

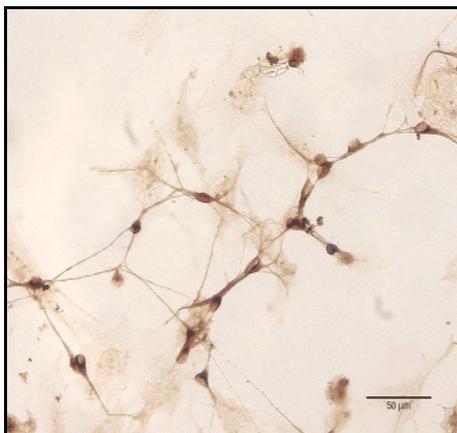
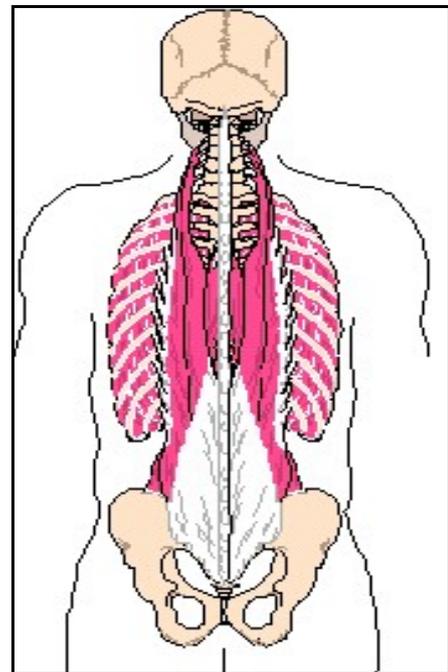
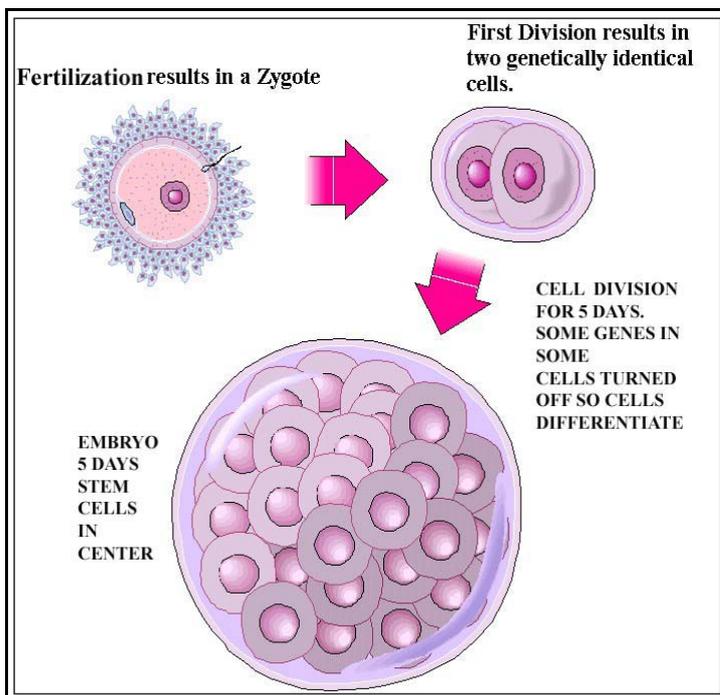


# The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**  
Volume 4 - Issue 9 - April 2004

WebSite - <http://www.lincolnshirepostpolio.org.uk>

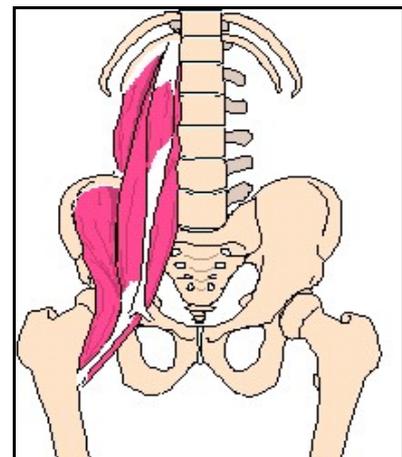
## STEM CELL THERAPY FOR POST-POLIO SYNDROME?



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Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Post-Polio Network. Although it does not provide an endorsement, it is provided as a service to those seeking such information.

ALWAYS consult your doctor before trying anything recommended in this or any other publication.

**Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177**

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**WE WOULD LIKE TO THANK THE FOLLOWING  
FOR DONATIONS RECEIVED TOWARDS OUR WORK.**

**Awards for All - £4,113 for equipment to give presentations.**

**West Haddon Players - £145**

**Other donations received since last newsletter will be in the next issue.**

**Lincolnshire Post-Polio Network - UK Registered Charity 1064177**

**Donations large and small towards our work are always welcome.**

**Lincolnshire Post-Polio Network,**

**69 Woodvale Avenue, Lincoln, LN6 3RD, UK**

**Tel: +44 01522 888601 Fax : +44 0870 1600840**

**[Do not dial first 0 if ringing from outside the UK]**

### **Membership Information**

**Renewal dates** are the first of the Months of Feb, Apr, Jun, Aug, Oct, Dec.

**Please make all denomination cheques/checks payable to 'Lincolnshire Post-Polio Network'  
Post to Membership Sec, 78 Heron Road, Larkfield, Aylesford, Kent ME20 6JZ, UK**

**UK Membership** - Life Member (LM) £150 or £5 x 30 months S.O. - Member £10 a year.

All UK Memberships payable by Standing Order - Forms from Membership Secretary.

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**European Membership** - LM E300 - Member E25 a year.

**USA** - LM US\$375, Member US\$25 a year - **Canada** - LM C\$550, Member C\$40 a year

Other Countries please contact [membership@lincolnshirepostpolio.org.uk](mailto:membership@lincolnshirepostpolio.org.uk) for details.

### **Next LincPIN Newsletter - June 2004**

**Articles for publication mid May by post or** - [newsletter@lincolnshirepostpolio.org.uk](mailto:newsletter@lincolnshirepostpolio.org.uk)

**Founder & Chair** - Hilary Hallam - [hilary.hallam@lincolnshirepostpolio.org.uk](mailto:hilary.hallam@lincolnshirepostpolio.org.uk)

**Treasurer** - Denise Carlyle - [denise.carlyle@lincolnshirepostpolio.org.uk](mailto:denise.carlyle@lincolnshirepostpolio.org.uk)

**Secretary** - Di Newman - [di.newman@lincolnshirepostpolio.org.uk](mailto:di.newman@lincolnshirepostpolio.org.uk)

**Membership Secretary** - Robin Butler - [robin.butler@lincolnshirepostpolio.org.uk](mailto:robin.butler@lincolnshirepostpolio.org.uk)

Mar-y-Mail - [mary.kinane@lincolnshirepostpolio.org.uk](mailto:mary.kinane@lincolnshirepostpolio.org.uk)

**Committee** - Pauline Butler, Mary Kinane, Sheila Dunnett

**Phone Team - Leader** Di Brennand - [di.brennand@lincolnshirepostpolio.org.uk](mailto:di.brennand@lincolnshirepostpolio.org.uk)

Phone Team - Pat Hollingworth, Margaret Edmonds

**Lincolnshire Post-Polio Network WebSite Administration**

Chris Salter - [netadmin@lincolnshirepostpolio.org.uk](mailto:netadmin@lincolnshirepostpolio.org.uk)

Editorial by Hilary Hallam.

The Committee would like to extend huge thanks to Life Member Bob Price from Jacksonville, Florida for being the postal address and paying in our USA\$ checks [cheques] for the last six years. He obtained funding for the computer for the WebSite 5 years ago and has added donations to almost every paying in slip. His support towards our work has been magnificent. Bob is now retiring and going to be visiting other parts of the USA. Our Best Wishes go with you.

I have to apologise for sending the last newsletter, by email, to Robin in the wrong Printer format. When this happens a few of the words can move slightly onto different pages. Corrected version is on the WebSite.

Great News. Sheila Dunnett has been completing applications for grants over the last few months and through her hard work we have now had our first success. Awards for All has granted us the sum of \$4,113 for the purchase of laptop computer, projector, screen and Microsoft PowerPoint software. This will enable us to give presentations at any venue.

Our first project will be to increase the number of presentations we can offer to a wider variety of audiences and timings available. If you have any information, photographs, news articles, short video clips, medical records, etc that would help us provide more visual effect then we would like to hear from you. Your approval would be sought before any of this information was used in a presentation and all original material would be returned. It might also be necessary/or you could request that we block out personal details/hospital names.

