



# The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**  
Volume 3 - Issue 7 - October 2001

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

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Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Post-Polio Network. Although it does not provide an endorsement, it is provided as a service to those seeking such information. ALWAYS consult your doctor before trying anything recommended in this or any other publication. **Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177**

### **Editorial by Hilary Hallam.**

As we have quite a few American members I would like to add our condolences to those which have been expressed from right across the world. Chris Salter and I were talking to one another on the phone on 11th September when the TV suddenly went over to the News Flash and we watched the scenario unfolding before our eyes. We know polio survivors living in that area and are pleased to tell you that all and their families are well. Jo Kelly and her husband Kevin - who Richard and I met earlier this year when they were in Florida - were on holiday in Crete and were unable to get home for a few days. Kevin is a New York Fireman. They were able to keep in touch with many of us from an Internet Cafe and Jo reported their safe arrival home via British Airways first class and that Kevin left for work within minutes of arriving home. He lost many work colleagues.

A newspaper article caught my eye regarding a disabled lady being saved from the 68th floor by two men who strapped her to a small wheelchair and carried her down. I thought that maybe we should once again consider what we would do if we had to evacuate a building we were in, and had cut and pasted the article to my temporary file for this newsletter. What I did not expect was how soon this would become even more important. At 1.30 on Saturday night at the IBIS Hotel where some of our members were staying the fire alarm sounded - see page 19.

**Our Fourth AGM** I am pleased to say was a success with a positive move towards planning for the future. Included are reports from the meeting which will give you some idea of our plans with more in the next newsletter. Please contact us if you have any comments to make or would like to be involved in any way. Involvement need only be as much as you can give and of course we understand that there are times when even this might become impossible, it happens to us as well, so don't let this deter you if you would like to help.

The **next LincPIN** will be our Xmas Issue. Letters to the Editor are welcomed for all issues, by post and email or if its just a question you want to ask then give us a ring and dictate it over the phone.

**RUKBA** - The Royal United Kingdom Beneficent Association - Helping elderly people stay independent (and the disabled over 40) - of which I am an annuitant - recently sent me an excellent **booklet called 60-wise**. It is full of useful information and contact details of organisations that we are likely to need as we get older. With their permission I include a two page letter giving some information about their organisation and their offer to send UK members a copy of the 60-wise booklet if you contact them directly.

**Lincolnshire Neurological Alliance Meeting** - Lynn Hobday and I attended this meeting. The Neurological Support Groups of Lincolnshire working together and speaking with one voice. 5% of the population have a neurological condition and this is a much better figure to work with when you want Health Organisations to listen to you and make changes. This meeting dealt with in-house matters of the constitution etc. At the next meeting on November 8th, Sue Riddell will be speaking on the NHS Plan for Neurology and listening to a presentation from us on our collective problems.

**Lincolnshire Modernisation Council** - As members of the LNA Lynn Hobday and I attended this meeting. This was to learn more about the new organisations being set up where patients have a voice. It was also to discuss seven areas of shortfall where Lincolnshire will not be meeting government targets in April. Of note - which we have put in writing to the Health Authority - is that at the two day planning meeting of health professionals across the board Neurology was **not** discussed. Therefore it was not on the Agenda for this meeting. We attended the workshop on Orthopaedics where we were able to bring up the point that many of our members incur double or even treble waiting times by being referred from GP to Orthopaedic, some then to Rheumatology before being referred to a Neurologist. We put forward the idea that if the GP sent patients for x-ray of the symptom area that these could then be triaged to the right Consultant for the first appointment. We also attended the workshop on Work Force and learned that there are shortfalls in nearly all fields of health workers. We informed the meeting that there are only 300 Neurologists in the UK, the lowest per capita for Europe. We do not have a Teaching Hospital in Lincolnshire which makes it less attractive promotion wise and we learned that some posts being advertised have not attracted even one reply.

**Meeting of Regional Neurological Alliances** - I attended this meeting in Manchester of representatives of other Neurological Alliances. In attendance are Nikki Joule, the Policy Officer of the Neurological Alliance and it is lead by Maureen Kelly who has wears many hats, the NA, the Merseyside NA and is based at the Glaxo Neurological Institute in Liverpool. We meet twice a year and share information on what we are doing and achieving and are able to take back to our local groups some great ideas with the format already planned and workable.

**Meetings Info on BACK PAGE.**

**Lincolnshire Post Polio Network  
Annual General Meeting  
Saturday 29th September 2001  
Ancaster Day Centre, Boundary St.,  
Lincoln.  
Chairman's Report.**

Good morning and welcome to the 4th Annual General Meeting of the Lincolnshire Post Polio Network.

As I started this I thought back to November 23rd 1995 when I heard for the first time from a Consultant that there were late effects of polio and that there were reasons for the symptoms that had started following my fall in October 1988. Seven years of being told you are fine, knowing you are weaker than before, falling more often, dropping things, suffering memory problems. MS and Alzheimer's was what I thought I had.

Imagine the relief that day when I read two articles about PPS. I was not mad, I was not alone, Hurrah.... I never imagined that there would be brick wall after brick wall still to get over because of the lack of adequate education to health professionals on polio and its known late effects. Again here is another condition where the support group and its members know more than most health professionals.

So how far have we come since that day. For most of us still struggling to get adequately assessed, diagnosed, advised and provided with appropriate aids and treatment it seems not very far. Your biggest complaint is that appointment after appointment is unproductive and a total waste of time and money.

However we have taken small steps forwards. We are trying to stop the incredible waste of NHS money in inappropriate and unproductive appointments. We are talking to all manner of Health Professional bodies about the fact that the age old form of assessment looking for weakness, Manual Muscle Testing, is subjective, it does not test pattern of movement, allow for substitution of muscles, or weakness on repetition or sustaining of the action tested. Simply this method of assessment does not confirm what we are saying experiencing and we have had enough of being disbelieved.

Although we are working nationally and in fact internationally we need to work locally. Lynn Hobday and I first contacted Lincolnshire Health in the middle of 97 and have continued

in our efforts to get round the table talks. The government decreed that patients must be part of discussions. As the LincsPPN we did not represent enough people but as the Lincolnshire Neurological Alliance we are speaking on behalf of 5% of the population and with one voice. Now we are being listened to.

There is no-one championing neurology in Lincolnshire. We are a rural county without a Teaching Hospital or Neurological Department. At a recent 2 day meeting of Health Professionals discussing the shortfalls that are likely in the government targets for April 2002 Neurology was not even discussed. This week at the Modernisation Council Meeting Sue Riddell offered to come and talk to the LNA at our meeting on Nov 8th about the NHS Plan for Neurology - and to listen to a presentation from us regarding our problems and the changes we think could be made to improve the situation. So we hope to give you more news after this.

I am present working on a pre-evaluation self assessment form and the local Rehab Department and other Health Departments have agreed to look at this and trial it. The idea behind this – which is in draft form and much larger than it will end up – is that we give the information visually and in table form of the changes that have happened to us in recent years. If anyone would like to help with this then please let me know. I will then be working on a Manual for Assessment of Polio Survivors and Dr. Dowsett has kindly offered to help with this.

Your committee need more help, especially from Lincolnshire Members, although work needs doing all over the country and we would be more than happy to talk to members in other areas about how you can do what we are doing locally.

We need people to attend meetings of the Lincolnshire Association for Physical Disability, Disability Lincs, and other related organisations. We are all struggling with our own problems but if we hadn't given up our time so far to achieve what we have the light at the end of the tunnel would be further away.

