



The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**
Volume 6 - Issue 9 — June 2009

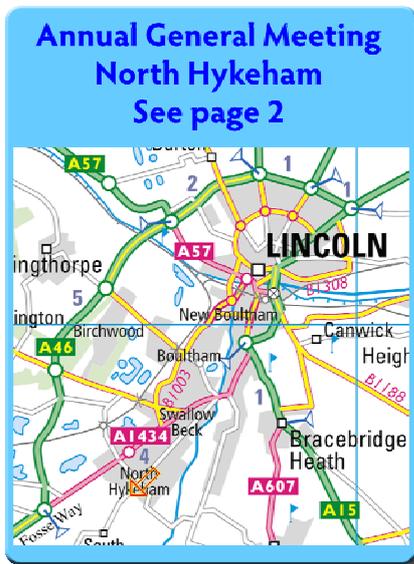
WebSite - <http://www.lincolnshirepostpolio.org.uk>



Photographed at the
Mobility Roadshow,
Kemble Airfield,
Wiltshire,
June 2009.

Left
Robin and Pauline Butler
Membership Secretary

Below
Member Paul Stanton,
Getting ready for a
Microlight flight.



This publication is provided as a service to those seeking such information. The opinions expressed in this publication are those of the individual authors and do not necessarily constitute endorsement or approval by the Lincolnshire Post-Polio Network. ALWAYS consult your doctor before trying anything recommended in this or any other publication.

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

CONTENTS

- Page 3** Editorial continued on page 17.
Pages 4 to 6 Message from the Chair.
Pages 7 and 8 Statins and muscle pain -- new research
by Trustee Dr. Ruth Bridgens
Pages 9 to 12 'If I had polio...A report on presentation by Prof. Caroline Young,
Consultant Neurologist, The Walton Centre, Liverpool,
at the British Polio Fellowship Super forum Leeds, 13th June 2009.
Pages 12 to 17 report on Lincoln's 'Meat and Greet' June 20th 2009.
Page 17 continuation from page 3.
Pages 18 and 19 Contact and Member Information.
Page 20 Dates for your Diary.
Page 20 and 'Diet info Charts' see page 3.

Our thanks to the following who have donated funds towards our work.

Jim & Jenny Rayner, D.W. Rose, Ann Telford, Victor Gabriel,
Mrs. O. West, Winnifred Hyam, Miss L.A. Forsyth,
J.D. Witheridge, V.M. Holland, Diana Nash, Mrs. L. Hobday,
Mrs Y.S. Grosse, J.C. Dobbie, Pauline Dunham,
Mr. & Mrs. Darlington, Elizabeth Watson, Frank Knights,
John Ward. Val Scrivener, Clinton Rogers,
Bridget Langdon, Clare Colfer, Mrs M.R. Allison, John Doohan,
Stephen Clynch, Hilary Davies, Mrs Gillian Reed,
Robert Price, and Virginia Ottonello.

Plus all those who work so hard for us for the time,
energy and financial savings donated to the LPPN from their PPS lives.

ANNUAL GENERAL MEETING

Saturday 3rd October 2009 to be held at North Hykeham Adult Day Care Centre, Neale Road, North Hykeham, Lincoln. Doors Open 10.00 for 10.30 start. 12.30 pm a Buffet Lunch will be served. Speakers start at 1.30 pm. Confirmed speaker of Tara Kellie from the Independent Budgets Network Lincolnshire. Whilst we fully appreciate Tara is Lincolnshire based, the core information is likely to be the same regardless of which county you live in. We will obtain local contact info for all those attending. We have also contacted two other health professionals to talk about managing your PPS but as we go to press we have not yet had confirmation. We will contact all members as soon as we have the content for the day finalised.

CONTACT INFORMATION IS NOW ON PAGES 17 AND 18

Copyright of material published in the LincPIN is retained by The Lincolnshire Post-Polio Network and/or the original author(s). Reproduction and redistribution of any material via any media requires permission from The Lincolnshire Post-Polio Network and where applicable, the original author(s). Where permission is given, original material must include a credit to the LincPIN; material from other sources should credit the original publication.

Editorial by Hilary Boone.

Choosing which articles to include and which to leave for another issue has not been easy this time. I wrote an article about a way of dieting that is working for myself and some other members but the only way I can include this is to précis it here. If you or a family member does not have internet access and would like more information on this please get in touch.

Last issue I reported this statement from a GP at our surgery who said “You now have Type 2 Diabetes and your cholesterol is too high for a diabetic. You are now at greater risk for heart attacks and strokes. I did have a patient who lost 70 lbs and got rid of their Diabetes but you are hardly likely to manage that!” I am very grateful for this remark because he gave a Polio Survivor a challenge and you all know how we love them and I did not want to take the diabetic drugs and statins if I did not have to. I had to wait three months to be tested again but am pleased to tell you that, without taking tablets other than the 2.5mg for blood pressure, that I have WON the challenge in 3 and a half months! Weight is down 48 lbs. Blood pressure, Blood Sugar and Cholesterol are all now in the normal range. Two other wheelchair user members have also lost 12 lbs each in the last couple of months.

I remembered Florida member Derek Paice’s article on managing your Diabetes with Diet that I referenced in the LincPIN August 2004. High Glycemic foods peaking and troughing your blood sugar levels make it harder to control Type 2 Diabetes by diet. Derek’s article is in full on David Mendosa’s Diabetes website www.mendosa.com/DiabetesAndDiet.pdf. I went to this site, read more about diabetes and looked at the labels on the food and drink that I was buying. I was horrified. My being good taking in plenty of fluid and ensuring my ‘five fruits and veg. a day’ by drinking 4 pints of diluted fruit juice and water a day was NOT GOOD. In fact I was **drinking my sugar allowance for the day** before taking into account what I was eating, let alone the odd chocolate bar of which I could never just eat one piece.

My Glycemic Load was far too high, I needed to lower it. I then found ‘The Low-GL Diet Bible’, The perfect way to lose weight, gain energy and improve your health by Patrick Holford. ISBN 978-0-7499-4167-3. All you have to do is follow two simple rules: Rule 1: Eat no more than 40 GLs a day [3 x 10GL for meals plus 2 5GL snacks] and drink no more than 5GL’s a day. Rule 2: Eat protein with carbohydrate. Knowing the Glycemic Index of food is ok but you still have to consider quantity of food and the Glycemic Load figure gives you that. I wrote down what I liked to eat, swapped high GL items for low ones. E.g. Breakfast of 30g of porridge oats, half a grated apple, a small tub of natural yogurt and some milk is 9GL units, but a bowl of cornflakes, a banana and some milk is 21 GL units.

