

# The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**  
Volume 5 - Issue 1 - December 2004

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## Post-Polio Syndrome and Inflammation

**Marcia Falconer, PhD**

Post-Polio Syndrome (PPS) has been a recognized condition for more than 25 years, with reports of similar symptoms going back to the 1800's. However we still do not have a grasp of the underlying cause, or causes, of PPS! We do not know how many polio survivors will develop PPS, estimates range from 20% to over 80%. We do not know why some polio

survivors develop PPS and others do not. There is no diagnostic test and PPS remains a diagnosis arrived at after exclusion of other somewhat similar conditions. We do not understand why there is a lag time between recovery from the acute illness and development of symptoms severe enough to compromise the quality of life. It seems there is very little that we do understand about PPS. However, if we can discover the underlying cause(s) of PPS; if we can find out what is happening at the cellular and even sub-cellular level, there is promise of being able to answer all of these perplexing issues. There is also promise of being able to treat and possibly even prevent the onset of many, perhaps most, PPS symptoms.

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*Seasons Greetings to All Our Members  
Their Families and Friends*

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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#### Next LincPIN Newsletter - February 2005

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# Editorial

We left the UK following a snowfall of some four inches and arrived in the USA at a temperature of 80 with hardly a cloud in the sky. It made me realise that with a membership spread as far as ours is that this coming Holiday will have a huge variety of celebrations, traditions and best of all meals and goodies. Therefore, let me wish you and your families all the best for the coming holidays and a healthy and happy new year.

Articles that we use in our Newsletters. The comment is sometimes made that articles that come from someone in another country are not relevant to your problems in your country. Our membership are served by a variety of health care systems and local services. Regardless of country finding services for polio survivors where the health professionals have a thorough understanding of polio, PPS and our problems is not easy. There are around the World a few excellent Clinics and Health Professionals. However, very few of our membership have access to these because they are too far to travel to in time and cost. Whilst we cannot cover the differences in the health care systems, the problems being experienced are almost identical regardless of country. Articles, stories, problems, hints and tips are shared widely around the world of PPS Newsletters. What you write for us today might be appearing in an Australian newsletter in the Spring and an American one in the Summer,

In this issue we start with a very informative article by Life Member Marcia Falconer which is continued on pages 8 to 11.

Mary Kinane your new Chair writes her message and we report on the AGM afternoon speakers.

We have an article on voice and facial problems. Having met quite a few members I can say that to my knowledge six,

including myself, have such problems. Do let us know of your problems and hints and tips for coping with these so that we can share this information. One of our members would lose her voice for a couple of days each week following 'calling the Bingo numbers'. Did she give up doing this job she enjoyed? No, the NHS [UK National Health Service] provided her with a small microphone to be worn round the neck and a speaker. Now she no longer strains her voice she whispers the numbers and all can hear.

Another article relates to my old favourite 'the strength of muscles'. This is written by Dr. Sophie Chun—who I have met in St. Louis, Dublin and Los Angeles. I am sure you will find this information helpful.

Exercising your Brain—is a great article written by Richard Daggett. I know Richard won't mind my adding this here but many Polio Survivors jokingly say the one brain cell that I have working is not doing too well today. Well on the flight over I was reading a book and the comment was made.... He is such an idiot if he had one more brain cell he would be a PLANT! I laughed and wondered what plant would you say I was?

Member Ellen Riddle has come up with ten tips to help you enjoy the coming season and sent a couple of recipes that might make a difference for us in the UK. As a child we had Turkey Hot, then Cold, then Chasseured, then Curried.

Hints, tips, bits and funnies—why not submit items for future newsletters.

Date for your Diary. Next years Annual General Meeting will be in Lincoln on Saturday 22nd October 2005.

Finally, Our sincere condolences go to a very special lady, Pat Hollingworth, a long time member of our Phone Team, whose husband died after a period of illness in November.

# Message from the Chair

Hello Readers,

It seems like yesterday when we were going to print with issue no. 48 of the LincPIN after our October AGM, and I was introducing myself as your new chair. I am certainly finding out that it takes some time to get to know the ropes, and trust that the membership and the rest of the committee will bear with me while I learn the various aspects of my new role.

We have some good news to report in this issue, thanks to the hard work of Sheila Dunnett who has been acting as administrative support to Hilary and the charity for some time. Earlier this year we were awarded a grant from Awards for All (which Sheila put a lot of energy into applying for) - this is to enable us to buy computer equipment. After dealing with what was a lot of paperwork, we are now in a position to invest in this new equipment to help develop our plans to deliver more presentations to more health professionals and the general public about the effects of post-polio, up and down the country.

Over the next three months, Denise Carlyle and I will be meeting up to work on our presentation-giving skills, sharing the equipment, and developing on some of the materials already put together by Hilary over the past number of years. Readers may remember that Hilary's presentation to physiotherapists in the Grantham area has been most successful in gaining the interest of allied health professionals in that area. Most of our time and energy at our last committee meeting was devoted to sharing information on this very topic. We will of course keep you, the membership, posted on this development, but in the meantime ask you to be patient with us while we familiarise ourselves with both the equipment and the materials. Importantly, we are also developing a wider network of contacts within the NHS Trusts, so that we can disseminate information about PPS as widely, and effectively, as possible.

We warmly welcome our members' viewpoints and would encourage you to let us know if you have contacts in your area whom you feel would be open to hosting presentations on PPS. We can only accurately reflect members' interests here in the newsletter and in the organisation as a whole if we get your input and your feedback on these issues.

Hilary continues to put together the newsletter on a regular basis and we are working together to improve both the layout and the content to reflect readers' interests and concerns. There are various ways of contacting us, which are all printed on the inside of the front cover. So please don't be shy - write, e-mail or phone us!

May I take this opportunity to wish all our members and their loved ones the best of the season, and safe journeying to those who will be travelling.

Mary Kinane, Chair

# Further report from our AGM October 2004

For our afternoon speakers, after the AGM in Lincoln this year, we invited two members of the Patient & Public Involvement Forums (PPIF) in Lincolnshire. Both Carrie Sheils (Forum Support Officer) and Pam Gwynn (Patient Volunteer) gave us invaluable information about the work of the Forums, and those attending exchanged views on current developments in the area.

Carrie Sheils began by giving a short general talk on how Forums operate, and can operate, for local people. There are 572 Forums across England, each of which is fully independent, but works with, a local NHS Trust. Whichever service you may use, there is an independent PPI Forum keen to hear your views.

PPI Forums are made up of groups of volunteers in local communities in England (for more information about similar developments in either Scotland, Northern Ireland or Wales, please see the web-links below). These volunteers are enthusiastic about helping patients and members of the public influence the way that local healthcare is organised and delivered. Of interest to our polio readership, is that not only is Pam Gwynn a "Patient Expert" but she and her brother contracted polio as children, although her case was only mild. She welcomed and encouraged members to contact her and/or to get involved in their own areas if they were interested. All contact information is given at the end of this article. Forum members come from different backgrounds and have a range of experiences and skills. They are keen to take action where necessary.