Your committee has worked hard this year, it is now coming together with a plan for the future for the benefit of all members. We need to make changes to the Constitution which Janice Eary will explain. The Lincolnshire Post Polio Network is internationally known among the polio world. We need to ensure that the work

continues and the services we provide are improved.

We have run from hand to mouth till now with all the work being done voluntarily. All the equipment, apart from the computer for the WebSite purchased 3 years ago by three firms in Florida, and most of the software, repairs and upgrades has been personally funded. Very little has been paid in the way of expenses.

I have personally attended six Post Polio Conferences with no funding from the LincsPPN, although for the International Conference where I presented – with Richards help – there were personal contributions from some members and the local health authority but they in no way paid all the expenses of this trip. Without the help from my family much of the work done would not have been possible.

In this last few days we have received an offer from Len Van Zyl – a Life Member - to take on the role of Fund Raiser. We have also received an offer from Susan Conley a USA member to put forward a proposal to local Rotary groups for us to be their International Project because of the work of our WebSite. We hope to give you more good news on that front in the next few months.

The LincPIN contains information that I find by searching the Internet, from other support groups newsletters that we receive, from talking with Polio Survivors and PPS Specialists across the world via email, and whatever is sent to me for inclusion. As often said in the newsletter we need you to write to us, to ask questions, tell us your problems and stories, and share your hints and tips with others. I look forward to hearing from more of you.

I would like to take this opportunity of thanking the committee for their hard work, we are now in a better position than we have ever been to continue with our work and improve the services for all our members. Thankyou (name those there) Thanks also to Chris Salter who cannot be here due to the distance for his continual work on our WebSite, all voluntarily and many hours each week. I would also like to publicly thank Bob Price, a US member who pays in all US checks to our US Account for us for his continual financial support. He also obtained the funds from three firms in Florida that allowed us to purchase a computer for the WebSite three years ago.

We need your help to do this and I hope that more of you will come forward to take a small share of the work to spread the load. Together we have a wealth of experience.

I would also like to take this opportunity of thanking my daughter Alison publicly for her continual help without which I would not have been able to devote the time I have to the work.

#### **Vice Chair Report.**

Janice Eary, our Vice Chair is away from home at the moment due to family illness. She is dealing with this subject and she will be doing a full report on this as soon as possible. Therefore this is just an outline statement so that you are aware of what is going to happen.

At the AGM a resolution was put forward that we have to make some slight changes to our Constitution. When we started we were mainly working with Lincolnshire but now we have members across the country and abroad and our Constitution needs slight rewording to reflect this. It was agreed at the meeting that this should happen. Janice Eary will now be discussing the proposed rewording with the Charity Commission and then will put this forward to all members for comment prior to voting via an Extraordinary Meeting.

#### **Secretary's Report.**

At the date of the Annual General Meeting we currently have:-  
UK - 139 Annual Members, 45 Life Members,  
Overseas: 33 Annual Members 10 Life Members.

If you are an Annual Member you will receive a renewal form with your last newsletter of that years subscription. If you wish to continue receiving newsletters you must return this before the issue of the next newsletter.

Please note all contact details are on the backcover of the newsletter. All membership, requests for Information Packs, copies of leaflets and articles to:-

**Hon. Sec. Wendy Grimmitt**  
<Hon.Sec@lincolnshirepostpolio.org.uk>  
**12 Larch Ave, Allington Gardens, Allington,**  
**Grantham, NG32 2DR**  
**Web and Mailing List Administration**  
**Report.**

This is going to be an unusual annual report but the LincsPPN is an unusual organisation. Unusual in the sense that in the few years that we have been operating we have achieved considerably more impact than could have been predicted from the resources at our disposal. That may in part be due to our capacity for self-criticism. I am therefore going to begin this report by admitting that during this past year web site development lost some of the impetus that had been built up in previous years. Our web site is still recognised as one of the foremost post-polio resources on the Internet. Nevertheless, by my own standards, and for various reasons, I have failed to adequately maintain and improve our web site in a number of areas. I am pleased to leave the negative behind and report that initial steps have already been taken to rectify this.

The primary goal is to redesign and rebuild the web site with a view to reducing the amount of work required for future maintenance and expansion. To this end I have already acquired development web space separate from our production web site. I am funding this myself for the moment.

We will in parallel be investigating and introducing additional facilities such as a members only area of the web site. However, I would emphasise that making post-polio related information freely available is still a priority. We cannot increase awareness of the range of issues affecting polio survivors by keeping information locked away.

We have already acquired one new domain name which during this first phase of development is an intermediate gateway to our production site.

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

Other domain names will follow. In conjunction with this first domain name we have also implemented a range of e-mail addresses e.g. [membership@lincolnshirepostpolio.org.uk](mailto:membership@lincolnshirepostpolio.org.uk) for all membership related enquiries.

In redesigning the web site we will be paying special attention to accessibility guidelines. The current production web site was designed according to principles that by and large have much in common with accessibility guidelines but pre-date them.

We have for some time been distributing via our medical professional mailing list, notices of

polio-related updates to Medline. Medline, produced by the US National Library of Medicine (NLM), is one of the foremost clinical databases used to identify references in the published research literature. Within a week or so this update service will be publicly available. We will continue to maintain our existing range of mailing lists.

The above constitutes the bulk of the work for the coming year. However, given the availability of resources, we hope to further investigate other potential educational media. For example, although a number of technical, presentation and content issues remain to be addressed, we already have the capability for low volume CD ROM production. Initial CD ROM publications might include reference library material and interactive presentations on specific post-polio issues.

#### Polio Network Lincs

This is a Members Email Discussion list. If you have an email address and are not subscribed and would like to be then please email me, [<chris.salter@lincolnshirepostpolio.org.uk>](mailto:chris.salter@lincolnshirepostpolio.org.uk) To remain on this list you will need to continue to be a paid up member.

Chris Salter.

#### Len Van Zyl - Fund Raiser.

We would like to express our thanks to Len Van Zyl, a Life Member and polio survivor, who has agreed to take on the task of Fund Raiser.

[<len.vanzyl@lincolnshirepostpolio.org.uk>](mailto:len.vanzyl@lincolnshirepostpolio.org.uk)

[Editorial Note - Following the Treasurers Report we include information given during the afternoon by our Speakers. Life Member Dr. E. G. Dowsett and Diti Ravner who is a Teacher of the Alexander Technique and a Homeopath. I met Diti on the internet some months ago and was able to put her in touch with a Dr. in Israel who I had set next to at lunchtime at the International Conference. We continued to correspond and she told me all about the Alexander Technique. She moved to London for four years in August. To watch the relaxed way she holds herself with a straight back and head up and see the fluid way she walks was impressive.]