Revised International Table of Glycemic Index (GI) and Glycemic Load (GL) Values—2008
By David Mendosa <http://www.mendosa.com/gilists.htm>

Individual Budgets/Direct Payments. Because of concerns that I have for folks with physical disabilities being assessed using the questionnaire attached to the new Individual Budgets/Direct Payment scheme coming into play across the country I contacted other physically disabled groups. None had been consulted so together we have requested a meeting with Social Services to discuss the self assessment questionnaire [SAQ] recently renamed in Lincolnshire ‘Needs Assessment Questionnaire’.

Member Jean Murdoch has been involved with the Pilot Project and explains a bit more. Having found wide discrepancies throughout the country on care provision the Government decided in 2003 to set up Fair Access to Care Services. Their intention was that each person, no matter where they lived, would be assessed under the same criteria and thus all people
Continued on page 17

Message from the Chair

Have you ever considered what you would do if there was a fire in your home? This is something that has always worried me, knowing that should such a fire occur when I was upstairs, I would be completely trapped. I knew that I ought to have smoke alarms, but as I couldn't fit them myself – or change the batteries - it was one of those things that I somehow didn't get around to organising. During a conversation with member Wendy Grimmit, this subject came up, and she told me that I could have a free fire safety assessment by my local Fire Brigade, who would fit smoke alarms and check the state of electrical outlets, and give advice on what to do in the event of a fire. Free? Sounded good to me, so I rang my local Fire Station to find out more about it, and an appointment was arranged for me.

This morning two burly firemen turned up and began their check. Sockets were checked for possible over-loading and then they proceeded to fit two smoke alarms, one upstairs and one downstairs. These have 10 year batteries, and don't need any maintenance. I was told to test them occasionally, and if there were any problems, to ring the Fire Station. I was then given a couple of leaflets, and we discussed a plan of action if (Heaven forbid!) there ever was a fire.

All in all, it was a well worthwhile exercise, and I feel a bit safer now. So if you would like to take advantage of the scheme, all you have to do is ring your local Fire Station and ask for a Home Safety Check. If you prefer, you can arrange this via the Internet, filling out a request form online at:

<https://www.fire.gov.uk/Home+safety/IsYourHomeSafe/HomeVisit.htm>

Mobility Roadshow

This year's Roadshow at Kemble Airfield, Cirencester, was every bit as good as usual. It's the sort of show that you can't easily get around in one day, and I had planned to go on all three days. Unfortunately, the NHS intervened, and altered an appointment at very short notice, which meant that the middle day was spent dashing up the motorway to London, instead.

It was lovely to meet some of our members – there's a picture of Robin and Pauline Butler (Robin is our Membership Secretary) on the front page – and I trust you all enjoyed the show as much as Paul and I did!

There was an enormous variety of adapted (or adaptable) cars on show, which you could test drive, and I was particularly pleased to be able to try out a vehicle that I shall soon be having through Motability. (More about that, later.)

I didn't take advantage of a ride in a skid car that was on offer, however! You could also try out adapted go-karts, but I knew that in the highly unlikely event

that I managed to get into one, I would never get out again! There were various sports, dance and fitness activities in the Sports Arena, which a huge number of people seemed to enjoy, and outside was an 'accessible climbing wall' if you were brave enough to try abseiling!

The British Disabled Flying Association and the Kemble Flying School were at the show, and this was something that both Paul and I really enjoyed. Both a two and a four-seat aeroplane were available for a half-hour flight, and also a Microlight. I don't know if you're familiar with these aircraft, but to me they look (and sound) like flying lawnmowers! Paul had always wanted to fly in one of these, and so a flight was arranged which he thoroughly enjoyed (Picture on front page). As I couldn't have got into the microlight, I took the more sedate two-seater plane option and had a wonderful 30 minutes touring the skies above Gloucestershire. Getting in and out of the plane was accomplished with a hoist, much like one sees in hospitals, but which lifts you much higher.

Back on the ground again, we explored the masses of products, services and information from a range of exhibitors which were well worth checking out.

Let's hope that you will be able to come to next year's show!

The British Polio Fellowship Expert Panel

We have a new Chairman - Professor Jim McKillop - whom you may have read about in The Bulletin. I found him extremely pleasant, very interested and keen - and best of all, he knows what we're dealing with as he had mild polio at age 5. He made an apparently full recovery but is now suffering PPS.

We spent some time debating the wording of some points in a new booklet that the BPF is producing, about the diagnosis and treatment of PPS.

Amongst a plethora of other concerns, we also briefly discussed the inadequacy of breathing tests and sleep studies, and this will be a subject for further discussion at the next meeting.

There will be opportunity at the next meeting to discuss current polio/PPS issues that have been referred to panel members. So if you have any concerns that you would like me to take to the next meeting, please let me know as soon as possible, either by e-mail at the address below, or by writing to me at P.O. Box 954, Lincoln, Lincolnshire, LN5 5ER.

The next Panel meeting will be on 3 November 2009.

Wheelchair Accessible Vehicles [WAV]

It isn't very nice when you finally realise that things have become too difficult, and that you have to rethink the way you manage. I've had to accept that

being able to walk enough to manage loading my wheelchair into the car by myself is just not going to happen. I've had a Motability car for just under two years, and knew that I would need to cancel my contract if I had another one before the 3 year period expired. I approached Motability with the problem, and I have to say they have been fantastic. I had to produce evidence to back up what I had told them of my condition, and then an assessment was arranged for me at the Disability Living Centre in Bristol. My physical ability to drive was tested. The test consisted of checking that I could do an emergency stop (i.e. could I stamp on the brake with my right foot), checking that I could see well enough, and taking note of how much mobility I had in both legs and arms. I was pleasantly surprised by the kindness of the people carrying out the tests. Once the tests were completed, we had a discussion about my particular difficulties, what adaptations I would need and about what I use the car for.

Measurements of everything from me to the wheelchair were taken, and the assessment was over.

