrome. This includes symptoms of morning headache, excessive daytime somnolence, and episodes of snoring or apnea during sleep. A positive history should prompt arterial blood gas sampling and consideration of referral to a respirologist and a formal sleep study. **[49]** Patients with SRDB syndromes are at higher risk of cardiac dysfunction, including cor pulmonale and pulmonary hypertension. Finally, preoperative evaluation should include an inquiry into symptoms of dysphagia and reflux disease.

Perioperative Considerations

An important consideration in the anesthetic management of patients with PPS is whether regional anesthesia is safe. Many anesthesiologists are hesitant to use regional anesthesia in patients with pre-existing neuromuscular deficits, because of the concern of exacerbating existing disease or difficulty evaluating complications. There have been no reports of adverse effects due to regional anesthesia in PPS patients, **[45]** but this does not necessarily mean that regional techniques are without risk.

Animal studies have determined specific intrathecal concentrations of local anesthetics that are lethal for

neurons. **[50]** It is not possible to know the number of healthy *versus* damaged motor neurons in an individual PPS patient. However, patients with PPS have fewer motor neurons than normal, at least some of which are likely to have residual dysfunction, or increased metabolic demand because they supply enlarged motor units (fig. 1C). These motor neurons may be more sensitive to drug effects. Therefore, theoretically, the toxic intrathecal concentration of a local anesthetic may be lower in PPS patients. However, to date, there are no direct experimental data to confirm or refute this concept. There is also no evidence as to whether there is an increased risk of adverse effects using peripheral nerve blocks or indwelling catheters in PPS patients.

Ultimately, the decision to use general or regional anesthesia should be made on an individual patient basis weighing the risks and benefits. If a spinal anesthetic is selected, a medication with a long history of safety, such as hyperbaric bupivacaine, should be used.

There are several considerations when administering general anesthesia to patients with PPS. Initially, it is important to ensure that the patient is comfortably positioned and that attention is given to limbs with contracture. Blankets or warming devices are particularly appropriate because of cold intolerance. Baseline twitch response to peripheral nerve stimulation should be measured before administering neuromuscular blockade, because this response might be abnormally small in some muscles. Traditionally in patients with neuromuscular disease, succinylcholine is used cautiously to avoid precipitating hyperkalemia. However, there are no specific data on the use of succinylcholine in patients with PPS. One study suggested that patients with a remote history of polio have increased sensitivity to nondepolarizing muscle blockers. **[51]** For this reason, selection of shorter-acting agents, such as rocuronium and mivacurium, along with careful titration of doses to desired effect, is important in patients with PPS. In some cases, completely avoiding neuromuscular blockade may be appropriate.

The fact that patients with PPS often have residual lesions involving the reticular activating system **[4,25]** may be of particular relevance to anesthesia. The reticular activating system is a theoretical site of action for most anesthetic agents, and patients with PPS may show altered sensitivity to anesthetic drugs. No data describing the dose–response characteristics of induction agents in patients with PPS exists, nor is it known whether there are differences in minimum alveolar concentration when patients with PPS are compared with the normal population. Considering possible altered sensitivity to induction drugs, maintenance agents, muscle relaxants, and opioids, caution in the selection of dose of virtually any medication administered for general anesthesia should be used in this patient group.

Emergence from anesthesia should be preceded by ensuring complete reversal of neuromuscular blockade. The risk of aspiration is greater in at least some PPS patients. As such, selected patients may benefit from prophylactic antiemetic medication. Careful suctioning of the hypopharynx before emergence is essential. Vital capacity “big breaths” before extubation may help to recruit a maximal number of alveoli. Doses of opioids should initially be low and carefully titrated to effect, and long-acting medications should be used cautiously. Other coanalgesics, such as nonsteroidal anti-inflammatory agents, should be used when possible.

Postoperative Management

As noted in the first paragraph of the Anesthesia and Postpolio Syndrome section, two reports have described postoperative complications, one resulting in death, in patients with PPS. **[46,48]** In these two cases, postoperative respiratory failure, associated with weakness, over-sedation, or both, was deemed contributory. Therefore, the most serious anesthesia-related risk for PPS patients may be in the postoperative period. Just as it is now recognized that more intensive postoperative monitoring may be needed for patients with a history of obstructive sleep apnea, it would be similarly appropriate to increase one’s vigilance during postoperative monitoring of patients with PPS. Ambulatory surgery in this population should be considered only in select patients. It would seem prudent to avoid “fast-tracking” the transfer from the operating room immediately to the ward in patients with PPS.