**Lincolnshire Post Polio Network - Profit & Loss - Date 25/09/01**  
**From Month 1, August 2000 to Month 12, July 2001**  
**Chart of Accounts: Default Layout of Accounts.**

	<b>Period</b>	<b>Year to Date</b>	
<b>Sales</b>			
Other Sales	740.64	740.64	740.64
		740.64	740.64
<b>Purchase</b>			
Purchases - Misc. Purchases	463.89	463.89	463.89
		463.89	463.89
<b>Direct Expenses</b>		<u>0.00</u>	<u>0.00</u>
		<u>276.75</u>	<u>276.75</u>
	<b>Gross Profit/Loss:</b>		
<b>Overheads</b>			
Travelling and Entertainment	151.30	151.30	
Printing and Stationery	5,128.77	5,128.77	
General Expenses	(4,375.18)	(4,375.18)	
Suspense & Mispostings	(635.23)	(635.23)	
		<u>269.66</u>	<u>269.66</u>
	<b>Net Profit/(Loss):</b>	<u>7.99</u>	<u>7.99</u>

**American Account.**

<b>Credit</b>	<b>\$2,249.29</b>	<b>Debit</b>	<b>\$1,147.50</b>	<b>Balance</b>	<b>\$1,101.79</b>
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**Period Trial Balance - To Period: Month 12 July 2001**

N/C	Name	Debit	Credit
1200	Bank Current Account	361.11	
2109	Accruals		804.02
2300	Loans	450.00	
4900	Miscellaneous Income		740.64
5002	Miscellaneous Purchases	463.89	
7403	AGM & Conferences	151.30	
7501	Postage and Carriage	56.00	
7502	Telephone	395.56	
7503	Internet	855.76	
7504	Office Stationery	3,458.28	
7505	Books etc		140.85
7506	WebSite	504.02	
8200	Donations		1,685.36
8201	Subscriptions		2,827.50
8204	Insurance	137.68	
9998	Suspense Account		<u>635.23</u>
	<b>TOTALS</b>	<u>6,833.60</u>	<u>6,833.60</u>

**American Account**

	<b>Credit.</b>		<b>Debit.</b>
Membership.	\$ 1,245.00	Internet Services	\$ 424.50
Donations	\$ 410.00	Conference	\$ 174.00
Opening Balance	\$ <u>594.29</u>	Books & Videos	\$ 49.00
	<u>\$ 2,249.29</u>		\$ 647.50
		Transfer of Funds to UK a/c	\$ <u>500.00</u>
			<u>\$ 1,147.50</u>
			<b><u>Balance \$ 1,101.79</u></b>

Transfer of funds USA to England	) 346.64	(\$500.00)
Transfer of funds from Deposit Account	) <u>270.00</u>	
	<u>£ 616.64</u>	

## **Managing your Lives by Dr. E. G. Dowsett.**

There are three main things to think about. Conserving your Energy, cutting down on Stress, and simplifying your work.

### **Conservation of Energy.**

Firstly do what you love to do, without that life is not worth living. Secondly do what you are obliged to do and seek every way of either delegating this to others or modifying how you do it to make it easier. Modifying this can be; doing this in small sections resting in between; using appropriate aids or equipment like a Blue Badge (used to be Orange but its now blue) so you can park nearer to the shop and not walk so far; a decent wheelchair that is comfortable; an electric rise leg raise chair to save your arms struggling in and out of ordinary chairs. The list is endless especially with the huge range of equipment now available.

### **Cut down on Stress.**

Physical and mental stress (and mental stress is worse) are the most common causes of worsening symptoms. One example that many of you will relate to is filling in a DLA form or other similar forms. How many of you felt terrible for days when dealing with forms like this? Stress is normally dealt with by glucose metabolism to the essential organs of the body. This mechanism fails in polio survivors and those with ME due to hypothalamic disturbance in the brain. I know you are perfectly capable of filling in forms but doing this will cause you stress so try and reduce it by getting help. Its not giving in to ask for help if not doing it means you are going to feel bad for days.

### **Simplification of work.**

Use every piece of equipment that there is to make the job easier. How many of you - including myself - have said 'oh that's only for the elderly or disabled and I am neither' without trying to see if using it means less pain and less fatigue. Have your work areas remodelled so that you can reach items easily with your elbows by your side rather than at arms length.

If you live alone then it might be a good idea to be assessed by Social Services to have help come in and do the heavy work for you. Don't struggle on alone only managing the basic of daily tasks. Have a word with your neighbours and friends and see if there is someone who can come and give you a hand and do the heavy part of a job allowing you to do and enjoy what you can do. Its not easy changing from the do-er to the overseer but if it helps you manage your energy to greater effect then

give it a go.

It is imperative that you continue with your hobbies, or if they are not possible then find new ones that you can do. If you can afford it some communication equipment like a computer, or a tape machine to record stories and poetry and get someone to type it up for you.

If you have a window of energy during the day or if you need to do something during a part of the day then plan for it. Even nightschool or adult education classes are possible so long as there is no pressure on you to complete tasks by certain dates. Plan your week so that you need do little else but attend that class. If its in the evening then laze around during the day and store up your energy for the evening. Continue to be strong minded and make plans that you can manage. Show the health professionals that you are seeing that you have a positive attitude to life despite your problems and dont be afraid to ask them for help so that you can continue to manage your energy levels to their best advantage.

If you haven't already got a pet then why not try 'Furry Therapy'. How many of you have a cat and get comfort from stroking that 'tummy', scratching them under the neck, and listening to that lovely purring. How about a hamster, budgie or goldfish, even though the last two are not furry, they can be a delight to watch.

Finally it might seem strange to you, but not wasting energy; using aids and equipment; pacing and resting each activity will actually allow you to do MORE of what you want to do.

If you get invited to something like a Wedding and Reception, don't just say no I can't manage without finding out more about the venue, and seeing if its possible to attend and still take necessary rests. You will have to

- rest up for a couple of days before,
- plan the day well taking rest breaks where necessary taking with you whatever you need to do that,
- decorate your wheelchair/scooter/cane or crutches to match your outfit
- if its possible then get your or a comfy chair taken to where the reception is being held
- and plan on doing very little days following it.

Remember you will feel better if you manage to do something that you really enjoy doing.

**Other similar articles on pages 20 and 21**

**ALEXANDER TECHNIQUE**  
by Polio Survivor Diti Ravner  
Teacher of Alexander Technique  
Homeopath  
Currently living in London  
Tel: 020 7586 5026  
Email: <ditiravner@yahoo.co.uk>

English is not my first language and I am not used to speaking to so many people but I do my best to tell you about the Alexander Technique (AT) and how it is helping me with my polio problems. First taking lessons and later on being trained to be a teacher of the technique.

I myself had Polio when I was one year and a half, in 1950. About the age of 40, problems started to appear, falling more often, as a result of collapse of the knee, or loosing control of my ankle. Pains aches and fatigue. At that time about 12 years ago I started taking Alexander Technique lessons. The Orthopedic consultant at that time recommended an operation, and his opinion about taking AT lessons was: "You don't have time for that nonsense". Never the less I began taking lessons and 10 months later I decided taking the training course.

A few words about Alexander himself, Alexander was an Englishman living in Australia, a reciter of plays on the radio. (1869-1955). He developed the technique at the beginning of the 20th century. Mainly after returning to London. He himself suffered from hoarseness, and could not over come it although the best doctors treated him. As a reciter the voice was his main tool of working. So he decided to try and solve the problem by other means. So he used a set of mirrors put around him and he discovered that his speech was affected by the way he throws his head backward while he is talking.

This led him to understand what he called the Primary Control which is the place the head sets on the spine. The head, neck and torso need to be properly aligned. If we achieve enough freedom there all the movement of the limbs are becoming more free.

Might this help explain.....The goal of this discipline is to bring the body's muscles into natural harmony. The Alexander Technique attempts to remedy these problems by discouraging habitual, counterproductive muscular reactions and allowing efficient natural reflexes to take over.

First Lesson - How to change habits. How to change the way I do the usual functions of the body: sitting, getting up from a chair, and walking. From my experience I believe now that each one of you know how much efforts he puts on his neck while doing those functions, and if you think about it the way we position our neck is not helping us to get up from a chair.