What we are looking to the NHS to provide is a standard throughout the country more appropriate route of referral for polio survivors to health professionals who have

enough knowledge of polio and pps to assess us correctly the first time. Sometimes we have a hard time convincing health professionals that situations have occurred/are still occurring. For instance one member has been given seven different diagnoses from seven different doctors from the same medical speciality. One week she happened to see one on the NHS and one privately and one said she definitely had MS and the other that she definitely did not have MS. We would be using this information in a positive way, e.g. chart to show how our stress levels and frustration increase as we try to obtain a diagnosis doing the rounds of hospital departments, the time it takes and the costs incurred.

A slide already used is one showing the variety of responses to our members:-

- 1 Are you sure you had Polio, you look fit and healthy to me.
- 2 The pain down your left side is 'all in your mind'.
- 3 PPS does not exist and if it did you would not have it.
- 4 You say you can only walk 25 yards now, please walk across my office [4 steps each way]
- 5 PPS? Oh! yes, I just read something about this new condition [first medically noted in 1875]

If you take the first response above, this member now takes a photograph with him to appointments showing him wearing callipers on both legs and a newspaper article about the polio epidemic in the village when and where he caught polio. His recovery was such that physically unless undressed and walking more than across the doctors office he does not easily look like the Polio Survivor the health professional remembers from his 20 minute lecture at College.

Your Network needs your help to get the message across. We look forward to hearing from you.

# Mar-y-Mail

Here is a synopsis of some of the emails that I deal with from our info@ and enquiries@ email addresses.

I'm the editor of a new monthly health journal, the Consumer Health Journal. I'm trying to fill a gap I've observed in health reporting -- health consumers are, in my opinion, smarter and more interested than much of the media gives them credit for.

If you have a few minutes, please visit Consumer Health Journal at ([www.consumerhealthjournal.com](http://www.consumerhealthjournal.com)) and pass the link along to whoever you think might be interested.

If you have any comments on the site or its content, please let me know. My goal is to improve the quality of consumer health information, and I'd appreciate your feedback.

Thank you for your time,  
Alison Stewart, editor  
Consumer Health Journal  
[www.consumerhealthjournal.com](http://www.consumerhealthjournal.com)

## Request from health professional.

Would appreciate information as to the advisability of a postpolio patient using the statin drugs in connection with cholesterol lowering.

In reply we sent a variety of links to medical and newsletter articles.

Dr. Julie Silver in a talk in Florida 2 years ago advised that we should not immediately say 'we cannot take that drug it is on a list of not advisable for PPS'.

It would be much better to discuss with

your health professional the need for the drug for the non pps condition and the information you have regarding this drug and PPS. It might be that together you come to a decision to try the drug at a low dose and monitor the effects because it is more important that you take care of the other condition.

**Disabled badge** - remember that the side that must be displayed is the one with the serial number and expiry date of the badge on it.

**Avon & Somerset** - I am looking for someone who has experience with polio so that I can get some much needed advice/treatment.

**Synopsis from email received.** [I thought those of you not on the Internet might be interested in this. Emails like these arrive in our email inbox every month.]

"After further investigation it was also discovered that Gen. Ibrahim Moussa did not declare any next of kin. Twenty millions Five Hundred Thousand UnitedState Dollars is still lying in my bank and no one will ever come forward to claim it. My suggestion to you is that I will like you as a foreigner to stand as the next of kin to Gen. Ibrahim Moussa so that you will be able to receive his funds."

Needless to say we delete these and do not respond but it would be nice if it was true.

## Denise Carlyle, Treasurer reports....

The West Haddon Players have sent us a further donation of £145 towards our work for which we are most grateful.

Mary Kinane - Committee Member.  
[mary.kinane@lincolnshirepostpolio.org.uk](mailto:mary.kinane@lincolnshirepostpolio.org.uk)

# STEM CELL THERAPY FOR POST-POLIO SYNDROME?

by Member Prof. Eddie Bollenbach, B.A. M.A.

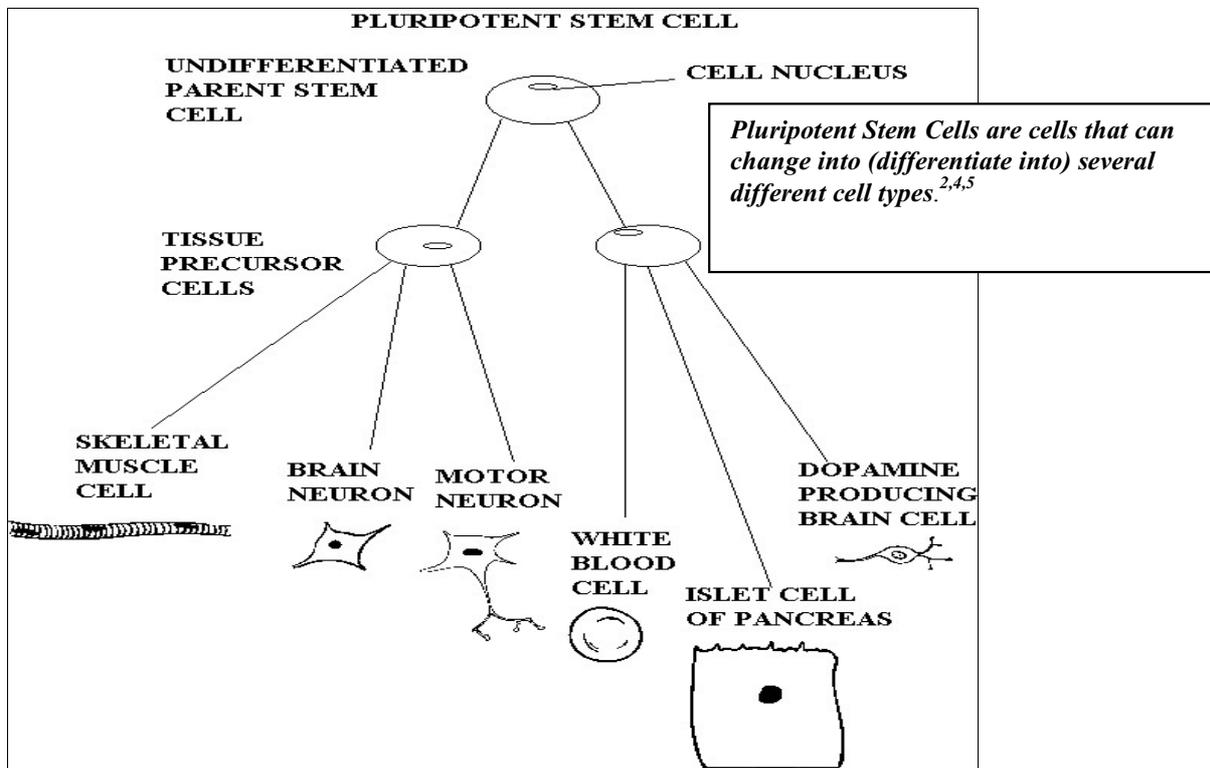
There's a magic in the distance, where the sea-line meets the sky.  
Alfred Noyes (1880-1958)

If you lose blood new blood cells of all types are formed from stem cells in the bone marrow, and after a time the composition of blood cells in the body will be entirely normal. This regeneration of adult cell types from simpler adult stem cells in bone marrow happens with blood and with other cells types too, but can it be for all cells?

If you break a bone and the bone is set and immobilized, after a month there will be new bone cells which bridge the gap. Where did these new specialized (**differentiated**) cells come from? The repair is expected, and even taken for granted, but exactly how does this happen?

There are cells in many areas of the body, which are primitive (**undifferentiated**) because they have not developed into specialized cells like neurons or muscle fibers, but they can, under special circumstances, differentiate and repair damaged tissue. Is it possible that we can collect and manipulate these cells in the lab, and grow these undifferentiated **stem cells** to make other specialized (differentiated) cell types? Cell biologists have been doing this for a while. Figure 1 gives a broad outline of the process.

Figure 1



This article will explain how these regenerative cell processes occur and will present much of what we have learned about controlling and directing new tissue regeneration in the lab (**in vitro**), and in test animals (**in vivo**). We will also discuss the prospects for the future with regard to Stem Cell Technology. Finally, we will examine the outlook for the application of Stem Cell therapy, and its derivative discoveries, toward mitigation and support of cells damaged by old polio. Finally, we will examine the conceivability of stopping, reversing, or improving Post-Polio Syndrome with Stem Cell Technology.