PPI Forums can do the following:

- \* Contact local communities to find out their views on local healthcare and present these views to the NHS Trust which they work with. By law, all trusts must listen to the PPI Forum and provide a response.
- \* Independently monitor the quality of local health services through regular visits. Reports of these visits will be given to the Trust and made available to the general public.
- \* Look at how wider issues in the local community, such as social care, transport or housing, affect health.

Forum Support Organisations (FSO's) are "not-for-profit" organisations that have been contracted through a competitive tendering process to support PPI Forums. The Shaw Trust in Lincoln is one such FSO. These organisations, independent of the NHS, use their knowledge, experience and existing contacts within local communities to support PPI Forums. They are single organisations or consortia that play a vital role in helping to shape the future of health provision throughout England. They are managed on a geographical basis by nine regional centres.

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(Continued from page 5) Further Report on AGM.

Contacts in Lincoln:

The Shaw Trust,  
Voluntary Sector Hub,  
Beaumont Fee, Lincoln LN1 1UW: 01522 551 751.  
email: [kirsty.regan@shaw-trust.org.uk](mailto:kirsty.regan@shaw-trust.org.uk) , Manager Shaw Trust,  
or  
[carrie.shiels@shaw-trust.org.uk](mailto:carrie.shiels@shaw-trust.org.uk)  
Forum Support Officer,  
or  
Mrs Pam Gwynn  
(Volunteer Forum Member)  
on: 01522 691225.

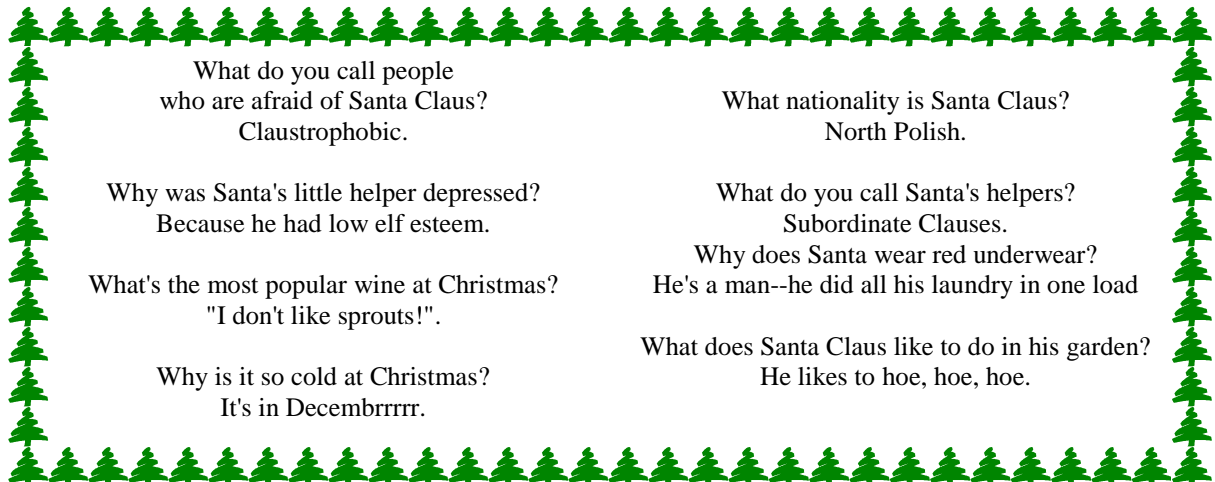
All PPI Forums are commissioned by government, currently by the Commission for Patient & Public Involvement in Health (CPPIH). The PPIF for East Lincolnshire works in partnership with the East Lincolnshire PCT (Primary Care Trust).

A good website to look up  
to find a PPIH Forum in your area is:  
[www.cppih.org/ppi\\_find.php](http://www.cppih.org/ppi_find.php)

We realise that there is a lot of jargon associated with developments in consultation with patients in England. However, we also wanted our readership in England to have a good overview of the “scene”, as it were, at this time in the health services, and to provide contact information where appropriate for people to add a voice in their own areas. It may well be that PPS’ers in areas other than Lincoln have already established good communication and working partnerships with forums in their areas, much like some are getting involved in the Long-Term Medical Alliance and the Neurological Alliance, either nationally or regionally (or both).

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

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I gave a short PowerPoint Presentation on the problems being experienced whilst we search for a diagnosis.

I explained that we have to ensure that the picture in our mind matches that of the person assessing us. If we are asked 'Can you do an action? And we answer "Yes." Do you think that the picture in the health professionals mind of how we are doing what they have asked is the same as the picture in our minds of how we actually do it?

The picture in the health professionals mind will be made up of how they see you at the appointment. Did you rest up the day before and get someone else to drive you to the hospital? Were you shown into a room to wait and the doctor came to you? Were you sitting down when he walked in? Dressed as you are now can he see any atrophy/orthotics/evidence of polio? Apart from taking your history were you given a thorough or just a few physical assessments? Maybe you left your electric wheels outside in the waiting room, or even in the car if there was only a few yards to walk?

I know we are all very proud of what we can do and the last thing we want to do is to admit, even to ourselves, that we might be doing things a little differently from the expected 'norm' now. However, are we helping ourselves, our families, friends and health professionals by not 'seeing' and giving up this information? Over the years, I have taken calls and emails from partners/family members worried about what they can see happening to their loved ones. "I offer to help when I can see they are tired but they always turn me down, what can I do?" The best advice we have is that you have to start talking firstly between the two of you and then gradually bringing in more family members/friends. Remember PPS does not just affect the life of the Polio Survivor but also all those they come into contact with. Most of us find that once we start talking a huge weight is lifted, we are alone no longer with our wonderings.

If you answered the question "Can you get up a flight of stairs?" "Yes" is the health professional likely to assume that you do it the same way he does, just walk up the flight of stairs without using the banister rail. When in fact you are going up right foot first, one step at a time, pulling yourself up with the banister rail and stopping halfway for a breather.

Think about how you do actions now and compare that to how you used to do them and ensure that you tell or show the person assessing you. You will be surprised at the difference it makes?

Why not make a list of the differences in your daily actions. Have you changed the way you do daily actions? Do you now....

- \* stand and lean against work surfaces to give you more support
- \* hold on to the work surface with one hand whilst you use the other
- \* slide the saucepans across the work surface instead of lifting them
- \* vacuum one room each day instead of doing the whole house once a week
- \* use an automatic gear box now instead of a manual because of new weakness in arm or leg
- \* Sit on a shower stool and leaning forwards with your elbows close into your body wash your hair instead of standing and using your arms above your head

**REMEMBER— TRY ANSWERING 'HOW YOU DO IT'.**

Hilary Hallam - Secretary  
hilary.hallam@lincolnshirepostpolio.org.uk



*(Continued from page 1) - Post Polio Syndrome and Inflammation.*

Little research has been done on PPS, probably because polio survivors are a dying breed. After world wide eradication of polio, the 'lifespan' of PPS will be equal to that of the youngest living polio survivor. Or will it? Poliomyelitis continues to cause paralysis although now the virus causing the illness is not the polio virus but the West Nile Virus, or enterovirus 71, or one of several Coxsackie viruses. The nerve damage caused by these viruses is identical to that caused by the polio virus and therefore it is likely that PPS, perhaps by then called Post-Viral Syndrome, will continue to bring new limitations to survivors many years after they thought they had recovered.