To change habits is very difficult for each person and especially for a person struggling to find balance on each step he makes. You can inhibit your habitual muscular responses by deliberately and consciously "doing nothing" so that your body can revert to its inherent natural movements. This is not an exercise in relaxation, per se, but rather a way of reclaiming an efficiency and ease of movement lost through years of poor postures and unnatural muscular response. As you "unlearn" inappropriate habits in the formal sessions, you'll be encouraged to practice your new freedom of movement as you go about your normal activities.

While I was still struggling with the change, my teacher introduced to me a different way of thinking into the body, giving the instruction mentally before doing.

Thinking into the body is to use the mental skills we have to allow us thinking about the action before doing it. For each person, and especially for a person with a disability, there are many things we cannot do but with the power of the thought is unlimited. It is difficult to explain this but if you take a lesson and experience this you will understand more.

Alexander says that mind wandering is a shortcoming. Awareness and concentrating into the body by:-

- Let the head come forward and up to allow the back to be longer and wider.
- Allow your back to release into length and width;
- Allow the hip joint to move freely, so the legs move freely
- Allow your shoulder blades release to the side and the back to become wider

In his writing Alexander mentions that Physical exercises could do some damage to the body, because always there is an uncontrolled strain.



Today I know how much damage to the weak muscle exercises can cause.

I remember the first time my heels, both of them were connected to the floor. I mean the feeling of solid ground under my feet. I felt kind of unity through all my body, I believe that because of the walking problem, each step is unbalanced. Putting your soles on the ground is a solid place to start from. Even if sitting to see with your mind's eye the soles on the ground gives the body kind of up lifting, it evokes a motion up ward.

The body is influenced by 2 powers. Gravitation the power from above down, and the power from inside Vitality this is the power that acts from down towards up. The balance between those 2 powers allows us to move.

Now I will go back explaining the basic of the AT:

- **Changing habits**, changing by stopping the will to act.
- **Inhibition**, Stop, undo, the key for change, actually this is the first time I refer to doing which actually is undo, stop. By preventing reacting as we used to we will have a chance to do it in a different way. I consider it also as the freedom of decision.
- **Wrong sensory-appreciation**, recognizing it. Seeing the gap between how we think we do things and how we really do those things. Wrong concepts, about ourselves, How we sit how we walk, what we can do or cannot do.

**About a lesson.** The teacher works through the lesson the giving the pupil directions.

Let the neck be free and the head leans forward and up to allow the back be longer and wider. The teacher talks the pupil through the lesson with the help of the teacher's hands, so there is listening to the words, with the ears, and the listening to the touch.

Let the head be free, do nothing, only thinking: 'My head is free'.

Let the head come forward and up, again not doing just thinking and the hand of the teacher will do it, very gently. While the head goes forward and up, the back becomes longer and wider, this how we achieve a better function of the limbs. It is important to see all those

directions as all at once and one after the other. In a repetitive and renewed manner.

By working on the head-neck-back relation we try to avoid the stiffening of the neck. Usually the neck presses into the body towards the spine, the head is thrown backward, the lumbar part of the spine stiffens as well.

This is what we call in the technique releasing the primary control, this is where we want to achieve maximum freedom.

From our experience we know that whenever there is a part with little movement, there is another part which is intense and stiff.

I can not lean on my left side but I learn to stand on both legs, My left side especially leg trembles, not because of the effort, but like some vitality goes through it.

Part of the work is done on a table. On the table the pupil can understand what does it mean - learning to give up holding the body. I myself started learning not to stiffen up all the time. It allows the body to rest physically and on the other hand working hard mentally, Movements that were impossible could now be possible and it feels as if my body is awakening.

Releasing the side that was responsible, and being able to let the teacher move the limb and arm without my interference.

I would like to speak about the joints. As much as possible I try not to lock the joint it strains the muscles, I used to imagine the freedom of the ankle-knee-hip joints as a puppet on a string, each joint causes the other one to bend.

My not stiffening up so much is becoming less, which means I am getting more confidence that I can give up what was holding me for so many years.

The undoing is very difficult, there is fear of failure, I have to think again and again that we are not dealing with success and failures, this is a different kind of learning, the teacher says: try not to involve your will.

With the time my back strengthens especially on the waist, lumbar part.

I found out the importance of overcoming the fear of the unknown, no more head thrown backward, no more stiffening the waistline to move has enabled me to stand, and move in a

more fluid way.

I found out the importance of saying “no” doubting the existing “knowledge” and overcoming the fear of the unknown, no more head thrown backward, no more stiffening the waistline.

From the book: “F M Alexander The man and his work” By Lulie Westfield An American who had Polio and took lesson and the course from Alexander himself in 1940. “On the first examination Alexander tell me he is not interested in the function of muscles, but the muscles would be affected through the work on the primary control. The walking is related very much to the situation of the back. When one has had Polio, it is as if certain connections in a telephone system have been destroyed. Exercises or surgery in a specific part of a harmed body may sometimes cause temporary improvement but in the long run they are likely to increase the mal-coordination of the body as a whole. And this in time will affect adversely the specific part.”

Judith Leibowitz also had polio in both legs, in her book “The AT” writes: “As I become more and more aware of my habits of movements, I begun to realize that in order to allow change to occur, I had to first give up my habits. I could change my habits of movement so that within my limitations I could operate at optimum efficiency.”

The work is hard. Now after years of being trained as a teacher of the technique, I experience deterioration in my ability to walk or stand, but I go back to the technique, I organize my body. Always I am going back to the directions, head forward and up, releasing the neck and lengthening the back. Looking straightforward and stretching the neck up.

I myself combined it later with studying then practising Homeopathy. In Homeopathy I could offer more help, for example I saw good results with problems of fatigue, and other pains and aches, and psychological problems as well. I believe the Polio was such a traumatic event to the body and mind that the help needed is on several levels and the Homeopathy combined them all, but that will have to wait for another talk.

**A short perspective  
on the Alexander Technique  
by member Mary Kinane  
who attended the AGM.**

About a month ago I received a gift of a free Alexander Technique Session at a local healing centre in Lancaster. I made an appointment with the Director, who is an accomplished practitioner in this field and teaches it widely in Britain and Europe. My session lasted 35 minutes - this is the normal time span for a session in this particular technique. Previous to this session, I had dabbled in exercises which I had found in books about the technique, and had some advice from a friend of a friend on how to lie on the floor on my back to ease back pain, with a book under my head.

The session started with the practitioner taking practically all of my weight (I am about 10.5 stone) in his hands and gently lying me back onto pillows, in a way which eased any discomfort I had. I didn't even have to take my shoes or calliper off. He didn't "teach" me anything as such, but took me through a series of movements during which he suggested I "...think of my spine as a parachute". Several times he told me to lift my "good" leg from the knee, but as soon as I would start to do as he told me, he would stop me in mid-movement. I followed his instructions and after a while these start-stops had the curious effect of lightening me up, and the image of my spine as a parachute became more and more real. About half way through the "lesson" he stood me up again - I didn't have to struggle, to push, or to lean on my hands - he took all the weight, and he lead me around the room still supporting me from in front and behind with his hands. Without actually instructing me to, he had me walking with my neck and head leaning forwards, and gradually loosening the tension which has become such a familiar part of my walking and sitting pattern these last few years.