## **EMBRYONIC STEM CELLS**

There are two broad categories of stem cells: adult stem cells and embryonic stem cells. When the sperm enters the egg the sperm and egg nuclei fuse and the genes from both sperm and egg mix. This fertilized egg, the **zygote**, is **totipotent**[2]. The totipotent cell has the capability to divide to form new cells and/or transform (differentiate) such cells into all the different cells and tissues in an adult. It is a developing embryonic cells that, when acted upon by cellular hormones and the environment [2] can switch blocked human genes on, and some active embryonic genes off and thereby transform (differentiate). Toti, the prefix, indicates the potential for transformation into all the cell types of the body to produce a new individual. If the human being is to develop normally this is imperative, as all the tissues must derive from the zygote. As this fertilized egg goes through the stages of embryo formation, growth, and differentiation of cells the process is called **embryogenesis**[3]

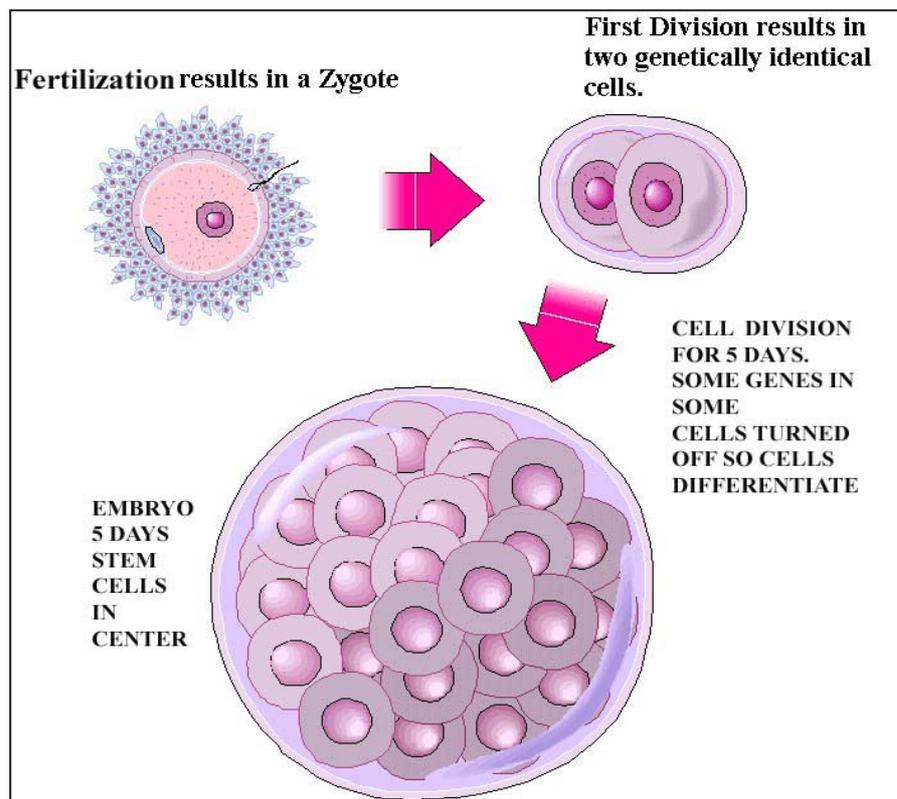
Before a sperm fertilizes a human egg it contains a single copy of all the genes a human being possesses. When the sperm penetrates the outer covering of the egg the sperm's genes mix with the egg's component of all the genes needed to be human. Now there are two sets of all the genes, which is the normal situation for every cell in the adult human body. The information each gene possesses, say for blood type, may be different in sperm and egg, but after fertilization there are two genes for blood type and for virtually every other human genetic characteristic. In the adult, however, there are different cell types, which make up different tissues. There are bone cells, skin cells, nerve cells, blood cells and the cells that compose organs. And, each general cell type, like a blood cell, has several different subtypes. Each differentiated adult cell expresses different genes and suppresses others[1]. In the adult body there are several trillion cells.

Embryonic stem cells, in the center of the spherical five-day embryo, given the proper nutrients and growth factors, seem to be able to divide and grow in a laboratory dish for a year or more without differentiating. Stem cells from an adult cannot[4]. The reasons for this have not been clarified but early embryonic stem cells "signal" to one another, and while many of these signal chemicals have been identified, and are used to direct cells to develop into particular tissue cells; bone, cartilage, muscle, or neurons, the distinctive chemical differences between adult and embryonic cells are unknown.[5]

Figure 2 below illustrates early embryo formation from which embryonic stem cells are derived. The source of these embryos has been in vitro fertility clinics where the

growth of the embryo has been stopped at the 5-day stage. Embryonic stem cells, from the center of the ball of cells of the blastocyst, are **pluripotent**, which means they can differentiate into very many different cell types of the body[6]. Many adult stem cells have failed in this regard but some adult stem cells, which are rare, but present in bone marrow, blood, brain, skin, and other tissues, have proven to be multipotent, and even pluripotent meaning they can differentiate many or a few tissues.[6]

## Embryogenesis



**Figure 2**

*The five-day blastocyst, used to harvest embryonic stem cells, abundant inside its ball of cells, is equivalent in size to a fraction of the size of the period at the end of this sentence. There are no specialized tissues, organs, nor self-awareness. However, the use of embryonic stem cells presents ethical concerns to many because of beliefs that this structure is a human individual and has potential to develop into a human being. The center of the ball contains about 30 stem cells.*

## EMBRYONIC STEM CELLS, ETHICS, AND LAW

Many contend that the fertilized egg is an individual and that life begins with fusion of sperm and egg. If after cell division the two resulting cells are separated, naturally or mechanically, identical twins can result. So the fertilized egg is certainly not an individual. Also, both the sperm and the egg are living human cells prior to fertilization. The strongest ethical argument limiting the use of embryos seems to be the fact that, if left alone, embryos implanted into a mother would develop into unique human beings. However, limiting the scope of ESC research funding to a few embryos already having produced stem cells, while discarding thousands of unused embryos produced by couples within in vitro fertility clinics seems by many to be misguided.

On July 31, 2001, the House of Representatives of the United States voted for a broad ban on human cloning which included the ban on cloning for research

purposes, including cloning embryos that could be used for stem cell therapies. The ban includes penalties of 10 years in prison and fines of 1 million dollars for anyone who generates cloned human embryos[7]. As this was passed the Department of Health and Human Services stated that there were about 64 cell lines that could be used. Later this estimate was decreased to 24 or 25. However, many stem cell researchers doubt that any of these stem cell lines will be useful for therapy[8].

These political and legal issues complicate the existing technical hurdles to developing stem cell therapies. For example, there is a knotty problem using embryonic stem cells in an adult recipient. These stem cells are foreign tissue with foreign markers on the cell surface. These markers alert the immune system to muster an attack against the foreign cells[17]. This must be solved for effective embryonic stem cell therapies to become reality.

One remedy would be to use a cell nucleus from the recipient of therapy and switch it with the nucleus in a zygote. If this could be done all the cells produced from that cell would be genetically identical to the therapy recipient. That should mitigate some rejection problems. However, you may realize at this point that the procedure described here is cloning (therapeutic cloning). Such research is not eligible for federal dollars in the United States. However, very recently Zwanka et al successfully altered the genetic composition of a human stem cell by removing a disease-producing gene[16]. This very recent breakthrough could lead to the genetic manipulation of stem cells instead of cloning zygotes. It is a “workaround”. This had been done with mouse embryos earlier but the technical obstacles to genetic alteration of human stem cells prohibited the same kind of success in humans. Zwanka’s group used an electroporetic approach to allow for gene insertion by recombination within a healthy cell genome.[16]

The British, who have no laws against Embryonic Stem Cell Research, draw the line of life at implantation in the uterus[9], which takes a middle ground approach between life beginning at fertilization and life beginning at birth. In any event these issues will be of significant importance as we learn more about how embryonic stem cells differentiate, with laboratory manipulation, to viable adult cell types. It is likely that some successful procedures will be more readily approached with Embryonic Stem Cells and some with Adult Stem Cells. In addition to the ethical and political barriers, as you can see, there are significant technical and scientific problems, which must be solved.

## **THE EMBRYONIC STEM CELL IN THE TREATMENT OF NEURODEGENERATIVE DISEASES**

Animal models, particularly rodents, have served valuably in much of the preliminary work on correcting neurodegeneration using stem cells. In 2002 American Scientists reported in Nature success in using stem cells from mouse embryos to cure Parkinson’s disease in rats/[10] Parkinson’s Disease affects about 5 million people worldwide and results from the degeneration of specialized brain neurons that produce the chemical dopamine. The most evident symptoms are movement and walking difficulties. Ron McKay of the National Institutes of Health transplanted a gene into a rodent embryonic stem cell that continuously reproduces, by cell

division, into a large number of the correct type of dopamine secreting nerve cells.[10] McKay's group transplanted these cells into a rat with Parkinson's symptoms. The animals resumed normal movements and stayed healthy for the equivalent to a lifetime for a human being.[10] Despite the fact that McKay was successful in rats we have a long way to go before such success occurs with humans. Rats and mice can be genetically engineered so that rejection of the tissue is not a problem. The adult human has an immune system that has to be sidestepped by therapeutic cloning or stem cell genetic recombination, and immune suppression[17]. And rat cells behave differently than human cells. McKay subsequently tried to do the same experiment by transplanting human embryonic stem cells into a monkey with Parkinsons but researchers were unable to get these stem cell derived dopamine neurons to secrete a large enough amount of dopamine. So some difficulties remain along with other problems discussed above.[11] The neurons within the brain, which die in Parkinsons disease, are all clumped together. So if the proper replacement neurons are cultured in large enough number, and if inflammation during transfer and immune rejection can be prevented, the cells can colonize the area in the proper number and allow for normal secretion of dopamine.