Very soon I received a fairly detailed report, which was forwarded to Motability. A few weeks later I received a letter saying that not only would they agree to my having a WAV, but that they would give me a grant for the required adaptations. This had been worrying me greatly, as I would never be able to afford the £6,000 + that they would cost. The vehicle will have a dropped floor, electric door and ramp, so that I can drive the wheelchair straight in, park it, and then transfer to the 6-way driver's seat. It lifts up, moves back into the car and then turns round so that you can transfer easily from the wheelchair. I didn't know such a creature existed!

The upshot is that I will shortly be having a home assessment – that is, the vehicle is brought to me at home to try out, to ensure that it fits all my requirements. Then it will take another 3 months or so for the adaptations to be carried out on the new WAV, and so by the Autumn, I should have my new car.

Maybe I'm a little biased, but I have found Motability to be genuinely helpful and aware of how much freedom to get around means to a disabled person. So far, after two years with them, I have no complaints whatsoever and would recommend any disabled person to think about taking a Motability car. What I like so much, is that if you were to get any problems with the car, they won't be *your* problems! Motability will deal with them, and deal quickly. No Insurance costs, no servicing costs, free RAC membership – it suits me just fine!

Mary McCreddie

mary.mccreadie@lincolnshirepostpolio.org.uk

Statins and muscle pain -- new research

By Trustee Dr. Ruth Bridgens

This article first appeared in a slightly different form in the BPF Bulletin, May, 2009

As a result of the government's attempt to counter rising levels of heart disease, prescriptions for statins, which lower blood cholesterol, are on the increase. It was estimated that guidelines issued in 2006 would increase prescriptions by 1.7 million people, and that by 2008 5.2 million people might be taking statins. A few years ago, the development of a polypill (a combination of aspirin, a statin and blood pressure lowering drugs) was suggested for everyone over 55 (Wald and Law 2003). In March 2009, the Lancet published the results of a polypill study on people without cardiovascular disease but with one risk factor, concluding that the combination of drugs would reduce risk of heart attacks and strokes by about 50% in healthy people or those with some risk (Yusuf et al 2009). Side-effects were no different from those for the drugs individually. However, there was no mention of whether healthy people should be risking the side-effects which does concern some doctors. At the moment, statins are prescribed to people who have heart disease, diabetes, kidney disease, inherited high cholesterol, or a combination of risk factors, which include age, blood pressure, cholesterol level, sex, and smoking history. One side-effect from statins that has been receiving attention is myalgia (muscle pain), which is of interest to anyone with polio or other neuromuscular conditions, and research is being conducted to find out how statins affect muscles. A recent BMJ article (Sathasivam and Lecky 2008) reviews some of this research and makes recommendations for patients who develop muscle pain with statins.

When statins were first used in the late 1980s, the only recognised muscle-related side-effect was rhabdomyolysis, a very rare condition in which muscle pain was combined with extremely high levels of the enzyme creatine kinase (CK). Since then, trials have found that up to 13% of healthy patients on statins, especially on higher doses, may develop muscle pain and cramping, often exacerbated by exercise, with or without raised CK levels. The pain usually begins within six months of starting statins and usually ends within three months of stopping. In the Lancet polypill study, about 8% had a 50% raise in creatinine (product of creatine) levels, but the 12 week trial was not long enough to monitor for muscle pain. Some of the proposed risk factors for developing muscle pain are thought to be:

- older age (> 80 years)
- female
- comorbidities such as diabetes, kidney or liver disease
- untreated hypothyroidism
- drug interactions
- infections
- genetic factors to do with muscle metabolism or blood statin levels

It is thought that the muscle pain may be due to the effect of statins on drug or muscle metabolism. One hypothesis is that some people are more genetically disposed for statins to impair the synthesis of compounds in the cholesterol pathway, such as coenzyme Q10, which helps the muscle create energy. Other

researchers are looking at the genetic susceptibility of the liver to take up more statins, creating an excessive blood level of statins. Muscle biopsies of statin patients with myalgia have shown evidence of myopathy (muscle damage) suggesting metabolic abnormalities, which reversed after statin treatment was stopped (Phillips et al 2002). A muscle biopsy study on statin patients without muscle pain even found evidence of minor damage in the muscle membrane, thought to be caused by lower levels of cholesterol in the membrane (Draeger et al 2006).

Studies on statin side-effects are conducted with patients who do not have neuromuscular diseases, so the effects on polio patients are unknown. However, there are types of statins which are less likely to cause muscle problems (hydrophilic statins such as pravastatin, rosuvastatin, and fluvastatin), and there are newer cholesterol lowering drugs which are not quite as effective but do not seem to cause myalgia. In the letters replying to the BMJ article, there were some suggestions for future studies on substances such as vitamin D, Q10, and carnitine, which affect muscle metabolism and are found to be depleted in those who develop muscle pain with statins. Since the BMJ article was published, a study has found that for those whose vitamin D status was low, supplements of the vitamin reversed the muscle symptoms (Ahmed et al 2009). For managing statin-induced muscle symptoms, the BMJ article suggests initially excluding other common conditions, and testing for creatine kinase and thyroid stimulating hormone. If rhabdomyolysis is suspected, the statin should be stopped and more tests (renal function and urine myoglobin) conducted. If the muscle pain is thought to be due to the statins but is mild, the treatment can continue. If more severe, the statin can be temporarily stopped and possibly restarted at a lower level after symptoms subside, or another class of cholesterol lowering drug should be considered.

References

- Ahmed W et al (2009) Low serum 25 (OH) vitamin D levels (< 32 ng/mL) are associated with reversible myositis-myalgia in statin-treated patients. *Translational Research*, 153 (1): 11-16.
- Draeger A et al (2006) Statin therapy induces ultrastructural damage in skeletal muscle in patients without myalgia. *Journal of Pathology*, 210:94-102.
- Phillips PS et al (2002) Statin-associated myopathy with normal CK levels. *Annals of Internal Medicine*, 137: 581-5.
- Sathasivam S. and Lecky B. (2008) Statin induced myopathy. *BMJ*, 337: 1159-62.
- Wald NJ, Law MR (2003) A strategy to reduce cardiovascular disease by more than 80%. *BMJ*, 326: 1419–24.
- Yusuf S et al, The Indian Polycap Study (2009) Effects of a polypill (Polycap) on risk factors in middle-aged individuals without cardiovascular disease (TIPS): a phase II, double-blind, randomised trial. *Lancet*, online 30 March.

If I had polio... presentation from Prof. Caroline Young, Walton Centre, Liverpool at the British Polio Fellowship Super Forum on Saturday 13th June 2009 in Leeds.