The Alexander Technique is a discipline, and I believe it has to be practised on a regular basis in order to get the benefit, but there are simple and do-able movements which polio survivors can do at home if they can learn a few lessons first from a good teacher. The fee for an average 35 minute session is £16.

This is a difficult experience to describe in conventional terms, and I am not claiming any instant or long-term change because of one session. I did leave the session feeling lighter, looser and in less need for the painkillers which I've been resorting to for the last year. This man is not available on a regular basis in Lancaster at the moment, so later this week I

have an appointment with a Practitioner in the Feldenkrais Technique, which uses a movement system quite like the Alexander Technique.

For people who attended the A.G.M. a few weeks ago in Lincoln, you will no doubt have noted the very impressive posture of Diti Ravner who gave her demonstration on the technique. As polio survivors we tend to be very sceptical of new things which others claim to change lives. But I also know that to try a "new" technique like this is to experience it for oneself, and to feel the possibilities for easing tension as it did the day I had my "sample" lesson - it left me wanting more...

**Mary Kinane - Lancashire.**  
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### **Have Vent Will Travel**

Having been a ventilator user for the past four years, I have tended not to want to stray far from my familiar surroundings. Since having my vent I have not been away on holiday and the only trips I have made with my vent have been to Papworth. for a yearly sleep study.

I knew the time would come when I would have to step out into the big wide world with my vent in tow. It came to pass this summer when I attended the wedding of my goddaughter Samantha.

The wedding had been in the planning stage for the best part of two years and was to be held in a castle in Northumberland. An occasion not to be missed, I had to get myself geared up and ready.

I had arranged for a friend to drive me to the venue in my car, before that could happen I had a lot to do, the worst part being taking Ben boxer up to the kennels.

The wedding was to take place on a Friday, that meant I had to travel up on the Thursday, then stay for two nights in a B&B, returning on the Saturday. I viewed this with trepidation, what would I do if my vent broke down? What if I could not get comfortable in the bed? What if it was cold? What if I could not sleep and looked like a wrung out rag at the wedding?

On the morning of my departure I was so busy I had no time to worry. The first job was to get Ben to the kennel. He took with him his toy frog, duvet and a supply of his favourite biscuits. On arrival at the kennels I had to drag

him from the car, he walked into his pen as if going to the condemned cell. This was all put on to make me feel bad. I drove away feeling as if I had committed high treason.

My next task was to load up all my gear. The most important thing was my vent, then five pillows, extra blanket, tablets for anything from malaria to the black death, new outfit, shoes which kill me, hot water bottle and snake bite kit. I then felt I was prepared for anything.

The journey was uneventful (no pun intended there) the weather was glorious, a perfect Summer day. Northumberland is a beautiful County and the scenery is spectacular. We were booked into a farmhouse B&B at Haydon Bridge, this proved to be a lovely old stone house, the garden a riot of colour, begonias, roses and lilies contrasting with the mellow stone.

We were greeted on arrival by a big old rooster, his little yellow eyes gleaming and his green tail feathers casting a metallic sheen in the strong sunlight. A collection of hens ventured out to view us and to inspect my car. A black Labrador added his voice to that of the rooster, which brought out the lady of the house, she was accompanied by a little border terrier. Things for me started to assume a brighter hue, I like to be surrounded by animals.

The farmhouse itself was a joy to behold. Large rooms full of antiques, steps up and down in unexpected places and squeaky floors. With some help I managed to convey all my gear up the creaking stairs and along corridors to my large bedroom. Then horror of horrors, I had forgotten the electric extension lead for my vent and the plug was on the opposite side of the room from my bed. Not to worry I was told, there was one in the house and I could borrow it for the length of my stay.

The first evening we had arranged to meet with the bride and bridesmaids, brides mother and brother plus a few more people in a pub in Hexham; there we planned to have a meal. This turned out to be a steak as tough as saddle leather, which after I had persuaded the pub dog to chew for me, was quite palatable. We returned to the farmhouse for the night, pausing to savour the scents of the Summer night and to listen to the soft crooning noises emanating from the hen house.

I retired to my bed sure I would not sleep a wink. I donned my mask and turned on my

vent. The next thing I knew it was morning, the sun was up and the whole World was dew kissed and golden. I was feeling ready for anything, especially a good breakfast, which we took in solitary grandeur in the large diningroom. We feasted on eggs freshly laid by the young lady hens we met on arrival, with toast and home-made raspberry jam to follow.

Then it was time to smarten myself up, squeeze my feet into my fashionable shoes and drive over to the castle for the wedding ceremony. The castle proved to be very impressive, huge rooms, thick walls and suits of armour. Each room decorated in the heavy baronial style. With much red drapery, shields, coats of arms and the like.

The actual wedding took place on the ground floor. The banqueting hall was right at the top of the castle, up seventy-nine steps. Luckily I was able to go up on the service lift.

The ceremony went off without a hitch, the bride was beautiful, and was attended by three bridesmaids and also her beagle. He wore a bow around his neck to match the bridesmaids dresses and he behaved perfectly, although he did tend to yawn rather a lot. We then all gathered in the castle courtyard to drink "Pimms", mooch around and wait for the feasting to begin.

The wedding jollification's lasted all the rest of the day, a ceilidh band played in the evening. I was not able to dance, so was free to let my mind wander. I sat in a window embrasure at the very top of the castle. Looking from the window into the warm Summer darkness, I reflected on what the castle would have been like a few centuries ago, what celebrations would have taken place. Who had lived and died here, worked, loved and hated here, what dramas had been played out in this place? How long will the castle stand and how many people in the future, will sit in the same window and wonder what had happened in the past?

Soon it was time to return to the farmhouse. We paused to watch the bats and to enjoy the scent of the flowers in the garden, then crept in, trying not to make the stairs creak, then into bed, on with the vent and a good nights sleep. Next morning after breakfast we started for home, nothing had gone wrong, I had worried for nothing.

I was desperate to collect Ben from the kennels, I got there as fast as I could. I just wanted to see the glad expression on his face

when he saw I had returned for him. I stood waiting by the car, suddenly there he was, galloping across the yard towards me. I opened my arms and said "come to mummy" he completely ignored me, ran straight past and jumped in the car. He wedged himself behind the passenger seat, his face like thunder. The kennel maid brought me a plastic bag containing Ben's duvet, "sorry" she said, "you have some washing" Ben has been peeing on his duvet. That will teach me to leave him behind when I go away.

This trip has done me a power of good, I now accept one should meet problems head on. I have always done that in the past. Now I realize I am getting out of that habit and anything which seems to be a problem is being put off as too hard to face, hence the lack of holidays. I hope in the future to be making a few more trips and broadening my horizons.

I returned home knowing I had another wedding to attend in a fortnights time. This time I was the bride. My wedding also went as planned, not a big wedding, no castle, bridesmaids or cake but, just as enjoyable. I hope in the future to be writing more articles for the "LincPIN" I will write using my new name which is Christine Horrobin..

Christine Horrobin.  
<christineayre1@ntlworld.com>

[Editorial note - Yes our Christine of Catley Abbey in Lincolnshire is back writing for us. Not only back but newly married and positively glowing when we met at the AGM. To you both our heartiest congratulations from all readers of the LincPIN.]

## **EATING WELL EASILY - PART TWO** **by member Vivien Holland**

In my last article I shared with you some of the ideas for meals that I find helpful. They were the kind of meals we as a family eat all year round, but I appreciate that now there's a nip in the air, we naturally feel the need for warming, comfort food too. So this time I'd like to give a few ideas for easy winter meals. Prepared in quantities that will last more than one day and freeze too, you'll have something already prepared for those particularly busy or tiring days. Also, having these meals on hand means that precious energy is freed up for other things.