Finally, coughing should be encouraged. Incentive spirometry and humidification of inspired gases should be considered for PPS patients in the recovery room.

Conclusion

Survivors of the poliomyelitis epidemics are now more than ever presenting for a variety of surgical procedures requiring anesthesia. Some of these survivors have developed PPS. In reviewing the pathology of acute poliomyelitis and PPS itself, multiple considerations for anesthesia become apparent. These include compromised respiratory function, SRDB issues, chronic pain syndromes, aspiration risks, and cold intolerance. In addition, postpolio patients may display altered sensitivity to any of the medications commonly used for regional and general anesthesia. Once aware of these considerations, anesthesiologists are better prepared to provide safe care, not only to patients with PPS, but to any patient with a history of poliomyelitis.

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Joan M Walker, PhD, PT [also in leaflet format copies sent as part of your Info Pack]

- You are going to have surgery - A guide for Polio Survivors
- Polio Survivors as patients - Guide for Emergency Care and Surgical Health Workers
- What you should know about your medications - A guide for Polio Survivors [UK Version]

Richard L Bruno PhD

- The Knife is not so rough if... [Preventing complications in polio survivors undergoing surgery]
- Be true to your PPS and your teeth won't be false to you: preventing complications in polio survivors undergoing dental procedures.

Polio Survivors sharing info.

Please send info for this page by email or letter. We know that may be difficult for a few members who are welcome to ring. Deadline for next issue is March 15th.

Do any other readers experience?

1. Able to sleep better during the day in recliner or bed if the tv is on [a program happy to drift in and out of] but if someone turns tv off then wake up immediately.

2. A few polio survivors already said this happens to them as well. If we have really overdone and crash out - usually with tv or music playing - then we drift into and out of various levels of consciousness. We report a level that is 'able to open eyes but not move muscles' - up to 40 minutes - and then we seem to sigh a big sigh and are able to move limbs. Do any other readers experience this? Noted is that an unexpected noise will wake us up with a start.

Things that have helped.

1. **Reducing ventilator mask leaks**. Using a bi-level ventilator takes a bit of getting used to - for user and anyone sleeping in the same room. The major issue we have had is mask leaks which disrupt the level of sleep for both of us. Just over a month ago whilst searching for a picture of the ventilator mask to put on information for new support workers we found some cotton mask liners and they have worked for us. They are American, took seven days to arrive. www.RemZzzs.com [n.b. This is a personal statement and not on behalf of PSN]

2. **Pain in hip when sleeping**. We now have physio at home twice a month and it is making a difference. 5th visit I asked if she could help with bad pain in left hip that comes on at night. She asked me to show her the position I sleep in - on my left side almost in recovery position to be able to breathe at my best. Immediately she told me that the pain was caused by my being over too far twisting my spine. She pulled me back straight, lying on side, and put a small pillow between my thighs. No Hip pain now but knee pain started. Two weeks later she advised another small pillow between calves and knee pain has gone. If I fall back onto my back I cant breathe as well and wake up. To prevent this she suggested using two pillows in this shape /\ but with the left hand pillow on top of the right at the top of the /\, to stop me rolling all the way back. My head is on the right hand pillow \. That too has helped.

3. **Talking to others in the same position**. Coping with the stresses and strains of getting medical and social care help now we have PPS can be tough. Not only for the user but for the carer as well. Having a chat with another polio survivor or carer/family member of a polio survivor can really help. Finding out that others are experiencing the same things and being able to discuss possible ways of improving the situation helps. Strangely there is often much laughter associated with these chats, and laughter really does help lighten the load.

Laughter IS the Best Medicine.

I was in the Mall in Lincoln last week and saw a new store with the name Tickle Fish. On investigation it was the strange new beauty treatment for feet where small fish called Garra Rufa nibble and suck at your feet to gently remove dead skin cells through natural exfoliation!

I came home, told my husband and said I was going to try this next time I was in town.

'And How Much Is This Going To Cost?' was his next clipped word statement. I replied with a smile 'that it was **only** £10 for 15 minutes'.

He paused and then said 'I suppose it is an 'All You Can Eat Rate' for the fish'.

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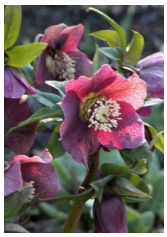

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