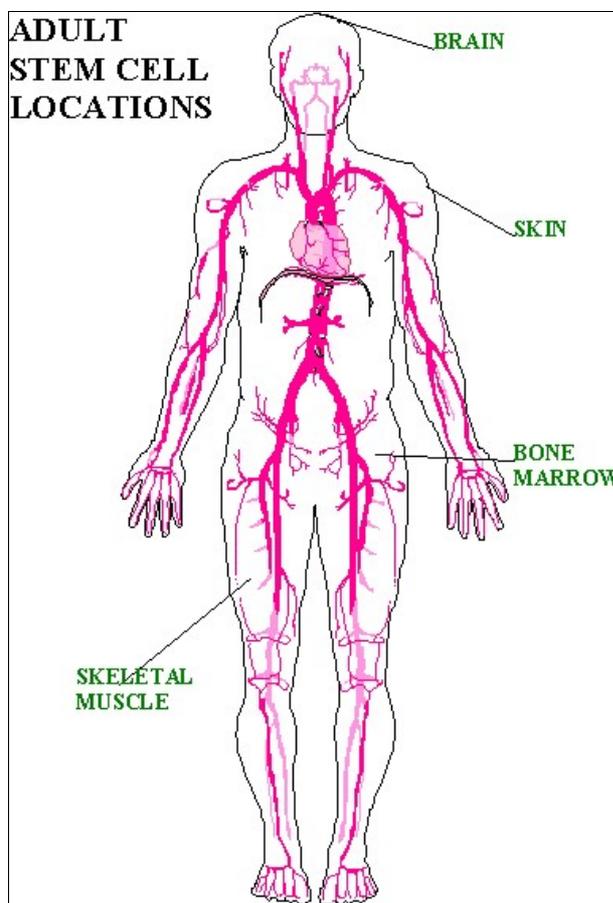
This problem becomes much more complex for polio-damaged neurons and their contingent muscles. Although we will talk about some strategies and therapies for polio we should understand that motor neurons from the anterior horn have their cell bodies in the spinal cord but long axons, sometimes over a meter long, must wend their way down, horizontally, or vertically to innervate microscopic skeletal muscle fibers, each of which is like a strand of hay in a haystack a mile away. To date, state of the art researchers in neuronal stem cell biology, like John Gage at the Salk Institute, cannot conceive of a way to guide these neurons to the muscle fibers to positively affect function, even if all the other problems can be solved.[12] Dr. Gage said to me, in response to a question I posed to him: "I agree that it is unlikely that in the damaged cord of any kind, that the transplanted cells will differentiate into functional neurons and send axons peripherally to the appropriate muscles.[12]" There is also the problem of regenerating skeletal muscle, which has died or become dysfunctional due to years of atrophy. We will consider these topics, but we must understand the additional difficulties that present for Polio, when compared to neurodegenerative Parkinsons and other brain cell function problems, where the neurons are all in one place.

## **USE OF ADULT STEM CELLS**

Embryonic stem cells have some disadvantages. As mentioned, they are readily rejected by the immune system of the recipient. Also, they convert more often to tumors than do stem cells derived from adult tissues.[11] Recently stem cells have been isolated from a number of adult tissues (Figure 2). Some of these cells are monopotent, able to produce only one type of adult cell, but some adult stem cells are pluripotent[13]. Some cells, reported by Catherine Verifaille, are pluripotent cells from bone marrow, which resemble stem cells but have other characteristics. She calls them Multipotent Adult Progenitor Cells or MAPC's[22]. However, the work has not been published in the United States and has been criticized because it has not been repeated in other labs.[23] Nevertheless, there is an improving outlook for

the use of adult cells in the arsenal of therapeutic applications of adult tissue remediation, particularly for neuron cells in the brain and elsewhere. It is more difficult to isolate and characterize adult cells because they are a very small component of the adult tissue, and there seem to be several lines of cells mixed together. Adult stem cells have actually been used for years when bone marrow is transplanted for malignancies or bone marrow disease. Within the bone marrow are hematopoietic stem cells as well, which replace all of the types of blood cells, red and white. In addition it has been demonstrated that these stem cells also have multi and pluripotency and have even produced several other kinds of tissue cells including neurons.[14] Stem cells from an adult tissue type that can produce another different tissue type are said to be plastic, or exhibit plasticity. For example, nascent umbilical cord has stem cells that can produce human neurons[15].

**Figure 3**



**Adult Stem Cells only recently were discovered to be suitable for use in therapy. Two recent discoveries buttressed this:**

- 1. The cells were found and cultured in brain and other organs and can be grown and maintained in the laboratory.**
- 2. Differentiation of these cells has been demonstrated in the lab (in vitro). So the adult stem cell is more plastic\* than previously realized.<sup>14</sup>**

***In addition to adult stem cells, stem cells derived from the Wharton's Jelly of the umbilical cord of humans shows great promise in cultivability and plasticity.<sup>15</sup>***

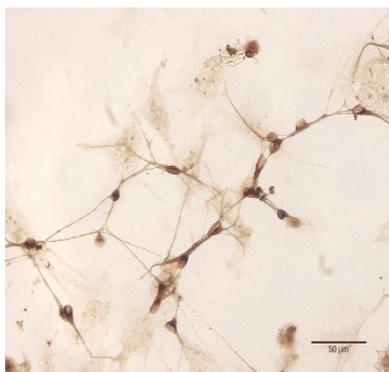
***\*Plasticity is the ability of an adult stem cell of one tissue to generate a specialized cell type of another tissue***

## **THE PROSPECTS FOR OLD POLIO REPAIR WITH STEM CELL THERAPY**

Polio, as far as I can see, has never been mentioned in the Stem Cell literature as a disease that can be helped with Adult or Embryonic Stem Cell Therapy. There is spinal cord injury, diabetes, Parkinson's disease, blood diseases and cancers (which have been treated successfully for 40 years with hematopoietic stem cells with marrow transplants), and even psychiatric illnesses, which result from poorly functioning brain cells, or damaged cells. Other diseases have also been mentioned

as possible targets for repair including skeletal muscle in muscular dystrophy, and organ replacement. There are several aspects of old polio damage that may be amenable to improvement with stem-cell therapy. In talking to researchers, working in neuronal stem-cell therapy, some seem to feel the prospects for polio repair are very promising given enough time and research [18], while others express doubt, particularly about guiding large numbers of the long motor neuron axons, feet, to its target muscle fibre [12] Muscle fibres themselves would also need to be replenished because of damage by atrophic processes over long periods of time.

**Figure 5**

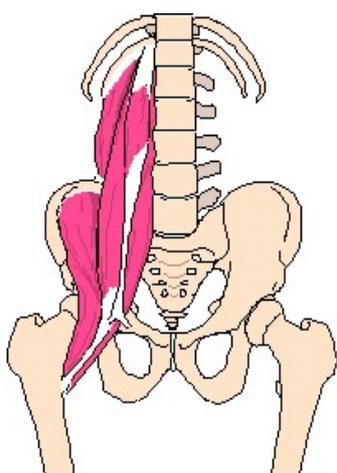


**Figure 5. Motor Neurons produced in the lab from embryonic stem cells. Note the stringy axons and small bushy end fibers. Printed with permission of Dr. Musharov.<sup>18, 20</sup>**

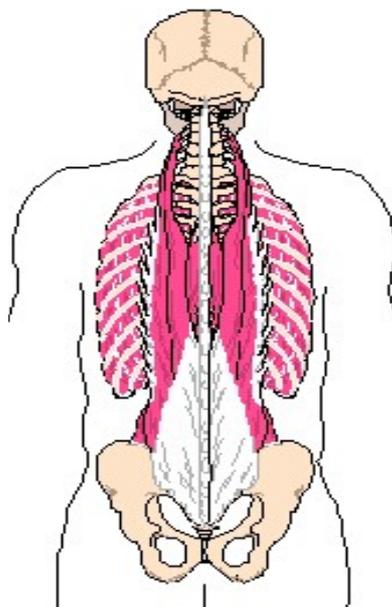
Skeletal muscle has been replaced in animal models and this should be possible, in time, for human polio. [1] Work on stem-cell therapy for muscles that have been destroyed by dystrophin as in Muscular Dystrophy have to be cloned or genetically altered to remove the damaged genes. Work is progressing in this field. For polio there is no need to genetically alter stem cells because polio is not a genetic problem. Also, stem cells are present in the adult muscle tissue, which can produce viable muscle. It may be possible to guide stem cell derived neurons [Figure 5] using biological materials such as chondritin or other biolo based scaffolding [18].