I appreciate that many of you make good use of ready-made meals, and there certainly are a wonderful selection to choose from these days

aren't there. As my husband and I still have a grown up son at home who has a large appetite, we would find these meals uneconomic so I've never had occasion to try them out very much - you would be the expert here and could no doubt share with us your own recommendations.

Casseroles and curries go down well when the weather is cold and seem to taste just as good the following day. I know that some of you might like to eat more vegetarian meals and the beans that I mentioned last time, (black eye, borlotti, flageolet, cannellini and chick peas) can be very useful here. I make a curry using chick peas and any mixed vegetables I have to hand, along with a jar of curry sauce. Also beans are very good to bulk up a meat casserole and make it go further so that you need less meat. Pale green flageolet beans go very well in a chicken casserole and black eye or borlotti beans go well with lamb or beef. And of course you are probably familiar with red kidney beans in any chilli dish, whether you are using lamb, beef or soya mince.

Lentils are very good in soups and casseroles. I make a really big pot of thick soup using two cups of split red lentils, about five cups of water, a couple of chopped onions (frozen would be fine) and two tins of chopped tomatoes. Add whatever dried herbs you like and a couple of stock cubes and you have a really cheap, nourishing soup that will last for several days or can be frozen. I find this a particularly quick, easy soup to make that doesn't involve cutting up loads of vegetables - quite a daunting task that isn't always possible. If you do want to add vegetables to this, the root ones like carrot, parsnip and swede go together well with the lentils. Also, if you are planning to make soup or a casserole, keep any vegetable water in the fridge from the previous couple of days - it's a shame to throw it away as it contains valuable nutrients.

Pasta is another good standby, although I feel it could be a mistake to rely on it too much. It's always good to aim for as much variety as possible. When you have pasta, try to make a balanced meal, including some protein. Mushrooms combine with pasta to form a complete vegetable protein, or you could add a little chicken or fish, preferably along with some green vegetables.

With casseroles and soups in mind, I'd like to tell you about a wonderful little gadget I discovered some months ago. It's a Heat Diffuser that's used on the hob under the saucepan and stops food sticking. It really is so effective that I wonder how I've been cooking for the last forty years and managing without it! I can leave virtually anything simmering on the hob, and put my feet up, confident that it won't burn or stick. As a result, cooking has become far less tiring. They're available by mail order from Lakeland Ltd. (Tel:

015394 88100), and cost £5.50 + postage. Their catalogue is full of other useful gadgets and items for the home and is definitely worth looking through.

As this will be my last article for a while, I would like to wish you all well in your efforts to keep going, knowing that many, like myself, are coping with the late effects of polio. We naturally wonder just how we are going to be affected in the future and hope that we can maintain what strength and energy we have. While I wouldn't want to raise any false hopes, I feel I must tell you about a supplement I have been taking for the past 18 months that has helped me personally. It is essentially a mineral supplement in liquid form that is very well absorbed. What is unusual about it is that it contains over 60 minerals, in fact all the minerals that should be in the soil and would be in our food if the world's agricultural soil had been properly cared for over the past century. There isn't space here to give full details, but if anyone is interested in having further information, I can send this to you. Unfortunately, it is quite expensive, but I would be able to supply it at trade price plus freight (£20.50 for a month's supply). Finally, I'd like to thank those of you who have written to me. I've really appreciated hearing from you.

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Little Johnny, and his grandfather entered the vacation cabin, and kept the lights off until they were inside to keep from attracting pesky insects. Still, a few fireflies followed them in. Noticing them before his grandfather did, Little Johnny whispered, "It's no use, Grandpa. The mosquitoes are coming

## **Poliomyelitis 'History' Summary**

### **Part One**

**by Phyllis Hartke, President  
San Francisco Bay Area Polio  
Survivors.**

I write this summary for polio survivors and SFBAPS members in response to enquiries about polio's history. This is a *very* abbreviated summary of polio's history and how the medical professional struggled to understand its facets and determine appropriate diagnosis and treatment methods. I try to provide the reader with:-

- 1 insight about the multi-century struggle of medical practitioners and researchers to understand polio epidemiology;
- 2 reason to appreciate our continuing struggle for medical and community awareness of polio's late effects and remedial needs;
- 3 knowledge about how polio's sporadic cases and epidemics created new fields of medicine and the 'public health' arm of local and national governments; and
- 4 reasons for being proud to be a survivor of a deadly infectious disease that has baffled the world for centuries yet contributed so very much to mankind worldwide.

The historical facts included in this summary were provided in 'A History of Poliomyelitis' published by Yale University Press in 1971 and designated 'Yale Studies in the History of Science and Medicine 6'. The esteemed author is John R. Paul, M.D. who the book's jacket references as emeritus professor of preventive medicine and epidemiology at Yale University, a leading investigator of poliomyelitis and its epidemics for more than 30 years, and a contributor to the advances that eventually led to its control.

### **Evolution of Polio Terminology..**

Names and terms by which 'polio' is known changed over time direct relation to increased knowledge, or confusion, about the nature of the disease.

The first term used - 'Debility of the lower extremities' - is credited to a pediatrician's description in 1789. The mid-nineteenth century saw multiple terminologies in use, based on the site of damage pathologists (a new field of science) believed caused the paralysis. Key terminology used is as follows:

'Poliomyelitis anterior acuta' is derived from both Greek and Latin words, and was later shortened to 'poliomyelitis' and ultimately its slang 'polio'. [Greek words for 'gray' and 'marrow' )the gray marrow of the spinal cord) and the Latin suffix for 'inflammation' are root words for poliomyelitis. 'Anterior' refers to the horns of the cord (i.e. the anterior part of the gray matter of the spinal cord). 'Acuta' was sometimes replaced by the word 'subacuta' when identifying the disease.]

French terminology of 'fatty atrophic paralysis of infancy' and 'essential infantile paralysis' was later anglicized and shortened to 'infantile paralysis' notwithstanding the fact that withered limbs were not always involved and the disease was not restricted to infants.

'Heine-Medin disease' terminology was introduced in 1907, honouring a German orthopedist and a Swedish pediatrician for their achievements that greatly expanded scientific understanding of the disease during the mid-to late-nineteenth century.

Interestingly, Poliomyelitis had become a fixed term, not able to withstand more evolutionary change, when its causative agent - the virus - was discovered in 1908. Instead of saying 'poliomyelitis virus', it was referred to as the *virus of poliomyelitis*. This terminology was shorted to *poliovirus* by the mid-twentieth century, and later, the family of enteroviruses absorbed the polioviruses.

### **Poliomyelitis Beginnings...**

It is suggested that *poliomyelitis* most probably dates back to the dawn of written history, even though early twentieth century epidemics made it a disease of that era. That era saw the introduction of modern sanitation and its impact on bacterial enteric infections and human immunity. Pestilences and epidemics of many kinds plagued the Dark and Middle Ages, as did an unusually high infant mortality rate, all of which likely overshadowed the endemic spread of the polio virus that silently infected and immunized the great majority who did not develop paralysis or die from the disease.