So it remains important to examine the underlying cause of new muscle weakness, central fatigue, pain, memory and word finding problems and other symptoms that accompany PPS. Fortunately, current research in other areas holds great promise for explaining what is happening to so many polio survivors.

The cause of virtually all PPS symptoms can be explained by one word: **inflammation!** Front line research in the fields of neurology, immunology, physiology and virology is coming together and the many pieces of the puzzle are being laid upon the table. A good analogy is to think about a jig-saw puzzle. When you dump a 1000 piece puzzle out of the box, some pieces land right side up, others upside down. There is little hope of assembling the puzzle until you turn all the pieces right side up. The next step is to put all the straight edged pieces in a pile and then assemble the outer edge of the puzzle to give you a general outline. After this it is helpful to group pieces with similar patterns or colours together. This is

approximately where we are today in our understanding of how inflammation is related to almost all chronic diseases; PPS, MS, ALS, CFS, Parkinson's, irritable bowel syndrome, arteriosclerosis and many, many others. This also gives you some idea of how far we have to go until we have a complete picture!

Let's look at the puzzle pieces that seem to belong to PPS. Inflammation has two major causes; injury—including viral and bacterial infection, cuts, strains, operations, etc. and stress - including major events such as death of a relative, divorce, and job loss, but also including milder, repetitive stress that is encountered every day. In a person with PPS, when the body suffers an injury, such as physically overdoing by climbing too many stairs, walking on uneven ground, etc. the first reaction is for the cells in the affected area to release a chemical messenger. This messenger, called a *proinflammatory cytokine*, tells specialized cells, whose job it is to protect you from invading organisms, to come to the site of the injury. At the same time the proinflammatory cytokines activate resident cells and cells that have migrated to the injury and all of them produce more proinflammatory cytokines setting up a cascade of events that will involve the entire body.

Two proinflammatory cytokines, Interleukin-1 and Tumour Necrosis Factor- $\alpha$ , are especially important in triggering an acute immune response, the body's first line of defense. The acute immune response involves developing a fever, fatigue, loss of appetite, sleepiness and other symptoms. It goes away within a few days. However if the injury is repeated often – say if a person with PPS persists

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in exercising a stressed out muscle – then a chronic immune response will set in. This response to chronic stress involves the entire body including the brain and it will produce **central fatigue, new muscle weakness, problems with short term memory and word finding, irritable bowel syndrome** and other symptoms.

Recognize them?

Indeed. These are the post-polio syndrome symptoms we are so familiar with. In an effort to keep this article shorter than a textbook on immunology, I have omitted the complex chain of events that takes place in the body between the original stress and the onset of PPS symptoms. There are many, many research papers that amply document what happens in the body after activation of the immune system by proinflammatory cytokines and that eventually results in symptoms identical to those of PPS.

Let's take a brief look at how proinflammatory cytokines may be the underlying cause of new muscle weakness. We begin with acute polio and the death of a large number of nerves whose job was to innervate muscles by telling the muscles to contract or relax and thereby allowing you to move a leg or an arm. If all the nerves leading to a leg or arm died, the limb was permanently paralyzed. However, clinical paralysis may be observed when 40 per cent of the nerve supply leading to a limb has survived. In many people, original paralysis or severe weakness eventually resolved, voluntary movement was restored and you could once again use your arm or leg. The body developed a neat trick to allow this to happen. The surviving nerves were able to send out 'neuronal

sprouts' to attach to and innervate muscles that had been orphaned when the nerve originally attached to them died off. Thus the surviving nerves were able to activate not only the muscle that they always innervated, but also surrounding muscles creating something called a "motor unit". This repair was essentially stable for many years.

However 30 or more years after recovery from polio, many people begin experiencing new muscle weakness. Often the weakness is in the 'good' arm or leg. This may be due to the fact that the 'good' arm or leg was used more. Clearly something happened to the neuronal sprouts; either they no longer could maintain full time attachment to the motor unit or else they may have died off completely. This caused the appearance of new muscle weakness. Once again, I've simplified this a bit – although the general picture is correct. But this is a description of what is happening, not an explanation of why it is happening.

Enter proinflammatory cytokines. Remember them? Researchers have well established that proinflammatory cytokines cause cells to release neurotoxic proteins. These neurotoxic proteins can damage or even kill neurons by a number of mechanisms including changing the outer membrane of the nerve cell resulting in cell death or increasing reactive oxygen inside the nerve cell which also leads to cell death. It is probable that the neuronal sprouts, that have served so well for so long, are more fragile and may be the first target of proinflammatory cytokines in the central nervous system.

A very important fact is that nerve death only occurs in an activated immune system. The next question is "Do

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people with PPS have an activated immune system?" The answer is **YES!** There have been a number of research papers indicating that polio survivors with PPS symptoms have an activated immune system while polio survivors who do not report PPS symptoms do not have an activated immune system<sup>1</sup>.

A very recent research paper<sup>2</sup> looked at cytokines in people with PPS, polio survivors without PPS, people with multiple sclerosis (MS), a well known inflammatory neurological disease, and people who had no neurological problems. They found that people with PPS and MS have proinflammatory cytokines in their central nervous system while polio survivors who do not have PPS and people without neurological problems do NOT have proinflammatory cytokines in their central nervous system.

What might cause the presence of these proinflammatory cytokines in people with PPS? One hypothesis is the presence of very low levels of polio virus RNA hiding in nerve cells. This polio virus RNA is not capable of infecting you or other people, but is capable of triggering the production of proinflammatory cytokines and with that, an underlying state of chronic immune system activation.

Other researchers have demonstrated a clear connection between the presence of proinflammatory cytokines and central fatigue<sup>3</sup>. Psychological stress – the kind that doesn't involve overdoing physically – is perceived in the brain and the brain produces proinflammatory cytokines. This can cause profound fatigue, inability to concentrate and other symptoms<sup>4</sup>.

Remember that 1000 piece jigsaw

puzzle we have spread out on the table? We are now able to put together some of the same coloured pieces to make small pictures that are part of the larger picture. In the same way, we are piecing together what happens when a person with PPS experiences physical or psychological stress. We start to see small pictures and we can just begin to discern the larger picture coming together.

We are coming to the place where it may be possible to treat PPS symptoms using anti-inflammatory medications. A very exciting trial, using intravenous immunoglobulin treatment, is currently underway in Sweden. Preliminary trials of this treatment in people with PPS have yielded dramatic improvements in fatigue and muscle strength!<sup>5,6</sup>

Other treatments to reduce PPS symptoms may be based upon traditional anti-inflammatory medicines such as aspirin, ibuprofen, indomethacin and others. All treatments would have to be done under the supervision of your doctor, but in the meantime, there are some things you can do that are known to minimize inflammation in the body – and with that you might have a reduction of PPS symptoms. You might try meditation. Yes it works... if you do it consistently. Appropriate exercise, under the guidance of a knowledgeable physiotherapist, will definitely lower inflammatory cytokine levels. Pace yourself and don't overdo. This is easier said than done but if you understand that seriously overusing muscles will start the proinflammatory cascade of events and with that bring on or intensify PPS symptoms, perhaps you will be able to justify resting before you go too far.