Prof. Young started with information on polio, post polio syndrome and the symptoms that many of us are reporting.

She reminded everyone that not every case of increased muscle weakness is PPS so careful consideration of symptoms must be taken as some conditions are treatable. Muscle weakness can come from not using muscles enough and the less they are used the weaker they become. It is therefore essential that polio survivors have a multi disciplinary assessment. There are no tests that will confirm PPS but there are tests, like EMG's that can eliminate other conditions if they are suspected.

She explained that most of us do not do the levels of activity that our bodies were developed to do. Tiredness is common and can happen for a variety of different reasons, overdoing, new weakness, chronic pain, muscle pain, sleep problems, reduction in breathing strength, etc. Polio Survivors talk about 'hitting the polio wall' as fatigue which as a medical term is quite complex and includes difficulty remembering, concentrating, summoning up enthusiasm to do activities. Fatigue decreases with rest. Surprisingly there has been very little research into muscle fatigue.

She told us that PPS is not caused by a recurrence of the virus. That the virus damaged and killed nerves. The nerves that were left sprouted axonal nerves that looked for muscle fibers with no nerve supply, made the link forming giant motor units. Some movement came back and we 'recovered'. One of the affects of aging is a loss of motor neurons and older people become less able. When Polio Survivors lose neurons they can lose 200 at one hit rather than the average 50. Some believe that the more you overwork these fibers the faster they fail.

Her explanation of research was very interesting. All research has basic rules and is continually checked by ethics committees. All research has to be on volunteers who have to give their consent. Before starting a trial there has to be decision as to how many people are needed to demonstrate a realistic result. Eligibility and exclusion criteria have to be fixed. These are then split into two comparable groups where one group gets the treatment and one does not. Drug trials have to be double blind – only the safety committee know who is and who is not getting the drug or the placebo. If you knew you were or were not getting the treatment your mind could influence whether you improved or not. This committee continually assess the results to pick up anything that might make it unsafe for someone to continue with the treatment.

How you get on trials is more difficult now with data protection. There are research databases, hospital records, clinics, putting the word out to groups.

People who apply first have to be prescreened against the eligibility criteria. If they pass this they are then sent a very long fully detailed information leaflet. They are then invited in for a face to face discussion and if they are happy to continue they sign the consent form. They are then fully screened to ensure they are eligible and then randomized as to which group. There is a time limit on the testing. If everyone does not join at the same time then there are extension studies till the last person completes the agreed time. Extension studies vary with some continuing as they were or they could be asked do you want to try the drug [you might or might not already be on this].

Trial results. There are three reasons people drop out. You do not have to give a reason, or you might be asked to leave for your own safety or because you are not complying, plus the

safety monitoring committee crawl all over the data looking for trends and if they think there are any safety concerns or too many drop out then they stop the study. Once all the data is in it is then analysed and the results published before a license for the drug can be given. In the UK NICE decide if a drug is cost effective for the treatment results before they agree to pass this.

There are other types of research. Questionnaires, Interviews, Focus Groups, Observations, Analysis of Databases and articles.

What can we do to help ourselves. There is no cure for PPS. A general diet is good. The role of exercise has been extensively discussed and researched. The scientific data from studies shows that exercise within our limitations is beneficial to our overall health. Exercise increases our metabolic rate, including cellular sensitivity to insulin which is separate from diabetes, helps us lose weight and reduce blood lipid and cholesterol levels.

She referenced various articles on exercise and PPS quite clearly stating that she is not saying exercise is mandatory because every person is different. This is the scientific information available. Do not flog yourself, listen to your body, work with post polio knowledgeable health professionals.

I found the following article whilst searching on the internet which covers all the information she gave. This is from Polio Network News, Spring 1999, Vol 15, No. 2.

Reprinted from *Post-Polio Health* (formerly called *Polio Network News*) with permission of *Post-Polio Health International* (www.post-polio.org). Any further reproduction must have permission from copyright holder.

The Role of Activity by James C. Agre, MD, PhD.

“To exercise or not to exercise, that is not the question for polio survivors; rather, the questions are these: what amount of exercise is enough? what amount is too much?” There is no easy answer for all polio survivors, but we can make some general observations about inactivity and exercise.

Adverse Effects Of Inactivity.

Limitation in physical activity results in progressive deterioration of cardiovascular performance and efficiency; metabolic disturbances; difficulty in maintaining normal body weight; disturbed sympathetic nervous system activity; reduction in muscular strength and endurance; and possibly emotional disturbances.

Beneficial Effects Of Regular Exercise.

In contrast, beneficial physiologic adaptations to regular exercise include reduction in heart rate and blood pressure; morphologic changes in skeletal and cardiac muscle resulting in improved physical work capacity and an enhancement of cardiovascular efficiency in delivering oxygen and nutrients to the tissues; increased muscular endurance; increased myocardial vascularity; reduced blood coagulability; reduction in adiposity and increased lean body mass; increased cellular sensitivity to insulin; and favorable changes in blood lipids and cholesterol. Beneficial psychological changes from regular exercise include reduction in muscular tension; improved sleep; and possible increased motivation for improving other health habits such as changes in diet (reduction in saturated fat consumption, for example) and cessation of cigarette smoking.

Evidence For Beneficial Effects Of Exercise In Post-polio Individuals.

Studies have shown strengthening exercise, aerobic conditioning exercise and ambulatory exercise to be beneficial.

Strengthening Exercise - In Feldman and Soskolne's study of six post-polio patients, the subjects performed non-fatiguing exercise three times per week for 24 weeks or longer. Strength either increased or remained the same in all muscles in all subjects except for one muscle in one subject that became weaker. The authors concluded that the strengthening exercise was, in general, very beneficial.

Einarsson and Grimby studied 12 subjects who exercised three times per week for six weeks. The subjects performed intervals of strengthening exercise interspersed with rest breaks. All subjects became significantly stronger in the six-week period.

Fillyaw and colleagues studied 17 subjects who exercised every other day for up to two years. The exercise intervals were interspersed with rest breaks. Over this period of time, all subjects gained significant strength.

At the University of Wisconsin, we conducted a 12-week study of muscle-strengthening exercise in seven post-polio subjects. Subjects exercised four times per week for 12 weeks at home. Exercise intervals were interspersed with rest breaks. After the 12-week program, the average increase in strength was 36%; also work capacity and endurance increased by 15% or more.