In the Carlsberg Glyptotek, Copenhagen, there is archaeological evidence of poliomyelitis in ancient times. An illustration depicts an Egyptian stele dating from the Eighteenth Dynasty [1580-1350B.C.] showing a crippled

young man, apparently a priest, with a withered and shortened left leg, with a foot positioned typical of flaccid paralysis, using his staff for support. Danish physician Ove Hamburger in 1911 identified paralytic poliomyelitis as the most probably cause of the priest's deformity, and few physicians examining this picture since then have doubted that diagnosis or its significance. [the stele will be reproduced in the Xmas issue with the second half of this article]

History reveals descriptions of skeletons with abnormalities attributed to polio. Paralytic polio descriptions are also found in biblical and Greco-Roman times.

In ancient Greece there developed an appreciation of a scientific attitude toward disease, contrary to the beliefs of supernatural or magical causation factors. Hippocrates, born in 460 B.C., was science's chief mentor during these times. This 'father of medicine' kept headquarters on a Greek Island in the Aegean, but travelled widely and saw different people, places and things. He was an astutely observant physician and an epidemiologist recognizing that disease varied under different conditions of climate and race.

Medical historians studying Hippocrates' two volumes 'Of the Epidemics' find no reference to a paralytic poliomyelitis epidemic. They conclude that its absence indicates paralytic polio outbreaks were rare and limited to sporadic cases rather than epidemics. Translations of the *complete works* of Hippocrates support this conclusion.

Notable Hippocrates' accounts of 'clubfoot' cases, and the accounts of 'club-foot' cases Roman physician Galen made 500 years later [138-201 A.D.] Medical historians maintain that this term included both congenital and acquired malformations, unlike today which covered most if not all deformities involving ankles and feet, including flail-like conditions of the lower legs and subluxations of the ankle joints leading to abnormal positions of the feet. They believe that sporadic paralytic polio surely caused some of these deformities acquired at an early age.

### **Eighteenth Century...**

It was not until the late eighteenth century that paralytic poliomyelitis was first described with a modicum of accuracy or that a fever was observed to precede limb weakness. The autobiographical account of Sir Walter Scott's

illness and resulting lameness significantly advanced the precision in diagnosing infantile paralysis.

In 1789 the first clinical description of poliomyelitis appeared in a medical text - Treatise on Diseases of Children (2d ed.) by Michael Underwood, a London pediatrician - under the heading 'Debility of the Lower Extremities'. He was the first physician to consider poliomyelitis as an entity. He had distinguished medical credentials and extensive experience as a surgeon before changing his career to midwifery and child welfare for which he earned prominence and the appointment of Physician to the Prince of Wales. In 1799 his 4th edition of this medical text included in the paralysis, or palsy, section considerably more information about diagnosis, treatment, and prognosis.

About this same time, another landmark in polio history emerged. Timothy Sheldrake, a mechanic by trade but an astute orthopedist by interest, was a trussmaker to London's Westminster Hospital. His wide experience in handling crippling deformities in children supported his London shop. His unique vision and efforts collecting, documenting, and classifying various kinds of foot deformities resulted in two books addressing clubfoot and acquired deformities in the legs and feet of children. Here is found the first series of paralytic poliomyelitis cases.

### **Early Nineteenth Century..**

During the next twenty-five years few took advantage of this new knowledge, and newly published medical texts stated nothing more about polio. The next landmark in polio history was in early nineteenth century. Although a well-known Italian physician and surgeon, a prolific writer of medical treatises, and supervisor of Italy's small pox vaccination program, few outside of Italy knew Giovanni Battista Monteggia. His 1813 medical treatise included a vivid clinical description of poliomyelitis from onset to late physical effects.

Monteggia was the first person to record the paralysis as flaccid without muscular response to sensory stimulation and without foot withdrawal when the sole is tickled. Although the nature of polio was still vague, he was the first not to reference 'teething' as a possible cause.

Ten years later, 1823, a medical text included London surgeon John Shaw's clinical

description of polio. Noted were paralysis and limb wasting during infancy that frequently causes spinal distortion, the sudden attack aspect of the illness, and that it affected children outside England, including first-hand observation in India. Now emerging was consideration of geography and environment as factors in the spread of polio (i.e. possibility of different strains or types existing elsewhere and the effect of poor sanitary environment).

Scottish neurologist Abercombe, uniquely aware of separate functions of different parts of the spinal cord, surmised in 1828 that only part of the grey matter - the anterior segment that controlled motor nerves, not the posterior segment that controlled sensation - was involved. This remarkable discovery is today a diagnostic element of paralytic poliomyelitis.

The year 1840 marks the greatest achievement in the understanding of polio. Published was a 78 page study of polio by Jacob Heine, a German orthopedist and exponent of physical medicine. (Several members of the Heines family were noted orthopedic surgeons. Jacob's father was the first to use osteometry to straighten bones, and Jacob's son was noted for his orthopedic writings).

Jacob Heine monograph was an accounting of his personal experiences with a series of paralyzed young patients that he decided to write after reading the 1836 immediate accounting by John Bedham in England of four cases. Dr. Bedham described accurately this apparent 'outbreak' - sudden paralysis in infants under age 3 ushered in by cerebral symptoms (drowsiness and abnormal state of pupils of eyes) without impairing the child's health - but failed to understand the nature of the malady (i.e. cerebral or cerebral-spinal lesion) and how to treat it.

By publication reaching a wide audience Dr. Bedham hoped to receive advice from more experienced physicians. This is perhaps the first evidence of a physician concerned about public health. Unfortunately Dr. Bedham died of tuberculosis at a young age (33) and before publication of Jacob Heine's 1940 report responding to Bedham's enquiry.

For the first time there was more than a review of cases. The entire 78 page report meticulously and systematically addressed all features of the disease then known that Dr. Heines considered important. He concluded that the central nervous system, the spinal

cord, was affected. He addressed therapy, bracing, and exercise. He listed clinical features prominent in every acute polio case, the stage preceding limb paralysis.

In the second edition of that book published 20 years later, Dr. Heine was even more convinced that the problem was in the spinal cord. He was perhaps the first to practice sensible treatment for paralyzed limbs - exercise, baths, simple surgical procedures, bracing. (Accepted practice in that era included purges, emetics, blisters and bleedings.)

Sir Charles Bell, a distinguished British neurologist, learned during consultation with a mother about her child with one waste leg about an 'outbreak' occurring in the early 1830's on St. Helena, an isolated island. This revealed that children over the age of 3 and up to age 5 were affected. Dr. Bell's case report noted that the matter deserved inquiry, clear concern about the nature and circumstances of the disease.

### **Mid- to- Late Nineteenth Century...**

Knowledge of the nature of polio proceeded slowly, notwithstanding these landmark events. Different and opposing theories continued to exist about whether polio lesions affected the brain or spinal cord. Physicians in the United Kingdom and Europe still classified cases as 'temporary paralysis in early life' and 'morning paralysis' and 'essential infantile paralysis,' observing the rather prompt disappearance of paralysis and seemingly complete cure. That controversy was finally set to rest some years later by the microscope. It revealed the cord lesions of poliomyelitis otherwise invisible to the naked eye.

In 1840, writings of orthopedic surgeon A. G. Walter indicate polio was in the United States as early as 1810. During this era paralysis acquired during infancy was not unusual and teething was still considered a cause. Walter's publication described a series of cases he treated in Pittsburg since 1837, popularizing in the U.S. treatment by operation - cutting tendons in clubfoot, subcutaneous section of the Achilles tendon. France and England were already using this treatment method.