Of course the shorter the distance from the cord to the muscle, the better the results should be. Post Polio muscle damage can be much more disabling at the hip or above rather than lower, for **Many Polio survivors have weak paraspinal and deep muscles that support the spine. This can be very disabling and destabilize the spine, resulting in impingement on adjacent nerves which compromise function. These muscles are very close to the cord and may be enervated by newly grafted motor neurons, which, because of the close proximity, would be more easily connected to these critical muscles. These new ideas in remediation of Post-Polio Syndrome should be considered in the context of stem cell therapy.**

**Figures 4a and 4b.**



*Weakness of the hip is more disabling generally, than weakness lower in the leg. Muscles are also closer to the cord where new anterior horn cells could be coaxed, theoretically, to new striated muscle fibers.*



*Deep muscles of the torso support the spine and are in close proximity to the cord. These would be easiest to strengthen and may provide significant improvement.*

Weakened hip, buttock, or paraspinal muscles (Figure 4a,b) can be very disabling, and are closer to the spinal cord. They provide support for muscle movement below. These critical muscles would be easier to tackle with neuron engraftment and could, if successful, provide significant support and improvement in function. So the easiest muscles to enervate could provide the most substantial improvement. But all this is still theoretical and many hurdles remain. Nevertheless, there are several ways that stem cell technology can be used to improve the outlook if the research and therapies bring clinical trials in the next 10 years. We are an aging population so time is controlling with regard to potential polio therapies.

Several signaling factors act between stem cells allowing them to differentiate and grow in vitro and in vivo. As stem cell research progresses we should uncover more of these growth and differentiation factors needed for cell differentiation, adaptation, connection to other cells within a tissue, and proper function. Imagine, if you will, a concoction of factors (some of which are already known) that can signal motor neurons to form synapses (connections) with new muscle fibers. Muscle signaling Cell Adhesion Molecules (CAM) attract the placement of synapses on muscle. Other factors may be used to guide cells to the proper muscle fibers. Without using stem cells some of these new derivative cellular hormones could be perfused into a trouble area. There are many possibilities; the only question is how long it will be until effective therapies are derived from Stem Cell Research.

Much of the advancement in stem cell therapies, and much of the realization of future promise will come as a result of lab work using model organisms like mice. A model of Spinal Cord damage, resulting in complete paralysis, has been mitigated in a mouse with neurons derived from stem cell engraftment so that after treatment the mouse uses its hind legs in walking motions where prior to treatment it could not. Rodents can be more easily engineered genetically and cloned so that rejection of implanted cell grafts does not occur. With a new model organism for polio, a mouse, reported in Polio Network News by Dr. Jubelt, there might be new opportunity to study post-polio rehabilitation with stem cell grafts. The possibility of using this polio mouse model did not escape my attention because of the success we have had using rodents to further our understanding of cell differentiation and the possibilities stem cell therapy.[24]

As this research progresses scientists are finding the cells that produce new signaling chemicals and cellular growth hormones as they examine how to prompt cells to differentiate in the lab.[19] It is conceivable that support cells can be implanted in the spinal cord alongside marginally functional motor neurons to provide nutrients and growth factors. Strangely, researchers have found stem cell muscle engrafts produce a lot of glial and astrocyte cells instead of muscle. Those are the very cells that support neurons. So these cells could be used for support of motor neurons either by fusion, or by secretion of helpful nutrient chemicals. Or, if the axons cannot reach distal muscle we could fuse new neurons, or other nerve support cells to existing giant motor units to support them, make them more healthy or even help them to produce and maintain more sprouts to muscle. This could result in a second recovery similar to the sprouting events that occurred during the first recovery from acute polio. All this is within the realm of existing stem cell

research and its future possibilities. Dr. Murashov, of Eastern Carolina Medical College, an active stem cell researcher, was happy to know this article or polio survivors was being written and he felt this should be discussed because of the possibilities he saw[25]. Dr. Murashov is working on spinal cord injury and is trying to produce sensory cells in the dorsal horn. With polio we need anterior horn cells where the effector muscles are further away and atrophied, or cell support for overburdened neurons living, but compromised or moribund. This is a new and an exciting prospect, but as with most polio research the need is grant money, access by researchers to stem cell lines, and increased interest in solving therapeutic problems..

## References

- 1.HHMI News: Researchers Produce Motor Neurons From Embryonic Stem Cells, [www.hhmi.org/news/jessell2.html](http://www.hhmi.org/news/jessell2.html)
2. *Stem Cells: Scientific Progress and Future Research Directions*. Department of Health and Human Services. June 2001. <http://www.nih.gov/news/stemcell/scireport.htm>
3. M. Schuldiner et al.; "Effects of eight growth factors on the differentiation of cells derived from human embryonic stem cells"; *Proc. Natl. Acad. Sci. USA* 97, 11307-11312; Oct. 10, 2000.
4. *Stem Cells, A Primer*, National Institutes of Health, September 2002
5. *Stem Cells: Dream or Reality?* Mariani, Sara, M., Highlights from the American Society of Hematology 44<sup>th</sup> Annual Meeting, December 6-10, 2002, Philadelphia, Pennsylvania.
6. *Stem Cells: Scientific Progress and Future Research Directions*, National Institutes of Health, Department of Human Services, 2001.
7. Ezzell, Carol, *Cloning and The Law: "Will therapeutic cloning end up being against the law"?* *Scientific American*, November 24, 2001
8. Ezzell, Carol, *Stem Cell Showstopper: " Without Cloning They Aren't Likely To Work"*. *Scientific American*, December 16, 2001
9. Mariani, Sara. *Stem Cells: A Plenary Policy Forum: Highlights from the American Society for Hematology 44<sup>th</sup> Annual Meeting*; December 6-10, 2003, Philadelphia, Pennsylvania. *Medscape General Medicine* 5(1), 2003
10. McKay, R. et al. Dopamine neurons derived from embryonic stem cells function in an animal model of Parkinson's Disease. *Nature*, 417, published on-line 20 June; doi: 10.1038/nature00900,(2002).
11. Pearson, Helen. *Stem Cell Hopes Double*. *Nature Science Update*, June 21, 2002
12. Fred H. Gage, Director of the Laboratory of Genetics of the Salk Institute at La Jolla, California, Personal Communication, February 8, 2003.
13. Kaji, Eugene, H. and Leiden, Jeffrey, M. "Gene and Stem Cell Therapies" *JAMA*, Vol. 285, No 5, February 7, 2001
14. Bjornson CR, Rietze RL, Reynolds BA, Magli MC, Vescovi AL, "Turning Brain into Blood: a hematopoietic fate adopted by adult neural stem cells in vivo. *Science*. 1999;283;:534-537.
15. Mitchell Kathy E. et al, "Matrix Cells from Wharton's Jelly Form Neurons and Glia" *Stem Cells*, 2003; 21:50-60 [www.StemCells.com](http://www.StemCells.com)
16. Thomas P. Zwaka & James A. Thomson, Homologous recombination in human embryonic stem cells. *Nature Biotechnology*, Published online: 10 February 2003, doi:10.1038/nbt788, [www.nature.com/cgi-taf/DynaPage.taf?file=/nbt/journal/vaop/ncurrent/abs/nbt788.html](http://www.nature.com/cgi-taf/DynaPage.taf?file=/nbt/journal/vaop/ncurrent/abs/nbt788.html)
17. Drukker, Micha et al. "Characterization of the expression of MHC proteins in human embryonic stem cells" *Proc. Natl. Acad. Sci. USA*, Vol. 99, Issue 15, 9864-9869, July 23, 2002

18. Murashov, Alexander K. Development of a Method for Generation of Spinal Cord Neurons from Embryonic Stem Cells for Treatment of Spinal Cord Injury, Murashov's Lab Page, February 13, 2003, <http://www.ecu.edu/physio/labakm/Stem%20Cells.htm>
19. Villa, A. et.al. Genetic perpetuation of in vitro expanded human stem cells: Properties and Therapeutic Potential., *Brain Res. Bulletin* 2002 Apr. 57: 789-94
20. Murashov, Alexander, M.D., Ph.D., Assistant Professor in Physiology, East Carolina School of Medicine, Personal Communication
21. Cossu, Giulio, Mavilo, Fulvio, " Myogenic Stem Cells for the therapy of primary myopathies: wishful thinking or therapeutic perspective?"
22. Verfaillie, Catherine, M. et al., "Pluripotency of mesenchymal stem cells derived from adult marrow", *Nature* 418, 41 - 49 (2002).
23. Wade, Nicholas, "Scientists Make 2 Stem Cell Advances" *New York Times*, June 21, 2002.
24. "Mouse Model Developed for Post-Polio Research", *Polio Network News*, Fall, 2002, Vol. 18., No. 4
25. Personal Communication Dr.. Murashov follows:

Ed, Thank you for writing to me about this important matter. I am very pleased that you are going to bring up the issue of stem cell research and its possible practical implications for therapy of neurological disorders including old polio. While I am not working in animal model of polio, I am optimistic about future of stem cell research in general. By changing properties of stem cells (either, embryonic or adult) one may be able to generate sufficient quantities of specialized cells to replace malfunctioning or missing cells in the tissue. The fascinating plasticity of stem cells together with directed differentiation may help to establish functional integration between transplanted cells and the host tissue. To me the possibilities are almost unlimited. I think that stem cells may be used for treatment of old polio as well. Theoretically, support cells may be developed to support compromised motor neurons. Surprisingly, in some cases stem cells "sense" the problem in the organism and differentiate accordingly to repair the damage. Of course more studies must be done before proposing cell therapy in patients. Unfortunately, scarce funding in stem cell research significantly slows the progress in developing cell therapies. You are more than welcome to use images from my website.