Aerobic and General Conditioning Exercise - Four such studies have been performed. Jones and colleagues studied 37 post-polio subjects: 16 volunteered for the exercise program while 21 served as control subjects. The exercise subjects performed stationary bicycle exercise three times per week for 16 weeks. They began with bouts of exercise of 2-5 minutes on the bicycle with 1-minute rest breaks, progressing up to 15-30 minutes of exercise per session. After the program, the exercise subjects were found to have significant improvements in their aerobic power and their capacity to exercise. The control subjects did not change in this same time interval.

Kriz and colleagues performed a similar study in 20 post-polio subjects (with 10 exercise and 10 control subjects); however, the exercise was upper-limb cycle ergometry (rather than lower-limb cycle ergometry). In this study, too, exercise subjects significantly increased their aerobic power and exercise capacity.

Grimby and Einarsson studied 12 post-polio subjects who performed submaximal endurance and strength training twice weekly for six months. Activity was interspersed with rest breaks. Except for one, all subjects were significantly improved from the training program. The exception reported excessive fatigue with the training program. Grimby and Einarsson concluded that combined endurance training and submaximal strengthening exercise can be generally positive in postpolio individuals, but that overtraining can occur.

Prins and colleagues studied 13 postpolio subjects. Nine performed a swimming and aquatic strengthening exercise program and four were controls. Intervals of exercise were interspersed with intervals of rest. The authors reported significant improvements in strength and flexibility in the exercise subjects and no change in the control subjects.

Ambulatory Efficiency- Dean and Ross studied 20 post-polio subjects. Thirteen were control subjects and seven performed treadmill walking exercise three times weekly for six weeks. The exercise was low-level, non-fatiguing and not painful. After the six-week program, the exercise subjects walked more efficiently, while the control subjects showed no change. The study concluded that regular exercise could improve movement economy.

Exercise studies have shown that judicious exercise can improve muscle strength, range of motion, cardio respiratory fitness and efficiency of movement in some postpolio individuals. These benefits appear to occur when they keep their activity and exercise within reasonable limits to avoid excessive muscular fatigue or joint or muscle pain. Post-polio individuals should avoid activities that cause increasing muscle or joint pain or excessive fatigue, either during or after their exercise program because the performance of activity at too high a level may lead to overuse/overwork problems.

James Agre, MD, PhD received his MD from the University of Minnesota in 1976. He completed residency training in Physical Medicine & Rehabilitation in 1979 and received a PhD in Physical Medicine & Rehabilitation in 1985 from the University of Minnesota. He has written many articles on the results of his research on post-polio syndrome (published in the referred literature) and has presented at many conferences. He is a firm believer, both professionally and personally, in regular exercise.

References

- Feldman, R.M., & Soskolne, C.L. (1987). The use of non-fatiguing strengthening exercise in post-polio syndrome. In L.S. Halstead and D.O. Wiechers (Eds.) Research and clinical aspects of the late effects of poliomyelitis (pp. 335-341). White Plains, NY: March of Dimes Birth Defects Foundation.
- Einarsson, G., & Grimby, G. (1987). Strengthening exercise program in postpolio patients. In L.S. Halstead and D.O. Wiechers (Eds.) Research and clinical aspects of the late effects of poliomyelitis (pp. 275-283). White Plains, NY: March of Dimes Birth Defects Foundation.
- Fillyaw, M.J., Badger, G.J., Goodwin, G.D., Bradley, W.G., Fries, T.J., & Shulkla, A. (1991). The effects of long-term non-fatiguing resistance exercise in subjects with post-polio syndrome. *Orthopedics*, 14, 1253-1256.
- Agre, J.C., Rodriguez, A.A., & Franke, T.M. (1997). Strength, endurance and work capacity affect muscle strengthening exercise in postpolio subjects. *Archives of Physical Medicine & Rehabilitation*, 78, 681-686.
- Jones, D.R., Speier, J., Canine, K., Owen, R., & Stull, A. (1989). Cardio respiratory responses to aerobic training by patients with post-poliomyelitis sequelae. *Journal of the American Medical Association*, 261, 3255-3258.
- Kriz, J.L., Jones, D.R., Speier, J.L., Canine, J.K., Owen, R.R., & Serfass, R.C. (1992). Cardio respiratory responses to upper extremity aerobic training by post-polio subjects. *Archives of Physical Medicine & Rehabilitation*, 73, 49-54.
- Grimby, G., & Einarsson, G. (1991). Post-polio management. *Critical Reviews in Physical Rehabilitation Medicine*, 2, 189-200.
- Prins, J.H., Hartung, H., Merritt, D.J., Blancq, R.J., & Goebert, D.A. (1994). Effect of aquatic exercise training in persons with poliomyelitis disability. *Sports Medicine, Training & Rehabilitation*, 5, 29-39.
- Dean, E., & Ross, J. (1991). Effect of modified aerobic training on movement energetics in polio survivors. *Orthopedics*, 14, 1243-1246.

When attending an appointment.

Firstly ensure you know the dynamics of the appointment. Who is in clinic, who are you going to see, how long is your time slot, have any tests been pre-arranged or are you likely to need some.

Remember when asked 'How are you?' Do NOT just reply 'Fine thank you', because your appointment may stop there. You need to be polite and continue but I have the following

issues I would like to discuss. If you have an article that you wish to bring forward please do so at the start of the appointment. [editors note, we recommend that you type/write up an appointment sheet with all your info, contact details, diagnoses, meds, allergies, and numbered notes on the issues you wish to raise and provide a copy].

Normally the procedure is to read back letters before you arrive and work through any unresolved issues from the prior appointment, then any you now have. If you do not have anything to raise then we will move to health screening issues. Weight, Blood Pressure, Blood Sugar, Cholesterol, etc. asking if you have had these checked recently.

‘Meat and Greet’ at the Lincolnshire Poacher, Lincoln. 20.6.09.

Richard and I sent out 17 letters and received 7 responses. 3 members joined us plus one husband. Another member and wife were unable to attend at the last minute due to a hospital visit. Three responded unable to attend this time, one because of transport difficulties.

Regardless of numbers, we had a very enjoyable long lunch and discussed many issues which surprised us all. Everyone agreed that being with ones peers and knowing others knew exactly where you were coming from made a huge difference. Please contact us if you would like to find a local accessible venue with food and drink as a meeting place for other members and their families near to you. We will send all local members the information. Despite having the camera on the table we forgot to take the photos!