Adipose tissue – commonly known as

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fat – is also a producer of inflammatory cytokines. If you needed a good reason to lose weight, here it is. Finally there are a few things you can try. Drinking green tea encourages weight loss and it has neuroprotective qualities. There are also reports that undenatured whey protein may be beneficial. These things are probably not as effective as direct medication to lower proinflammatory cytokine levels, but as we incorporate them into everyday life, they will bring positive benefits.

And let's keep working on that jigsaw puzzle!

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Reprint requests should be addressed to Marcia Falconer.

Marcia Falconer met Hilary online many years ago and became a Life Member. She also visited and spoke at our 2000 AGM. Here are just a few facts from her extensive C.V.

Polio history - Non-paralytic polio at age 7 (1949). Quarantined for about 1 month. Symptoms included fever, leg and back pain, weakness in both legs and right arm, also generalized weakness for a period of months followed by complete recovery. Led a very active life swimming, ice-skating and cross country skiing. PPS symptoms first noticed (in retrospect) in 1985 with fatigue, and leg weakness becoming severe by 1996. Received a diagnosis of "probable PPS" in 1997

B.Sc. in biology, Simmons College, Boston, Massachusetts USA. 1964.

Research Assistant in cell biology laboratory at M.I.T., worked with human tissue cultures, polio virus (strain 3) and various pesticides. 1964-1966

M.Sc. in plant cell biology, Carleton University, Ottawa, Ontario, Canada 1985.

Ph.D. in neuronal cell biology, University of Ottawa, Ottawa, Ontario, Canada. 1990.

Post-doctoral studies in molecular biology, Massachusetts Institute of Technology, (Center for Cancer Research), Cambridge, Massachusetts, USA. 1990-1992.

Co-author with Professor Eddie Bollenbach MA in biology– also a LincPPN Member.

'Non Paralytic Polio and PPS'  
A Lincolnshire Post Polio Publication  
January 1999.

'Late Functional Deterioration in Non Paralytic Polio'  
*Am J Phys Med & Rehab* Jan/Feb 2000.

Other articles awaiting publication.

# How to survive the Holiday Season as a PPSer

As over-doers and perfectionists the fast approaching holidays hold a lot of challenges for most of us.

Even those of us who somewhat succeed at pacing and resting can get caught up in the annual frenzy of decorating, baking, shopping and wrapping.

So as I sit on the precipice of jumping in the fray I've come up with this simple list of some do's and don'ts which I've put under magnets on my refrigerator door. Seeing them daily will hopefully help me avoid crashing into the infamous 'polio fatigue wall' this season.

1. Don't shop without both my powerchair and an able bodied person along. When this person starts telling me they are tired and need to rest I can then stop with them for a cup of coffee and a snack for their good, not my own. If I go it alone I will just keep on rolling in and out of shop after shop till my fingers ache from working the joy stick and my legs feel weighed down under the packages that don't fit on the back of my chair.

2. Don't bake. Really, buy buy buy cookies, pies and cakes. This is difficult for me to adhere to, but I have to remember how long it took me to make my upside down pecan/apple pie from scratch... and how hard it was to roll out the pie shells.. Sara Lee's will have to do this year.

3. Buy gift bags instead of wrapping all those gifts (or pay to have them wrapped in the store).

4. When doing holiday cards: print out a one page letter with signature. Do NOT sign cards or write those personal

messages inside. This is the first year I really did this and I actually have my cards ready to mail already.

5. Wait to do any regular household cleaning until the day before any guests are arriving. Our daughter and her room mate are coming up this Saturday evening for their holiday visit. I will dust and 'spit shine' on Friday.

6. Balance all the sweets by getting a high protein, carb free breakfast. Having one 'good meal' has to balance out all the cookies, pies, potatoes, stuffing, etc.

7. Stay out of the kitchen.. let others cook and clean up. Be a queen or king and sit and relax, or sit in on the edge of the kitchen giving moral support to those hardy workers.

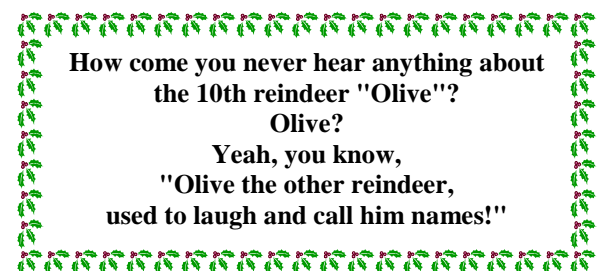
8. If family meals are at your place forgo the dishes and use pretty paper plates or volunteer guests to clean up.

9. When the celebrations are at night give yourself a restful morning still in your robe [dressing gown] and take plenty of rest in the afternoon and enjoy the evening.

10. Finally, when all the above fails and you find yourself in the thick of things remember you can always stop and let someone else finish.

In fact, now that I think about it last year my husband ended up rolling out the pie crust... putting the heavy pie into the oven and inverting it onto the platter. Hummm no wonder he encouraged me not to make it this year.

By Member Ellen Riddle  
The one-armed bandit  
Elmari@lonellen.com





## MY PHILOSOPHY ON HOUSECLEANING!

I don't do windows because... I love birds and don't want one to run into a clean window and get hurt.

I don't wax floors because... I am terrified a guest will slip, hurt themselves, I'll feel terrible and they may sue me.

I don't mind the dust bunnies because... they are very good company, I have named most of them, and they agree with everything I say.

I don't disturb cobwebs because... I want every creature to have a home of their own.

I don't Spring Clean because... I love all the seasons and don't want the others to get jealous.

I don't pull weeds in the garden because... I don't want to get in God's way, he is an excellent designer.

I don't put things away because... My husband will never be able to find them again.

I don't do gourmet meals when I entertain because... I don't want my guests to stress out over what to make when they invite me over for dinner.

I don't iron because... I choose to believe them when they say "Permanent Press".

I don't stress much on anything because... "A Type" personalities die young and I want to stick around and become a wrinkled up crusty ol' woman!!!!

Author Unknown.

## Real Creamy Corn

1 pound of frozen cut corn  
1 package of cream cheese [8oz]  
2 small cans of green chilies (mild or hot to taste)  
one small jar of diced pimentos (for color)

Put all into a crock pot and let it slow cook stirring occasionally as the cream cheese melts. If needed you can add a small amount of milk or cream.

This very simple to make dish is very tasty and adds a festive touch to a usual holiday meal

## White turkey Chili

This is an adaptation of a chicken recipe we've had for a few years. A great leftover turkey meal... and, easy to prepare.