Sincerely, Alex

Alexander K. Murashov, M.D., Ph.D.

Assistant Professor in Physiology

East Carolina University School of Medicine

Brody Bldg. #6N-98, 600 Moye Blvd., Greenville, NC 27858

Phone: 252-816-3111 - Fax: 252-816-3460

Email: [murashoval@mail.ecu.edu](mailto:murashoval@mail.ecu.edu)

<http://www.ecu.edu/physio/labakm>

End of references]

**Professor. Eddie Bollenbach, B.A., M.A.**

[<edward.bollenbach@snet.net>](mailto:edward.bollenbach@snet.net)

Eddie Bollenbach is a Polio Survivor and teaches Microbiology, Biology, and Chemistry at Northwestern Connecticut Community Technical College.

See his articles on Polio Biology in our Website Library.

## ***The Long (and Bumpy!) Road to Retirement***

**by Member Dinah Foweraker**

The onset of PPS affects lives in many ways. Not only are there the physical and psychological difficulties to be faced, but careers may also be at risk. Even if we are not high fliers, a job confers status, a sense of purpose and financial rewards. When those are threatened, it is only natural to react at first with denial, later on with anger and depression. And then there are the knock-on effects for family and friends.

Three years ago I took early retirement after nearly thirty years of working full-time. The relief was enormous, but even so the absence of work left an emotional gap in my life which proved hard to fill. I have no regrets about retiring because realistically there was no other choice, but it was still a loss, and eventually I realised I had to let myself grieve a little, just as I would have done if a relationship had ended, however impossible it might have been.

In 1954 at the age of four, I contracted polio, which affected my legs and back. After intensive physiotherapy, I made a reasonable recovery, and regained my ability to walk, but the weakened muscles in my back meant that as I grew I began to develop a scoliosis, in my case a double curvature of the spine. Years of out-patient appointments, X-rays and different types of back supports followed. I underwent three operations to try to correct the curvatures, but the methods used in those days were fairly primitive, and none was particularly successful.

Despite my scoliosis and weakened legs, I went on to lead a fairly normal life,

though I was never able to participate much in games or strenuous physical activities. I suppose I was a typical polio survivor, for years in complete denial, fiercely independent and refusing to acknowledge I had a disability at all. To compensate for my physical limitations and disappointments in other areas of my life, I worked hard at school, and in the early 1970s won a place at university to study for joint degree in Librarianship and English Literature.

In 1971 I qualified as a librarian and subsequently worked full-time in libraries for nearly eighteen years, until, in 1989, I resigned my job as a college librarian. Unresolved differences and conflicts with the new style of college management were mainly to blame, and although these weren't connected to my disability, I suspect a certain amount of bigotry and prejudice lay behind the way I was being treated. Impossible to prove, of course, and if I'd complained I would most likely have been subjected to hostile denials and accusations of having a chip on my shoulder. It was a long time ago, but a stressful and unhappy time.

Unable to find another library post, I embarked upon a six-month intensive post-graduate secretarial course. This I regarded as a stop-gap, as I fully intended to return to library work once the opportunity availed itself. But soon after qualifying and finding my first job as a secretary the recession of the early 1990s struck and I was stuck. By the time the recession was over, I was well into my forties and my health was declining. As a secretary I had far less autonomy than I'd enjoyed as a college librarian. Then it was possible to pace myself plan my work in order to avoid overloads wherever possible, and there were staff to whom I could delegate. Now I was the one to whom the work

was being delegated and there was nothing below me apart from the floor. The people I was working for were all making conflicting demands on me: their deadlines became my deadlines, their panics my panics. I consequently found the work a lot more stressful because I was no longer in control of my own workload.

In 1992 I began working in an academic department of a university helping with the administration of post-graduate courses. The post-graduate office was underfunded and understaffed. It was consequently a very pressurised job, and I was continually juggling with a wide range of duties and acting as trouble-shooter and peace-maker to mature students many of whom were experiencing problems of one sort or the other. Occasionally I was aware of an inner voice telling me 'This is all getting too much for you' but I did nothing about it and attributed my increasing tiredness to the pressures of the job. From about 1995 my problems intensified. I blamed this on a gynaecological condition, and in 1996 underwent a hysterectomy. The complete recovery I anticipated never materialised and instead my energy levels continued to plummet. I was having difficulties in concentrating and applying myself to tasks and seemed less able to cope with the pressures of the job and the stress that went with it. My muscles felt weaker, I could no longer walk as far and gradients were particularly difficult.

During the winter of 1997/8 I experienced what felt like a low-grade flu: my throat was inflamed, I went hot and cold in turns and felt very unwell for weeks. By this time I could no longer pretend even to myself that nothing was wrong. I'd heard of post-polio syndrome years before in connection with the Earl of Snowdon, but dismissed it at the time

as something which couldn't possibly happen to me. Now I wrote to the BPF, obtained some articles from them and the Web and went off to see my GP, who'd never heard of PPS (what a surprise!) but after doing some research for herself decided some of my problems 'could' be polio-related. She suggested that as there was no cure for PPS that I should try to rest more and use self-management techniques to try to counteract my difficulties. She did not offer to refer me to a consultant.

To add to my problems the department where I worked was now in trouble, following an ill-fated merger with two other departments. There were financial difficulties, morale was low, and many staff, including myself, were under threat of compulsory redundancy. Although this threat was eventually lifted, many staff had already taken voluntary severance, increasing the pressure on those like me who remained.

Looking back now I realise this was the point where I should have looked for a part-time job, which might have enabled me to carry on working for longer than I did. Instead, I took another full-time position, still in the University, but in central administration. I reckoned that without direct contact with students, a more reasonable workload and fewer responsibilities I could continue to work full-time. I was mistaken. To begin with, I was utterly exhausted from the stresses of the old job and trying to learn new routines and skills when I was already worn-out only exacerbated my problems. I simply didn't have the stamina to make a success of it and my health continued to decline.

For another eighteen months I struggled on, by which time I was so exhausted by the end of the week it was as much as I could do to get into the office on Fridays,

never mind achieve anything once there. Weekends were spent recovering. My GP now referred me to a consultant, but I was faced with a waiting-list of six months.

It was at this point that my elderly mother was admitted to hospital to have what was thought at the time to be a straightforward bladder operation. Unfortunately, she developed complications, which meant she underwent a second operation shortly afterwards. The stress of trying to work, cope at home, visit my mother in hospital and deal with concerned family and friends proved the final straw. I was forced to go to my GP and ask to be signed off for a month.

Unable to wait to see the consultant on the NHS, I arranged a private appointment with him. Although this enabled me to be seen quickly, the consultation turned out to be a disaster. I suppose I was naïve, but I was totally unprepared for the lack of concern verging on hostility which this man displayed. He turned out to have no understanding of, or interest in, PPS which he informed me 'only affects the body from the neck down' and which he regarded as being the same thing as what he called 'post-polio muscular atrophy'. He said I showed no sign of this, nor of any progressive disability directly related to the old polio. (How could he know this when he'd never seen me before?) He barked questions at me, but didn't listen to the answers. Any symptom I mentioned which did not fit into his views was dismissed. My chronic fatigue and cognitive problems were the result of 'psychological problems' and he would recommend to my GP that I took some 'mood enhancing drugs' (e.g., anti-depressants.) It was evident he regarded me as a neurotic, menopausal

female who ought to pull herself together. He refused to make any recommendations about early retirement on medical grounds until I'd had some EMG tests and suggested that as these would probably prove negative I should carry on working until I was 60 in order to enjoy the company of 'congenial colleagues.'[!!] I left the consulting room utterly downcast and feeling it was somehow my fault I was ill. Later on my depression turned to anger for allowing him to intimidate me with his arrogance and patronising attitude. (I saw this consultant in April 2000, and was not called for the EMG tests until March 2003. Had I chosen to remain under his 'care', I would have been forced to carry on working up that date, with no guarantee even then that he would have supported my application. The only alternative would have been to resign without benefit of pension.)