Here are the subjects we discussed and whilst some relate specifically to Lincolnshire we know the same problems exist in many other areas.

Driving from an electric wheelchair. One member has been assessed and it has been agreed to supply her with a drive from electric wheelchair vehicle. Great, one would think, but if your local Wheelchair Service says you do not qualify under their rules and they cannot supply you with one then how do you find out which Chair is right for you and which vehicle? We have made extensive enquiries and so far have not found a list of which chair fits which cars and have been sent on a never ending try ‘another phone number’ to be given the first number again five numbers later. We will continue our enquiries and report again.

Public Transport and wheelchair access. One member and her electric wheelchair live in a village and were able to catch the bus to Lincoln bus station but had to take a w/c taxi up to the Pub. She told us that she is able to get an accessible bus to Scunthorpe every hour but has to hope that no other wheelchair user is in the space! For another meeting in Lincoln she is able to get there by bus but sometimes has to let four or five buses go by before a wheelchair accessible one arrives to take her home. When fixing a meeting place for disabled groups it is essential to consider the plight of those that use expensive accessible public transport.

She is part of the Disability Network for West Lindsey which is campaigning for increased services. <http://community.lincolnshire.gov.uk/DisabilityNetworkWestLindsey/section.asp?catId=17029>

Bus Pass and Travel Tokens. People over 60 and the eligible disabled can apply for a Bus Pass to travel freely all day in Lincolnshire and at off peak times elsewhere in England or Travel Tokens – the value of which is fixed by each District [e.g. Lincoln City £25, North Kesteven £22] which may be used for Taxis and some train journeys. Sounds great but one six mile round trip wheelchair accessible taxi journey to the Theatre cost us £20.

Dial-a-Ride. Transport Service for people with Disabilities. Lincolnshire is split into areas. You have to be a member at a cost of £10 [£18 for a couple] and pay 65pence per mile. 8.30

to 5.30pm Monday to Friday. You can book a journey up to 7 days in advance. Wheelchairs and Scooters [you are not able to travel sitting on a scooter] must be seen and passed when joining to ensure the correct tie-downs are available. A carer can travel with you at a reduced fee. Whilst this is a good service you may not be able to book the times you need.

http://www.lincolnshire.gov.uk/upload/public/attachments/921/DialARideguide08_5.pdf

Call Connect - Call Connect forms part of the Interconnect bus network and is a public bus service that operates only in response to a pre-booked request (on a 'dial a bus' basis). Most Call Connect services are fully flexible and are operated by modern fully accessible minibuses. Anyone can use Call Connect for any purpose such as shopping, medical appointments, work, training or just meeting friends.

<http://www.lincolnshire.gov.uk/section.asp?catid=1981&docid=35955>

Naidex and the Mobility Roadshow. Excellent venues for finding out what is available for the less able, but costly to attend in money – It's FREE, the costs are travelling and hotel bills - and energy levels. Hiring accessible transport for this year was prohibitive but we will be seeking quotes for next year.

Disabled Parking Spaces. Lincoln City from April 1st 2009 now charge all Blue Badge Holders and anyone living in a Residents Permit Parking area also needs to purchase a Permit. It is OK saying that there are Disabled Parking spaces throughout the City but some of us have larger vehicles with wheelchairs and even if there is a space you may not be able to reverse into it. [Mary McC says Contact Mobilise – this is where they really excel!]

Hospital Parking. Queens Medical Centre in Nottingham has always had Parking problems. There is a multi storey car park – closed on 29th September 2008 because of structural defects - but with high curbs on the ramps and larger vehicles being unable to turn in one go. The Disabled Parking Areas were mostly normal sized spaces where we had to arrive at least an hour in advance to ensure that we could get parked and unload the wheels in time. Lincoln County Hospital has large car parks with some disabled parking but you need an early appointment to ensure getting a space. If there is no space then you have to park elsewhere and go to the Reception Desk with your Blue Badge to get your ticket endorsed to exit free. Are there problems where you live?

Community and Car Schemes for medical appointments. There are approximately 22 community car schemes across Lincolnshire; all are independent charitable, non-profit-making groups. <http://microsites.lincolnshire.gov.uk/travellincolnshire/>

Shop Mobility - Shopmobility is a scheme which lends manual wheelchairs, powered wheelchairs and powered scooters to members of the public with limited mobility to shop and to visit leisure and commercial facilities within the town, city or shopping centre. You will need to contact yours for costs of using their facility. www.shopmobilityuk.org/

Going to the GP Surgery and some Hospital appointments. We were surprised at the comments about accessibility to consulting rooms for those that have to use electric wheelchairs and scooters. Not being able to operate the doors, narrow corridors that do not allow you to turn into rooms, tiny consulting rooms. Being booked for examinations/tests without thought of your particular needs, e.g. getting on and off couches and weighing scales, x-rays where you need to stand and are told off for holding on to keep your balance.

Orthotics and Shoes – One member regaled us with the story of her shoes [we howled with laughter when she started that her problems started in the last century!]. For years she bought very suitable completely flat soled lace up soft leather shoes from Marks & Spencer. Sadly

they stopped selling these and she had to turn to the Orthotic Department at the local hospital. Her need for something similar was not understood and the first pair arrived as fairly sturdy lace ups with a quarter of an inch heel – too heavy and not flat soled. Many months went by before she got her shoes. [She was never told she was entitled to two pairs]

About two years ago she returned and asked for a second pair exactly like those she was wearing and amazingly gave up one of her only pair of shoes as a template. She wore slippers for SIX weeks before it was returned. When she went for her ‘first fitting’ of her new shoes she was horrified to see that they looked as if they had been made for an elephant with a huge gathering of leather at the front of the shoe. A couple of months later she was called back and this time took a friend with her. This time one was fine and the other was awful. The back at the heels was far too high and rubbed and she asked for this to be lowered. 2 or 3 months more passed and the next time the back at the heel had been cut so low that it hardly stayed on. More months passed and at her last visit she was told there was good news and bad news. The good news was the shoes were back but the bad news was that they still needed finishing off and the company had gone bust. She was told if they are OK they might be able to find another company to complete them. They looked great and just what she wanted but one fitted and the other was too small.

She has been told, ‘your needs are special’ and ‘other polio survivors do not have your problems’. True, her feet are two different sizes but she used to buy her shoes from M&S! So over a year since her request and with her one pair of shoes deteriorating further she waits again whilst another specialist Shoe Manufacturer is found.