4 to 5 cups of cut up leftover turkey  
2 cans of chicken broth  
2 cans of white beans (northern, butter,)  
2 cans of cream of chicken (or cream of mushroom) soup  
2 small cans of green chilies (mild or hot)  
cumin and chili powder to taste

Add all of the ingredients to crock pot. Let it slow cook all day for a lovely supper.

From Ellen

Translation!!!

Cut Corn is Corn off the Cob  
Cans are same size in UK.  
A cup is half a normal size coffee mug.  
Broth—I think must be chicken stock.

# Understanding Muscle Strengths with Sophie Chun, M.D.

Chief of Post-Polio Services,  
Rancho Los Amigos National Rehabilitation Center,  
Downey, California, U.S.A.

Reported by Mary Clarke Atwood  
Editorial Assistance by Richard Daggett and Sophie Chun, M.D.

This report is based upon Dr. Chun's 2003 presentation to the Rancho Los Amigos Post-Polio Support Group in Downey, California. It includes information on diagnosing post-polio syndrome (PPS), the importance of muscle testing (including several ways to test muscle strength), the meaning of muscle grades, exercise, contractures and bracing.

## What is Manual Muscle Testing.

Manual Muscle Testing is a method to test the strength of a muscle group by an examiner who provides the opposing force. This method is best used for the weaker muscles – those that are in the 0-3 range.

The person being tested is asked to push or pull against the resistance of a trained examiner. The muscle strength is graded on a 0-5 scale. In the past, muscle strength descriptions such as "fair", "poor", and "good" were used. The meaning of numbers is explained in the following table.

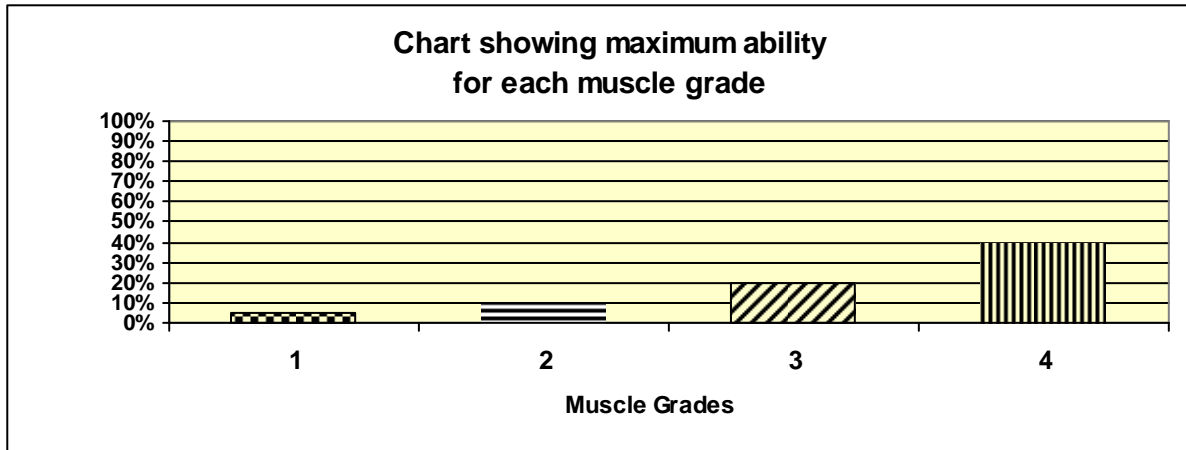
		The muscle being tested....
0	Zero	Has no muscle twitch.
1	Trace	Has some muscle twitch that can be felt.
2	Poor	Is only able to move the limb when gravity is eliminated.
3	Fair	Is able to move the limb against gravity.
4	Good	Is able to provide good resistance against the examiner.
5	Normal	Is as strong as the maximum resistance provided by the examiner.

It is important to note that this scale does NOT have equal range between each number such as 1=2=3=4=5. Hence, Grade 1 muscles are less than 5% of normal, Grade 2 muscles are approximately 5 to 50% of normal, Grade 3 muscles are approximately 15 to 20% of normal, and Grade 4 muscles are approximately 40% of normal. (Beasley WC, Quantitative Muscle Testing: Principles and Application to Research and Clinical Studies. Arch. Phys Med Rehab 42:398-425,1961).

In general, at least a Grade 3 muscle is needed to perform usual function because it is able to move a limb against gravity. However it is important to know that a Grade 3 muscle does not have much endurance and will tire easily.

*(Continued on page 15)*





Muscle grades can also be defined more specifically by adding a plus or minus sign that designates “something in between”:-

Examples: 1,1+, 2-,2+, 3-, 3+, 4-, 4+, 5.

Muscle Grade 3+ can resist the force of 2 fingers plus gravity.

Do you understand the meaning of muscle grades?

Test yourself, Yes, or No.

- |  |     |
|--|-----|
| 1. 4 out of 5 means 80%                        | No  |
| 2. 3 out of 5 is likely getting a “C” in class | No  |
| 3. 5 out of 5 means 100%                       | No  |
| 4. 3 out of 5 for the hip extensor means 20%   | Yes |

### **Torque Muscle Testing**

Another way of measuring muscle strength is Torque testing. This method is best used for testing stronger muscles.

Torque testing uses a machine (like an exercise machine at the gym) to provide the opposing force. This testing is performed under the supervision of a trained examiner. The results in Torque tests are then calculated and the muscle group strength is graded as a percentage of normal rather than the 0-5 scale of MMT.

### **Why is Muscle Testing Important?**

There are 3 reasons why muscle testing is important:

1. To help diagnose PPS.
2. To evaluate a person's muscle/nerve reserve, i.e. to determine his ability to exercise and help answer the following questions:

- Which muscles are at high risk for getting weaker with overuse?

*(Continued on page 16)*

*(Continued from page 15) Understanding Muscle Strengths with Sophie Chun MD*

- How much can or should a person exercise?
  - Which muscles can tolerate exercise and which muscles cannot tolerate exercise?
3. To help the physician prescribe for and advise the patient:
- What type of brace and which joint mechanism can substitute specifically for a given muscle that is found to be too weak to perform its function during walking?
  - What lifestyle modifications need to be suggested?
  - Could it possibly be time for the “Chair”.?

### **Muscle Testing Helps Diagnose PPS.**

A finding of “random patchy weakness” can be determined by thorough manual muscle strength testing and can also help establish that the person has a history of having had acute poliomyelitis. “Random patchy weakness” refers to muscle weakness that does not follow any specific pattern, e.g. one may have right arm and left leg weakness, as opposed to left or right sided weakness as seen in a stroke.

The criteria for a diagnosis of post-polio syndrome from the March of Dimes International Conference on Post-Polio Syndrome Identifying Best Practices in Diagnosis & Care, 2001 are:

- “1. Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscle on neurologic examination, and signs of denervation on electromyography (EMG). [Dr. Chun stated that EMG might not be necessary].
- “2. A period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neurologic function.
- “3. Gradual or sudden onset of progressive and persistent new muscle weakness or abnormal muscle fatigability (decreased endurance), with or without generalized fatigue, muscle atrophy, or muscle and joint pain. (Sudden onset may follow a period of inactivity or trauma or surgery.) Less commonly, symptoms attributed to PPS include new problems with breathing or swallowing.
- “4. Symptoms persist for at least a year.
- “5. Exclusion of other neurologic, medical and orthopaedic problems as causes of symptoms.”