Despite this setback, following my mother's recovery and my return to work, I made the decision to 'come clean' with my employers and admit I had a problem. They were extremely sympathetic, taking work away from me and supporting my application for early retirement. Because of the continuing deterioration in my health, I decided part-time work was no longer a realistic option. I was sent to Occupational Health for assessment, but the consultant there turned out to be as useless and as hostile as the first one, concurring with the opinion that I should take antidepressants and continue to work. It took me another nine months to find a consultant who would support my application and I was eventually able to retire from my job in February 2001. For the last year of my working life I was undoubtedly a "lame duck" employee.

What lessons can others who may be in similar positions learn from this? First of

all, anyone who is experiencing difficulties at work which may be caused by post-polio symptoms, should not ignore them, but go to their GP and insist on being referred to a consultant. Although PPS is not curable, a good consultant may be able to suggest measures to help slow down the decline and enable someone to go on working for longer. If retirement is the only option, a supportive report from a consultant may be essential in order to make a case for retiring on grounds of ill-health. However, as I discovered, finding a suitable consultant is not be easy, and this is why it is important to begin the process as soon as possible. There will probably be a waiting-list of at least six months until the first appointment and this will not be the end of the story, because an instant diagnosis is unlikely and further tests may be required which will take more time. Seeing a consultant privately if this is affordable will hasten the process, but not guarantee better treatment.

Another reason for seeing a consultant is to avoid having to rely solely on the opinion of an occupational health doctor. People with chronic illnesses I have talked to since have all had negative experiences when referred to such doctors by their employers. Although occupational health staff are presented to the employee as being neutral, the fact is that they are being paid by the employer and will be looking for a solution which while conforming to employment law will be the best solution from the employer's point of view. Apart from this, the doctor will probably have no specialised knowledge of the condition and will only recommend medical retirement if convinced there is no long-term prospect of recovery. If anyone out there has had a more positive experience than mine I do hope they will feel able to share it.

If a consultant is not sympathetic the best advice I can give is to ditch him or her, and look for someone else rather than trying to complain, or attempting to change the mind of someone with intractable opinions. Neither is likely to be worth the time or energy. If a suitable consultant can't be found within a health authority it is usually possible to go outside as long as the GP will provide a referral and the consultant agrees to see the patient. (I am currently seeing a neurologist outside of my own health authority.)

Whatever the problems at work, it is important to start thinking about realistic solutions to them sooner rather than later. There are no ideal solutions, nor decisions which will turn out to be absolutely right or totally wrong. We can only do is what is possible and what seems best at the time.

Dinah Foweraker  
Avon and Somerset, UK  
March 2004

## **SUNDAY LUNCH MEETING JUNE 20TH 2004 - BRISTOL**

I am organising a Sunday Lunch Meeting, 11.30 to 3.30 on Sunday 20th June 2004 in the Bristol area, close to the M5. Venue will depend on numbers wanting to join in, either house or local pub. Hilary Hallam will be joining us en route back to Lincoln after the Exeter ME/PPS Conference [See back page].

If you would like to join us then please email me  
dinah@FOWERAKER.FSNET.CO.UK  
or drop me a line with your name, address and phone number and I will send you the details. Please address it to Dinah Foweraker c/o LPPN - 69 Woodvale Ave, Lincoln, LN6 3RD.

## **Questions about Sleep Studies; C-paps and Bi-paps** possible thing from a to z.

**By Ellen, the Texas one arm bandit**

I seem to have arrived at another one of those dreaded mile-stones of coping with Post Polio Syndrome.

It seems I have always had some problems sleeping as far back as I can remember. (And my memory only goes back to around second grade or so as I blocked most of it before, during and shortly after having had polio)

Mostly, it was a dislike of sleep. I always felt it was a waste of time and so would sit up for hours after bedtime just watching the moon make its slow, silent journey across the sky. I was always the first one up in the house as I relished getting outside as the sun crept up over the horizon.

There was a period of time when I really slept. I slept soundly and needed two or three alarm clocks set within five minutes of each other to wake me in time to dash off to work. But, then I was working, going to night school and keeping up a social life.

Since I have been dealing with PPS over the past 11 years or so I found I have periods where sleep seems good. I have little trouble falling asleep and awake refreshed. Over the past few years these have become extremely rare occasions.

I have become used to having my sleep disrupted by Charlie horses [cramps] in either my calf or the arch of my foot; especially if I have been 'mis-behaving' and on my feet much more than I should be. As, I have also become used to tossing and turning on nights after a day or two of general 'over-doing' as my mind takes over and ponders every

But, the last six months or so this has changed. My sleep problems are different. I seldom wake up feeling really refreshed and ready to at least take on the morning. I am awake, but find myself wanting to stay in bed; maybe if I do I'll feel more refreshed. Yet, if I do this doesn't really work either so I drag myself up and greet the day. My attention span is shorter than ever, and I seem to lack the motivation to get busy on much of anything.

I only rarely waken with a head-ache [which could be not getting rid of carbon dioxide properly] but I do wake up during the night often with a start or due to a dream of nightmarish quality. Sometimes it seems my heart is racing; at others I am awake but can't seem to move for some moments.

There are nights I'd swear I slept soundly, but still don't feel refreshed. There are others where I am up almost every hour or so from midnight on. On these nights I usually give up and stay up from 4 or 5am.

The worst thing is the daytime fatigue. It zaps me. I lack motivation to start projects, much less finish them. And this does lead to a mild depression which then feeds on itself.

My voice is also changing. Usually it is the same in the morning as it always has been, but come afternoon or evening it takes on a husk-iness and at times is so soft that even if I think I am yelling no one hears me. This is very frustrating to put it mildly.

All of this led me to go get it checked out and long story short I am going in for a sleep study the end of this month.

A part of me feels I am premature. It is this part that really is sort of hoping the sleep doctor gets back to me in mid-May telling me I don't need any help, that I don't really have any kind of sleep apnea.

This is normal for me. I just don't want to be any 'worse'. I try to deny this possibility every step of the way. But, I also try to read, listen to others and taking a deep breath go get it checked out.

In my reading I made many discoveries. I explored why the preference is for us to get a bi-pap rather than a c-pap. I'll share what I've learned over the past months. Remember I'm not a doctor or medical person. I've asked my doctors a lot of questions, I've asked members of some of the support lists for information from those ahead of me on this part of our PPS journey, plus, I've done a lot of web-searching to fill in the blanks..... Here are some of the questions with the answers I've found.

### **1. Why and when is a sleep study done?**

A sleep study is done when it becomes more and more difficult to get a good night's sleep. It is time to think of having one when you start awakening feeling 'unrested', find yourself being more tired than usual, start to have nightmares, wake up at times during the night with a start, and maybe have a headache when awakening. In short when you know something isn't working right it is time to go to your doctor, who, if he/she agrees that it may be time will refer you to a sleep doctor, who then checks you out and determines if a sleep study is needed.

NOTE: A surprise titbit my sleep doctor gave me while examining/talking with

me. She suspects my problems with sleep apnea are at an 'early stage'. Now, of course, my reaction is. "good I can come back later". Her answer to this is that she has found that if sleep problems are treated earlier on the treatment works better and longer then when the person waits until it is really a major problem.

### **2. What may be causing the problems?**

This answer can vary even among ppsers's. I have found through studying the various articles on PPS and sleep apnea that it isn't unusual for many of us to develop some form of sleep apnea.

One form is obstructive apnea. (The most 'usual' sleep apnea treated these days) This can be caused by weakened neck, tongue muscles, or even other problems that non-ppsers's can have.

Another form is central apnea. In the case of being PPS related this is directly related to Bulbar Polio and involves a problem with the nerve relay system where the brain literally misses giving us the instruction to breathe. It is important to mention that we could have had bulbar involvement at the time of our original polio without it showing up with any significant breathing problems at the time. Just because we weren't told we had bulbar polio or if we did that it was 'mild' doesn't mean we didn't have it and that we will be positively be 'free" of running into this problem. As with so much of what is being learned now about how our original polio affected our whole body; not just the part that 'showed a problem'; it is becoming more and more evident that this can also be true of the involvement of the bulbar area of the brain.

A third area that is causing many of us

PPSer's problems is our increasing muscle weakness. It is simply getting more and more difficult to breath... this will be more of a problem at night during REM sleep when all muscles but our diaphragm is 'paralyzed'. During the day we are using other muscles to help, along with gravity.