Would you be surprised to be told that last December, Hilary and her friend accompanied her to a meeting with a Senior Manager raising the issues up to that time and were asked if we could give them the name of another company. We gave them details of polio survivor and bespoke shoemaker with 40 years experience, Philip J Taylor, The Cordwainer. 99 Railway Road, Leigh, Lancashire. WN7 4AD. Tel: 01942 739700. We also told them about his report. ‘If the shoe fits’ original report sponsored by the British Polio Fellowship and emPower. www.bespokeshoemaker.co.uk/shoe%20fits.html Philip Taylor is a member of the British Polio Orthotic Panel as is polio survivor Dr. Mark Edworthy who took the Orthotic Workshop at the British Polio Fellowship Superforum last Saturday in Leeds. Hilary will be passing the information to them and will contact the Hospital Manager.

Delicate Skin – two members reported how one has to be very careful as you age when your skin becomes thinner and easily torn. Take every precaution because you can end up in hospital on a ward where no-one has any knowledge of Polio or post polio or other equipment that is necessary to your health and wellbeing.

Bi-level Ventilators and lack of knowledge by NHS staff. Patients with sleep apnoea for a variety of reasons need ventilators. There are two basic types. CPAP is a machine that provides constant pressure both for in and out breaths. A Bi-level device is necessary for anyone with neuromuscular weakness who does not have the strength to breathe out against the same incoming pressure. E.g. settings are 15cmH2 in and 7cmH2 out. Two members attending use bi-level ventilators when sleeping at night and resting during the day. Both are reporting lack of knowledge not only of polio and post polio syndrome but of the need for and use of these machines not just essential for their health but continuing to ‘live’. This includes Ward Staff, Doctors and sadly even some professionals working in some hospitals respiratory clinics who respond ‘we only know about CPAP’s’. Both members have had considerable problems in the last few years and are seriously concerned about being admitted to hospital again in the future and their needs not being met. This is a serious issue

that the Lincolnshire Post Polio Network has been raising for years with unsatisfactory response from medical professionals. We will continue to make every effort to ensure that the issues are taken on board by the NHS as soon as possible. [Mary McC raised this at the last Expert Panel meeting].

Walk in Surgeries – The Government has said there should be a walk-in centre within every primary care trust area by the end of 2009 and have awarded a £700,000 set-up grant to NHS Lincolnshire. The question asked was ‘Do they have to report the results of your appointment to your own GP?’ We will check this.

Direct Payments and Insurance needed for employing people in your homes. Talk to your household insurance company - they might provide cover.

Panic Buttons. Organisations are now offering help to assess your home for safety and fit equipment where necessary. One member reported a Panic Button being fitted at her front door which is silent and responded to by a central unit of the company. She queries that being silent – whilst not alerting the intruder that you have raised the alarm – it does not alert your neighbours who could be with you very quickly. We wonder which idea is best?

Disabled Toilets – One member at the PUB on the day asked for the Radar Key for the toilet and when they could not find it explained all 3 had now been stolen. They opened the door with a Knife. Another member reported recently having to ask for Radar Keys at a hotel reception. Another at a venue with Portacabin toilets found all cubicles were narrow with nothing substantial to assist getting off the toilet. Much laughter and comments that once you decide you are at the toilet it is hard to turn off the ‘need to go switch’ and find another loo. There are also problems in Toilets in two local stores where there is not enough room to turn round in your wheelchair to lock the door. Raise issues with your local Accessibility Group.

Hotel Accessible Rooms. Quite a few reports of different hotels, including one opened this year and two totally refurbished last year, with bathrooms far from being usable. A sink to the right of the toilet so close that you could not sit with your knees facing forward. Towels on racks at standing height. Baths and no way of getting in and out. Shower controls at shoulder height. Many where you have to go past the bathroom door to turn on the light, backup and open the door and do the same on your return. Beds so low – told lowered specially for disabled people! - that they had to change to a normal room and struggle in the bathroom. Doors with a return spring so strong you cannot open it without help. One member reported a bathroom with so little room to manoeuvre in and out in their electric chair that they ended up washing in the room in the litter bin!

Cameras – Advice and tips required as to how you manage to take photos from a wheelchair and/or with weak arms.

Needing the loo whilst travelling and not having enough time and energy to get out. We discussed She-wee’s and Pibbles [both fairly new devices with small openings and spouts to enable ladies to pee into a receptacle but needing loads of practice in the shower before trying when out!] Female bottles that are ok but have no lid to screw on afterwards to prevent spillage. Travel Johns and similar which are plastic bags with crystals in that turn the fluid to gel which have a plastic shaped opening. Peeing into the small sample bottles given to you by the doctor [use something else and tip it in afterwards is the obvious answer] We laughed a lot as we described our own trials and tribulations.

The huge cost of buying equipment and having alterations done that you are told you do not qualify for or pay for because you cannot wait the years it takes to get through

the procedure.

How you feel about not being able to do what you should be doing at your age and how having to ask for help is hard. We talked about feeling 'being watched' to ensure you were doing actions safely but also how one felt being the watcher desperate to ensure that 'they' did not fall with all the problems that causes. How you do not realise till you lose a partner how much they did for you. How difficult it is 'living alone' or 'when both are disabled but at least you do have some idea how the other person feels'. How hard it is having someone come into your home to help you with personal stuff and the housework and finally the major issue all members had experienced.

The lack of knowledge of polio, post polio syndrome and the difficulties that we experience from NHS, Social Services and Government staff as we seek help for our new problems. The STRESS, of the continual never ending battles we go through, placed on us and our carers and families as we try to get the 'help' that we need is detrimental to our health and wellbeing. We advise any members that can find the time and energy to join local Disability groups and ensure representation on Government Department Committees so that our views are at least heard across the country. Sadly hearing what we say and doing anything about it happens far too frequently. If you do not have the energy and time then contact someone and ask them to come and visit you and take it up on your behalf.

continued from page 3.

within an area would be assessed the same and if the disabled person moved to another area the assessment would hold good. Unfortunately it has never worked, even after six years some counties are very poor at applying FACS. Lincolnshire is no worse than most.