*(Continued on page 17)*

*(Continued from page 16)*

## **Exercise/Activity Recommendations.**

Results from manual muscle testing can help a physician advise how much or how little an individual can exercise. Exercise can help maintain and possibly strengthen muscles that are Grades 3+, 4, or 5 as long as a person doesn't over do it, but exercise can be detrimental/harmful to muscles that are Grade 3 or less. A Grade 3 muscle can move the limb full range against gravity but it has only 15 to 20% of normal strength so it has very little endurance.

Grade 3 to 3+ muscles are considered at high risk because they can get weaker by both too little activity and by too much activity. A person with PPS and Grade 3 muscles has a daunting task of trying to find the correct balance to prevent losing muscle strength either from disuse or from overuse. In addition, if a Grade 3 muscle weakens and becomes a Grade 2 muscle it can lead to a decline in function if this is a key muscle.

Grade 2 muscles may need some bracing support, especially in the lower extremities, because they do not have the strength to overcome gravity.

## **Determining Bracing Needs**

There are three key muscle groups that are tested in the lower extremities to help the physician determine the most appropriate type of bracing needed to substitute for the weak muscle groups. These muscle groups are called "key" muscle groups because their strength determines whether a person can walk safely or not:

- Hip extensor muscles [Glutes]
- Knee Extensor muscles [Quadriceps/Quads]
- Ankle Plantar Flexor muscles [Gastrocs or calf muscles]

Experience at the Rancho Post-Polio Clinic has shown that the calf muscle often is the first muscle to show signs of overuse weakness in survivors who are walking in the community. A person with weak calf muscles often substitutes for this weakness by locking his knees. This substitution can be functional except that over time, the "locking" of the knee causes an overuse of the knee extensor muscles [quadriceps] and can also lead to low back pain. A person with weak calf muscles can sometimes feel unstable and is not able to stand for very long.

A person with symptoms caused by weak calf muscles as described above is at risk of further overusing the quadriceps muscles, so a physician will prescribe an AFO [ankle foot orthosis] specifically designed to substitute for the weak calf muscle. The physician prescribing the brace should understand the patient's gait and know what type of joint mechanism is needed to substitute for the muscle weakness found in the manual muscle testing. A "wrong" brace can actually cause further overuse resulting in more muscle weakness.

*(Continued on page 18)*

*(Continued from page 17) Understanding Muscle Strengths with Sophie Chun MD.*

There are very specific joint mechanisms but in general, one should know that a KAFO [knee ankle foot orthosis] is used to substitute for weak quadriceps [knee extensors] and that an AFO [ankle foot orthosis] is used to substitute for weak ankle muscles including the calf muscle. A cane is often the best support for weak hip muscles.

### **Range of Motion Testing.**

Range of motion testing for each joint is often done in conjunction with the manual muscle testing. This testing helps determine the flexibility of the joints and determines if there are any contractures.

A contracture is the tightening of soft tissue that results in a limited range of motion. Not all contractures or limited range of joints is bad. A good or a “useful” contracture can act like an “internal brace”, while a bad contracture puts a person at a mechanically unstable position.

An example of a “useful” contracture is Achilles tendon tightness because it can act as an internal ankle brace [AFO]

An example of a “bad” contracture is knee flexion contracture, i.e. a permanent bend at the knee. This is a bad contracture because if a person does not have adequate muscles to extend the knee, the knee contracture can cause the knee to buckle.

Some abnormality in range of motion is not always bad. For example, a person who back knees may benefit by locking the knee for added stability. However, an excessive back knee or [knee hyperextension] can cause pain in the front of the knee over time.

### **Quiz**

Based on the information in this report, in the following examples try to determine:

- Who can walk safely?
- What joints need to be braced?
- Who needs to ride?

Assume that none of the persons below have any useful contractures.

Person 1      Hip Extensor Grade 5, Knee Extensor Grade 4, and Ankle Plantar Flexor Grade 4.

Answer        All key muscles in this person are greater than 4, therefore he can walk safely without a brace.

Person 2      Hip Extensor Grade 5, Knee Extensor Grade 0, and Ankle Plantar

*(Continued on page 19)*

(Continued from page 18)

Flexor Grade 4.

Answer This person has zero Knee Extensor [Quadriceps]; therefore he needs a knee brace [KAFO] to substitute for the inability to lock his knees.

Person 3 Hip Extensor Grade 4, Knee Extensor Grade 5, and Ankle Plantar Flexor Grade 0.

Answer This person has zero Ankle Plantar Flexor [calf muscles]; therefore he needs an ankle brace [AFO] to substitute for his weak calf muscle.

Person 4 Hip Extensor Grade 1, Knee Extensor Grade 0, and Ankle Plantar Flexor Grade 2.

Answer All key muscles are less than 3, which are not strong enough to provide support for walking, especially if they do not have any useful contractures. This person needs to “ride”.

Person 5 Hip Extensor Grade 0, Knee Extensor Grade 4, and Ankle Plantar Flexor Grade 1.

Answer The only muscle that can help this person walk is the Knee Extensor Muscle [Quadriceps]. This person can probably walk, but would need the assistance of a cane and an ankle brace [AFO]

## Conclusion.

The information in this report should help a person with PPS have a better understanding of muscle testing and what the numbers mean to him. By knowing one’s own muscle grades a person will have a better understanding of how to protect the strength he has.

Muscle testing provides good baseline information. It is not necessary to repeat MMT until a person’s symptoms change. “If you are having new PPS symptoms it means you need to slow down”, said Dr. Chun.

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Dr. Sophie Chun is Chief of Post-Polio Service at Rancho Los Amigos National Rehabilitation Center. For more than five years she has worked closely with Dr. Jaquelin Perry who established this polio clinic many decades ago. Dr. Chun has dual board certification in Physical Medicine & Rehabilitation and Internal Medicine. In 1993 she received her MD from Loma Linda University and then completed their dual residency program. Her other responsibilities at Rancho Los Amigos include Medical Director of Outpatient Clinic & Rehabilitation Services; Chief, Neuro-medicine Stroke Service; and Director, Women with Disabilities GYN/Wellness Clinic. In 2000 Dr. Chun was named “Physician of the Year” at Rancho Los Amigos



★ Hints, Tips, Bits and Funnies.

★

★ I was driving to town when my car quit  
★ on me. I was sitting in the car at the side  
★ of the highway, contemplating my next  
★ move, when a pigeon flew down and  
★ landed right in the middle of the hood of  
★ the car. It seemed fairly tame, and I soon  
★ became fascinated in watching it up close  
★ as it strutted around and made cooing  
★ noises.