#### 4. What is the difference between a C-pap and a Bi-pap machine?

There a lot of very good websites that explain what a c-pap, bi-pap and a bi-pap+ machine are and what they do. Just type bi-pap into Google and you'll be surprised at how much information there is.

Here is a brief answer to this question:

A c-pap is a positive pressure air machine that simply gives the user a constant supply of air pumped into the air wave passages to keep these unobstructed. This helps to keep a lazy tongue from slipping back and blocking the way, and/or to help weakened throat muscles from collapsing during the deep REM sleep.

The user has to push the air back out on their own against the constant pressure.

THIS is why a bi-pap is preferred for ppser's. While a c-pap may work at first, over time already weak/overused breathing muscles will find it increasingly difficult to push the air out unaided.

A bi-pap helps with this. This machine provides both positive and negative pressure... pushing air in and helping to bring it back out thus assuring that the person has good breathing throughout the night and enables them to get the much needed REM sleep.

The Bi-pap+ machine also has a sensor that picks up when the person doesn't

breath in for x amount of time (so many seconds). It will kick in and breathe for the person. This is needed with central apnea.

#### 5. What about the noise of the machine? And how does one get used to having a mask on one's face?

These two questions address my biggest fears. So much so that I asked both my sleep doctor and new pps doctor about it and these are the answers they have given me.

1. The 'noise' is a soft continuous sound that is more like 'white noise' (I still have my doubts, but will find out soon enough <Grin>)

2. The mask really isn't that uncomfortable.

3. But the main thing they tell me is that after a few nights sleeping with it I will feel so much better and will sleep so much better it will fast become a 'good friend'.

Some other PPS-ers already using either a c-pap or a bi-pap have also confirmed the above.

One woman said it most poetically,  
**“sleeping with my bi-pap  
is like having satin sheets  
and chocolate truffles.”**

Now this I can understand.

Two PPSers who are partners made me laugh in an email the other day when they jokingly asked me if I thought they did single machines with two hoses.

EllenRiddle@sbcglobal.net  
or write to me c/o the LincsPPN address.  
I would love to hear from you.

## TO EXERCISE OR NOT TO EXERCISE?

1. It is well documented that for every mile that you jog, you add one minute to your life. This enables you, at age 85, to spend an additional 5 months in a nursing home at \$5,000 per month.

2. My grandmother started walking 5 miles a day when she was 60. She is now 97 and we don't know where on earth she is.

3. The only reason I would take up jogging is so that I could hear heavy breathing again.

4. I joined a health club last year, spent about \$400. Haven't lost a pound. Apparently you have to show up.

5. I have to exercise early in the morning before my brain figures out what I am doing.

6. I don't exercise at all. If God meant us to touch our toes, he would have put them further up our body.

7. I like long walks, especially when they are taken by people who annoy me.

8. I have flabby thighs, but fortunately my stomach covers them.

9. The advantage of exercising every day is

that you die healthier.

10. If you are going to try cross country skiing, start with a small country.

11. I don't jog - it makes the ice jump right out of my glass.

## FUNNY THOUGHTS

Why is the time of day with the slowest traffic called rush hour?

Monday is an awful way to spend 1/7th of your life.

Support bacteria - they're the only culture some people have.

Depression is merely anger without enthusiasm.

If at first you don't succeed, destroy all evidence that you tried.

A conclusion is the place where you got tired of thinking.

Experience is something you don't get until just after you need it.

For every action, there is an equal and opposite criticism.

No one is listening until you make a mistake.

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## Sand and Stone

A story tells that two friends were walking through the desert. During some point of the journey, they had an argument, and one friend slapped the other one in the face. The one who got slapped was hurt, but without saying anything, he wrote in the sand:

Today my best friend slapped me in the face.

They kept on walking, until they found an oasis, where they decided to take a bath. The one who had been slapped got stuck in the mire and started drowning, but his friend saved him. After he recovered from the near drowning, he wrote on a stone:

Today my best friend saved my life.

The friend, who had slapped and then saved his best friend, asked him, "After I hurt you, you wrote in the sand, and now, you write on a stone, why?"

The other friend replied: "When someone hurts us, we should write it down in sand, where the winds of forgiveness can erase it away, but when someone does something good for us, we must engrave it in stone where no wind can ever erase it.

Learn to write your hurts in the sand and to carve your blessings in stone. Author Unknown

## INSTANT LOW-CAL BREAD PUDDING FOR TWO

Regular: takes 2 servings of crustless white or french bread torn or cut into small pieces and put into microwaveable dish.

In another dish add one whole egg beaten with fork and whisk in 1/4 cup milk - 2½ fl. ozs - and add to your taste - cinnamon, allspice and vanilla.

Pour mixture over bread and if desired Add 1 small box raisins (1 1/2 oz)

Mix well, store overnight in refrigerator.

Next day microwave on high for 2 minutes. Serve warm or cold.

Try dressings of plain yoghurt, lots of cinnamon (or nutmeg or both) and a bit of artificial sugar or spoonful of unsweetened apple sauce or Cool Whip. A warm spoonful of sugarfree jelly is nice over plain pudding.

Chocolate bread pudding is made the same with or without raisins or nuts added. Just add a couple spoonfuls of chocolate instant, sugarfree pudding.

This is a good dessert for the calorie counting, exchange seeking diabetic. Half this recipe is one serving with 3/4 fruit exchange, 1 bread exchange, 1/4 milk exchange and 1/2 egg exchange. I regulate my own Diabetes II with diet by staying on a 1500-1800 daily diet. Tasty and sweet enough for company too!

LaVonne Schoneman,  
HOW TO COPE books  
vonnejo@aol.com

## Actual Analogies and Metaphors Found in High School Essays

1. Her face was a perfect oval, like a circle that had its two sides gently compressed by a Thigh Master.

2. His thoughts tumbled in his head, making and breaking alliances like underpants in a dryer without Cling Free.

3. He spoke with the wisdom that can only come from experience, like a guy who went blind because he looked at a solar eclipse without one of those boxes with a pinhole in it and now goes around the country speaking at high schools about the dangers of looking at a solar eclipse without one of those boxes with a pinhole in it.

4. She grew on him like she was a colony of E. coli and he was room-temperature Canadian beef.

5. She had a deep, throaty, genuine laugh, like that sound a dog makes just before it throws up.

6. Her hair glistened in the rain like a nose hair after a sneeze.

7. He was as tall as a six-foot-three-inch tree.

8. The revelation that his marriage of 30 years had disintegrated because of his wife's infidelity came as a rude shock, like a surcharge at a formerly surcharge-free ATM.

9. The little boat gently drifted across the pond exactly the way a bowling ball wouldn't.

10. McBride fell 12 stories, hitting the pavement like a Hefty bag filled with vegetable soup.

**CONFERENCE - JUNE 18th 2004**  
**MYALGIC ENCEPHALOMYELITIS/POST POLIO**  
**AT THE BUCKERELL LODGE HOTEL (BUCKERELL SUITE)**  
**TOPSHAM ROAD, EXETER, DEVON EX2 4SQ**  
**9.30 AM – 5.00 PM**

**Guest speakers:**

Dr Betty Dowsett; MB ChB Dip.Bact.  
Hon. Cons. Microbiologist Essex

**Subject: Research into M.E. Where have all the Scientists gone?**

Prof. Malcolm Hooper from Sunderland University

**Subject: New Developments in M.E. Definitions and Overlapping Syndromes!**

Dr Anne Macintyre; former Medical Advisor to Action for M.E.

**Subject: Managing the Illness**

Hilary Hallam; Founder and Chair Lincolnshire Post-Polio Network.

**Subject; Power Point Presentation:- How Self Assessment can Provide More Pertinent Facts for Health Professionals.**

Shirley Purves; Retired Neuro Physio, Devon and & Son Bruce; Teacher

**Subject; Working 'IT' Through – Life with M.E.**

Penny Lilley; Neuro Physio (Hants)

**Subject; Power Point Presentation on,  
Long-Term Rehabilitation-Variied**

**QUESTION & ANSWER TIME FOR ALL 'THE PANEL'**

**Admission by Ticket; £15.00: to include Tea & Coffee Breaks.**

**Variety of meals from £2.50 soup and roll, jacket potato with filling £3.95,**

**Platter of sandwiches and fruit £5.00, order and pay on arrival.**

**Full menu available you must choose and pay me before the event.**

**For further information write to Member Barbara Taverner or contact LincsPPN.**

**Please send cheques 'Mrs. B. N. Taverner' - your full contact details  
number of tickets and request for Map / Full Menu / Wheelchair space required**

**Please enclose S.A.E. otherwise unable to reply;  
to 81 Halsdon Avenue, Exmouth, Devon EX8 3DH**

Donations can be made to Lincolnshire Post Polio Network  
via Charity Cards and online at [www.charitycard.org](http://www.charitycard.org).  
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[www.CAFonline.org](http://www.CAFonline.org)