In order to be eligible for care provision it is necessary to fit into the "eligibility framework" bands laid down by government, critical (8 points), substantial (6 points), moderate (4 points), or low (4 points) these are known as "eligible needs". The bands describe the "seriousness of the risk to independence or other consequences if needs are not addressed". Lincolnshire will meet the first three bands, many councils only meet the critical band.

The Government Guidance on Fair Access to Care is on the Department of Health website under publications. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009653] You need to read this if you want to know the Governments intentions together with Implementation Questions and Answers. However if you go the Lincolnshire County Council adult social care web page and run down the list at the bottom of the page you will see Fair Access to Care, if you click on this it will bring up a page which you can download, it is only 4 pages. [Other counties change the county name or ring for it to be sent to you] This is Lincolnshire County Council's interpretation of FACS and is applied to any person requesting care to see if their needs are "eligible" and this is decided at assessment by the assessor. (Mine was done by a Community Care Officer 4 months into the job!!). Support will only be provided to meet "eligible needs" so some needs may not be met but others will depending on the "seriousness of the risk to independence or other consequences if needs are not addressed".

It is important to know what are laid down as "eligible needs" so you can focus the assessment on these and not leave it to the assessor to judge whether they are eligible or not. We need to find out with self-assessment if the questions themselves automatically equal different risk bands or whether the assessor still makes this decision.

**If you have found this newsletter helpful
why not support our work by joining us**

**Sharing information with others
who know where you are coming from
is a HUGE stress reliever**

Membership provides

Our newsletter the LincPIN - 4 times a year

Extensive Website including 100+ article Online Library

Email Membership Forum

Be put in touch with other members in your area

Need an answer to a Question

Write to us - Ring the Phone Team - Email info@

And we will endeavour to find you an answer

Name

Address

.....

Post or Zip Code Country.....

Phone

Email

I enclosefor membership / as a donation

I am a Polio Survivor [year] carer,/ family member / friend

Health Professional

If you do not wish to cut the newsletter
then please copy the information to a letter. Thank you.

LINCOLNSHIRE POST-POLIO NETWORK

A Post-Polio Information Service for Polio Survivors and Medical Professionals
Registered Charity No. 1064177

Website - www.lincolnshirepostpolio.org.uk

WRITE P.O. Box 954, Lincoln, Lincolnshire, LN5 5ER, UK
PHONE UK 01522 888601 From Abroad +44 1522 888601
FAX UK 0870 1600840 From Abroad +44 870 1600840
EMAIL info@lincolnshirepostpolio.org.uk

JOIN or RENEW Membership Secretary,
13 Derville Road, Greatstone, New Romney, Kent, TN28 8SX, UK
Or email:- membership@lincolnshirepostpolio.org.uk

Cheques Please make payable to 'Lincolnshire Post Polio Network'

Membership Fees:

UK	Life Member	£ 150	S.O. £ 5 x 30 [Form from Sec.] Member £ 12.50
Europe	Life Member	€ 300	Member € 25
Canada	Life Member	C\$ 550,	Member C\$ 40
USA	Life Member	US\$ 375	Member US\$ 25

[Post US\$ checks to LPPN - c/o 4212 Blanding Blvd, Jacksonville FL 32210]

Other Please contact membership secretary.

Newsletters - The LincPIN - Next Issue September 2009

Articles/Items/Tipbits/Letters/Questions must be received by 21s August 2009
Post or email:- newsletter@lincolnshirepostpolio.org.uk

Management Committee [Trustees]

Chair & Email List Facilitator - Mary McCreddie mary.mccreadie@lincolnshirepostpolio.org.uk
Vice Chair - Lynn Hobday - lynn.hobday@lincolnshirepostpolio.org.uk
Secretary - Hilary Boone - hilary.boone@lincolnshirepostpolio.org.uk
Treasurer - Denise Carlyle - denise.carlyle@lincolnshirepostpolio.org.uk
Committee Members - Ruth Bridgens - ruth.bridgens@lincolnshirepostpolio.org.uk
Jim Pullin - jim.pullin@lincolnshirepostpolio.org.uk
Glenna Tomlin - glenna.tomlin@lincolnshirepostpolio.org.uk

Operations Team

Membership Secretary - Robin Butler - robin.butler@lincolnshirepostpolio.org.uk
Phone Team - Di Brennand (Leader) di.brennand@lincolnshirepostpolio.org.uk
Margaret Edmonds and Judy Barter
Administrative Support - Sheila Dunnett, Pauline Butler, Barry & Olivia Branston
Internet Services Administration - Chris Salter - netadmin@lincolnshirepostpolio.org.uk

REMEMBER - DONATIONS TOWARDS OUR WORK, LARGE OR SMALL, ARE WELCOME

DATES FOR YOUR DIARY

11th July 2009

BPF Super Forum at the Holiday Inn, Filton, Bristol.

The Western Region will be joining with Wales. Speakers, workshops, exhibitors and fun.

19TH September 2009

BPF Super Forum. The South, including Home Counties. Hilton Hotel, Reading, Berks.

26th September 2009

BPF Super; Forum, Home Counties, Holiday Inn, Elstree, London

3rd October 2009 - Our Annual General Meeting in Lincoln see page 2.

24th October 2009

BPF Super Forum. Scotland, at Stirling Management Centre, Stirling.

**Charts relate to Dietary Information in Editorial page 3.
The items in each column are all 5 Glycemic Load Units. 450 grams = 1 lb.**

FRUIT	VEGETABLES	BAKERY
7g 1 date	29g ¼ baked potato	14g ½ bagel
19g 1 fig	44g ½ sweet potato	14g ½ slice gluten free bread
75g 10 grapes	133g 1 carrot	15g ½ slice white wheat flour bread
120g 1 orange	250g of broccoli	17g 1 thin slice wholemeal wheat bread
200g of cherries	375g of green beans	19g 1 thin slice wholemeal rye bread
600g of berries	950g kale	25g 1 slice rye (pumpernickel) bread

CEREALS	DAIRY PRODUCTS	PASTA AND RICE
7g of cornflakes	14ml condensed milk	26g brown rice pasta boiled 16 min
9g of Puffed wheat	90ml rice milk	39g dried rice noodles boiled
11g of Special K™	100g Low fat fruit yogurt	41g gluten free maize starch pasta
12g 1 Weetabix™	31ml regular ice cream	43g white wheat spaghetti
25g of All Bran™	150g Soya yogurt	56g wholemeal spaghetti
75g porridge oats	333g plain yogurt	60g meat filled wheat ravioli