★

★ A few minutes passed, and two more  
★ pigeons flew in and joined the first bird.  
★ Pigeons seem to be attracted by crowds,  
★ and soon I was sitting there with a whole  
★ hood [bonnet] full of pigeons, all cooing  
★ loudly and beginning to change the color  
★ of my hood. Gradually I noticed that the  
★ birds seemed to be trying to get my  
★ attention, which was unnerving, since I  
★ had always regarded pigeons as rather  
★ stupid birds. But, sure enough, several of  
★ them were dragging a piece of rope  
★ around on the hood, and several others  
★ were flying out in front of the car and  
★ returning to the hood.

★

★ All of a sudden, I realized what they  
★ were doing, so I yanked open the door  
★ and wildly chased them all off ... No darn  
★ way was I going to be pigeon-towed!!!!

★

-----

★ How would you punctuate this? Do it  
★ two different ways and you can make it  
★ say exactly the opposite.

★

★ Dear John I want a man who knows what  
★ love is all about you are generous kind  
★ thoughtful people who are not like you  
★ admit to being useless and inferior you  
★ have ruined me for other men I yearn for  
★ you I have no feelings whatsoever when  
★ we're apart I can be forever happy will  
★ you let me be yours Anne

★

★ From Member Barry Branston.

★



## THE LEGEND OF RUDOLF

A long time ago, in Communist Russia, there  
was a famous weather man named Rudolf.  
He's always had a 100% accuracy rate for his  
forecasts of the Russian weather conditions.  
His people loved him and respected him for  
his faultless foresight. He was particularly  
good at predicting rain. One night, despite  
clear skies, he made the prediction on the  
6:00pm news broadcast that a violent storm  
was approaching. It would flood the town in  
which he and his wife lived. He warned the  
people to take proper precautions and  
prepare for the worst.

After he arrived home later that evening, his  
wife met him at the door and started arguing  
with him that his weather prediction was the  
most ridiculous thing she had ever heard.  
This time, she said, he had made a terrible  
mistake. There wasn't a cloud anywhere  
within 10 miles of the village. As a matter of  
fact, that day had been the most beautiful day  
that the town had ever had and it was quite  
obvious to everyone that it simply wasn't  
going to rain.

He told her she was to be quiet and listen to  
him. If he said it was going to rain, **IT WAS  
GOING TO RAIN.** He had all of his Russian  
heritage behind him and he knew what he  
was talking about. She argued that although  
he came from a proud heritage, **IT STILL  
WASN'T GOING TO RAIN.** They argued  
back and forth for hours , so much that they  
went to bed mad at each other.

During the night, sure enough one of the  
worst rainstorms hit the village the likes of  
which they had never seen. That morning  
when Rudolf and his wife arose, they looked  
out the window and saw all the water that  
had fallen that night. "See," said Rudolf, "I  
told you it was going to rain." His wife  
admitted: "Once again your prediction came  
true. But I want to know, just how were you  
so accurate, Rudolf?"

To which he replied, "You see, Rudolf the  
Red knows rain dear!"



<b>T RN</b>	<b>Y Y Y MEN</b>	<b>STO N E</b>
<b>HAIR</b>	<b>DRINKS HOUSE</b>	<b>CYCLE CYCLE CYCLE</b>
<b>FEW FEW MENTION MENTION</b>	<b>WEAR LONG</b>	<b>123456789 1SAFETY9 123456789</b>

No one can mishear a Christmas carol better than a kid. Sing along with these new takes on old favorites:

**DECK THE HALLS:**  
Deck the Halls with Buddy Holly...

**WE THREE KINGS:**  
We three kings of porridge and tar..  
Good tidings we bring to you and your ma,

**THE TWELVE DAYS OF CHRISTMAS:**  
On the first day of Christmas my tulip gave to me..

**WINTER WONDERLAND:**  
Later on we'll perspire, as we dream by the fire.  
In the meadow we can build a snowman.  
Then pretend that he is sparse and brown.

**SANTA CLAUS IS COMING TO TOWN:**  
He's makin' a list, chicken and rice...

**THE FIRST NOEL:**  
Noel. Noel. Barney's the king of Israel.  
With the jelly toast proclaim...

**RUDOLPH THE RED NOSED REINDEER:**  
Olive, the other reindeer...  
You'll go down in listerine!

**FROSTY THE SNOWMAN:**  
Frosty the Snowman is a ferret elf, I say...

**SILENT NIGHT:**  
Sleep in heavenly peas...

**JINGLE BELLS:**  
Oh, what fun it is to ride with one horse,  
soap and hay...

**OH COME ALL YE FAITHFUL:**  
Come, froggy faithful...

And from a School teacher neighbour..  
Our Father who art in Heaven,

**SEND US YOUR  
CAPTION FOR THIS PHOTO**



**Entries by 15th Jan 2005 please.**

# Exercise improves brain function

By Richard Daggett

Reprinted with permission from Rancho Los Amigos Post-Polio Support Group Newsletter June 2004.

Oh no, not another log on the “more exercise” or “no exercise” debate fire. I’m afraid so. I was going to call this article, ‘Uh-oh, I’m in Trouble Now’ but decided on the more descriptive title.

First a little background on me. I had what could be fairly described as a severe case of polio. I was in a tank respirator for six months, and hospitalized for the better part of three years. Even so, like most polio survivors, I’ve led a pretty full and active life. When I left the hospital I was walking, and for about thirty years my level of function was stable. In the early 1980’s the late effects of polio began to take their toll, leading to the point where I now use a power chair and ventilator.

As I’ve become less mobile and lost strength I’ve also become what is loosely described as, “out of shape”. Let’s face it. I couldn’t fight my way out of a paper sack. I know from personal experience that inactivity leads to weakness, and too much activity leads to weakness. What to do? What to do?

Now another study indicates that inactivity, physical inactivity, is detrimental to your brain. Actually, what the study found was that physical exercise improves brain function. Researchers at the University of Illinois established that brisk walking or other aerobic exercise could make the brain work better and more efficiently.

The study, recently published in the Proceedings of the National Academy of Sciences used neuro-imaging to observe the effect of exercise on the brain’s structure, specifically that area of the brain that involves decision making.

A group of people, aged 60 to 79, were given tests before and after six months of brisk walking. The tests showed increased connections between neurons in parts of the brain that makes a person better able to pay attention, compared with people who were physically inactive. Those in the exercise group were able to focus more clearly on goals while disregarding competing but relevant information.

William Thies, vice president for medical and scientific affairs for the Alzheimer’s Association, said “It’s a powerful demonstration of the fact that there’s a direct relationship between fitness and brain health. People are often reluctant to engage in physical exercise because they think they have to run marathons and look like Arnold Schwarzenegger. But this shows that with a relatively modest aerobic plan you end up improving brain function.”

The National Institute of Aging provided funds for the research. Molly Wagster, director of the neuropsychology of aging research program at the Institute stated, “Here’s a demonstration where physical exercise in humans is something that produces not just a hedging against cognitive decline with age, but actually shows that one can have improvement of cognitive function. The findings are very interesting and very hopeful.”

Interesting? Yes. But hopeful, I’m not sure. About all the exercise I can handle is bringing a fork to my mouth, brushing my teeth, and standing to transfer. Even

eating and brushing my teeth are tiring. On the other hand, if I'm in bed for more than a day my remaining strength diminishes.

The only hopeful thing I can find is that similar studies have found the same kinds of brain neuron improvement can occur in purely mental exercise. Most research into this area suggests that doing crossword puzzles, playing cards with friends or board games with the grandchildren, can stimulate the brain. Even shopping helps keep the brain fit.

So, here I sit, staring at the computer screen, trying to make one sentence follow another in logical order. I can't do the "brisk walk", so I'll have to content myself with some brain exercises. Uh-oh I'm in trouble now!

Actually, exercising your brain does not mean you have to "beef up" your brain, and the image of a muscular brain is not one that fits the physiological mould. As uncomfortable as we might be with the thought, our brains are primarily fat – apparently about 60% of the brain is fat.

An article in the Tufts University Health and Nutrition Letter suggests 10 ways to keep your brain in top shape. Using this as a guide, and adding information from several other sources, I'll share some of the things I've learned.

As we age we have a harder time absorbing vitamin B12 from the food we eat. This vitamin is necessary for proper neurologic function. Without enough B12 we could have trouble with memory. As odd as it may seem, even if we can't absorb B12 from food, we can still absorb it from supplements. A supplement should have at least 2.4 micrograms of the nutrient.

It is also important to eat a diet rich in

vegetables, fruits, grain products, and legumes (peas and beans). Moderate amounts of beef, poultry and fish are also recommended. These food groups have been linked to better memory and reasoning ability.

One in four adults has high blood pressure, a documented risk for heart disease. Evidence also points to high blood pressure having a negative impact on mental function. A study by the National Institute of Aging linked people 50 and older, with a history of high blood pressure, with lower scores on language and memory skills. Tests also indicated that high blood pressure often led to brain atrophy – not something very pleasant to contemplate.

So, what can you do to improve brain function beside eating the right food, exercising, and keeping your blood pressure under control? You can start by having fun!

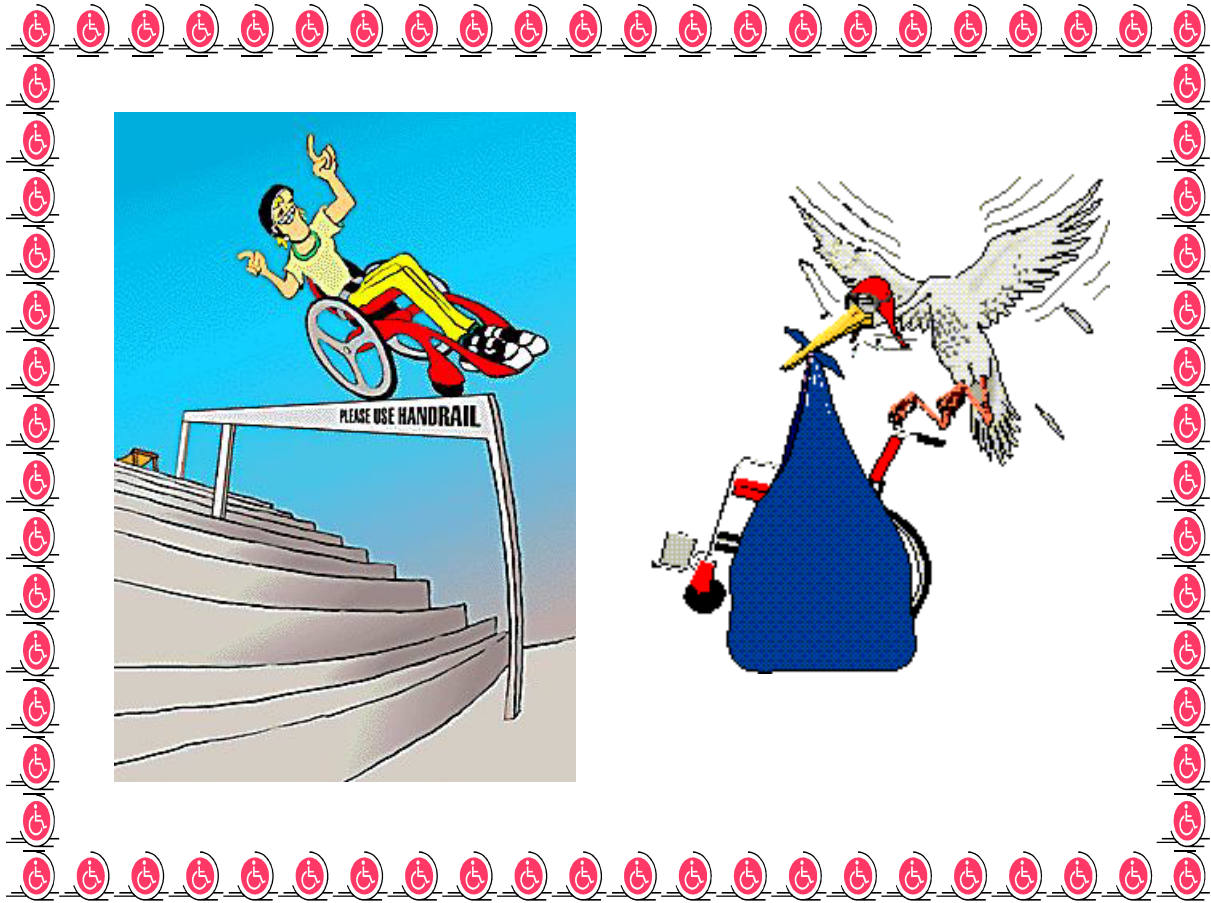
Yes, that's right. Studies have shown that having fun, or doing things that bring enjoyment, can improve brain function. Here are a few that were suggested in my research.

Remain socially active. Socializing is one of the best mental workouts you can do for yourself. Connecting with others has the potential of a good brain "buzz" of mental stimulation, which improves the pathways between neurons.

Play mind games. Studies indicate that the more active you are mentally with leisure activities such as hobbies, reading, crafts, etc., the stronger the connection between brain cells.

Reduce stress. Chronic stress, anxiety, and negative distraction can actually do permanent damage to your brain.

richarddaggett@comcast.net



**A CUTE IDEA FOR USING  
CARBOARD TUBES AND ODD CHILDRENS SOCKS.**

- |                                      |  |
|--------------------------------------|--|
| * 3 pieces of paper, 2"x2" for faces | * 3 pieces of tan paper, 1"x2" for songbooks |
| * 3 paper tubes                      | * 3 child size socks                         |
| * Paint                              | * 3 elastic bands                            |
| * Ribbon                             | * Paintbrush                                 |
| * Stamps, optional                   | * Glue                                       |
| * Black marker                       |  |

**Directions**

1. Paint paper tubes and set aside to dry.
2. Stamp or decorate tube to embellish if desired.
3. Cut out the face and add eyes and a mouth. Glue to tube.
4. Cut off the foot of the sock and close end with an elastic band.
5. Cover elastic band with Raffia, ribbon, wool, cloth, etc.
6. Place hat on tube.
7. Fold and glue songbook to Caroler.

Print or draw sheet music onto tan paper and attach with glue.