Then in 1841, the third epidemic was reported. The place was West Feliciana, Louisiana. Dr. George Colmer, an English physician who settled in Springfield, Louisiana, reported the epidemic. The short note in an American medical journal stated the facts and attributed



'teething' as the cause given the age (under two) of affected children.

Great medical advances were made in the second third of the nineteenth century. Cellular pathology was advanced by the now perfected magnifying power of microscopes. Previously invisible cellular and tissue changes could now be seen. Physiology and pathological anatomy set clinical medicine free to develop its own scientific potential. Led by Louis Pasteur, the 'germ theory' of disease and new fields, bacteriology and microbial infection, developed.

Neuropathologists advanced the study of poliomyelitis. They explored the site of the lesion in the spinal cord. French scientists Jean-Martin Charcot and his associate V. Cornil viewed under a microscope autopsied sections of the spinal cord. This showed large motor nerve cells in the cord's gray matter, with particular loss of nerve cells in the anterior horn of the gray matter when paralysis existed. This confirmed Heine's views thirty years earlier.

In 1888 Scandinavian neuropathologist Rissler's investigation revealed that poliomyelitis was primarily an acute systemic infection with lesions not necessarily limited to the central nervous system, the latter being the most serious lesions because of the resulting paralysis damage. He was convinced of Charcot's theory that motor cells were the site of the destruction (myelitis) caused by some injurious agent, on the heels of which neuronal degeneration rapidly occurred, leaving atrophy and scarring in its wake. (The first accurate account of the cerebral type - encephalitic polio occurred in 1884 in Vienna. Charcot's ablest pupil Pierre Marie corroborated Strumpell's observation the next year.)

American knowledge of the disease, including neuropathology and neurophysiology, was scarce and faulty until Dr. Mary Putnam Jacobi brought to American physicians 'the idea and evidence that meticulous studies of the neuropathology of poliomyelitis could be rewarding and that the real seat of the trouble lay in destructive lesions in motor nerve cells in the spinal cord.' In 1886 the distinguished Dr. Wm. Pepper (professor at Univ. of Pennsylvania at Philadelphia and the acknowledged dean of American physicians) chose Mary to write the scholarly and exhaustive chapter on poliomyelitis for the 5-volume medical textbook '*System of Medicine by American Authors.*'

Dr. Jacobi's training and superior knowledge of the subject peculiarly qualified her to write this scholarly 50 page review article 'Infantile Spinal Paralysis.' A member of the New York publishing family, she received a pharmacy degree in 1863, and her medical degree the next year. After two Civil War years, Mary determined her medical education was inadequate and went to Paris to get a second medical degree. She enrolled in courses at the Sorbonne in 1866, attended lectures, did autopsies, and studied histology before entering medical school. This exposed her to the exciting work of Charcot's clinic and other Frenchmen studying the neuropathology of poliomyelitis, and aroused her pathology and physiology interests. (Returning to the United States in 1873, Mary Putnam opened her internal medicine practice in New York City and married Dr. Abraham Jacobi who later became the father and founder of American pediatrics.)

As to treatment of polio, Dr. Mary Jacobi followed the time honoured medieval remedies (ice applied to spine internally or subcutaneously in order to divert blood circulation to the surface, mercury ointment rubbed in along the spine, followed by blisters and treatment with iodides, and with electrical stimulation starting one week after paralysis). It took a long time before more effective approaches were devised.

Clinical medicine had come of age worldwide, and poliomyelitis was swept along in that movement. Recognition of polio occurring in adolescents and adults, its infectious nature, and the presence of epidemics fuelled the explosive clinical understanding of poliomyelitis. Scandinavia was the site of the first polio epidemic.

Public health records reveal the first epidemic was in 1868 in Norway, near Oslo. The second occurred in 1881 in Umeo in northern Sweden. Epidemics were also beginning to be reported outside Scandinavia. France had an epidemic in 1886.

### **Late-Nineteenth and Early-Twentieth Centuries...**

Scandinavia took center stage for advances in clinical studies of polio from 1890 to 1914. Stockholm pediatrician Oskar Medin (thoroughly reliable, articulate and experienced) gave a convincing and comprehensive presentation on the clinical features of the disease to the Tenth

International Medical Congress held in Berlin in 1890. It was Medin who first expressed the view that there exists a systemic stage in the beginning - minor symptoms and signs such as slight fever and malaise signified a generalized process, which coincidentally and later was occasionally followed by serious damage to the central nervous system that almost amounted to a complication.

Medin possessed that intangible quality that makes a great clinician, and when the suggestion was made that he deserved a place in the history of infantile paralysis, there was quick response - hence the name *Heine-Medin* disease. Although it may have been satisfying nomenclature, a disease as common as poliomyelitis could not remain designated by proper names for long.

Physicians and pediatricians from far and wide were surprised that they should have had to put to use so promptly the information about epidemic poliomyelitis that Medin had supplied. The world did not have a long wait for another epidemic - just three or four years. This time it came to North America.

The first polio epidemic in America was in Vermont, summer 1893 (26 cases), but the first substantial *epidemic* was in Vermont in 1894 (132 cases) and was the largest reported in one year anywhere in the world. (An outbreak even half that size would have been the largest.) It was the first large epidemic to be studied systematically by a full-time local public health official, Dr. Charles Caverly. History also credits him as among the first to recognised the occurrence of a few nonparalytic cases.

Like in Scandinavia, American epidemiological phenomenon of 'infantile' paralysis revealed an epidemic in sparsely populated area and a shift to increasingly older children and adults afflicted during polio epidemics. It is suggested that the Vermont epidemic could have been anticipated by the polio cases in nearby Boston the previous summer, interrupted by the cold weather and starting up in spring or summer in nearby territory. Also, the 'contagious' and 'infectious' causes of the disease was not yet recognised.

How the disease spread throughout the body and the community came under intense scrutiny during the devastating 1905 Swedish epidemic (1,031 cases). Ivar Wickman, a pupil and ardent admirer of Medin, systematically studied the 'contagious' aspect of this epidemic. Included in his case count were

abortive and non paralytic cases as well as those with paralysis. He was the first to grasp the implications of observing the infection sometimes missed the central nervous system altogether, and the first to realize that abortive cases might equal or exceed paralytic ones and that they had a profound significance on the spread of human poliomyelitis.

By physically going door-to-door interviewing residents in order to trace the spread of the disease through abortive and paralytic cases throughout the hot summer of the 1905 outbreak, Wickman was able to designate a local school as the primary site from which the infection disseminated. Striking was the relationship between roads and railways and the spread of that epidemic.

Wickman concluded correctly that poliomyelitis must be regarded as a highly contagious disease, that mild cases should be considered along with the severe, that the disease was not entirely or even chiefly a disease of the central nervous system, that polio spread primarily through the median of subclinical infections, and that the incubation period averaged 3 to 4 days measured from the time of exposure to the beginning of the minor illness.

The next recorded polio *epidemic* was in 1907 in New York City (750 to 1200 cases). The NY Neurological Society appointed a 12-member committee, composed of the foremost authorities in the country, to study it. Polio outbreaks in the US sharply rose from 1908-1912. The committee's report was published in 1910 and incorporated medical advances made during the interim.

Simon Flexnor, first director of the prestigious and well-endowed Rockefeller Institute for Medical Research created in 1903, was a key participant of that committee and changed the course of medical history. Having discovered the bacillus organism responsible for dysentery in 1900 in the Philippines and formerly chairman of the Federal Plague Commission that investigated the bubonic plague of 1901 in San Francisco's China district, Flexnor was a champion of the experimental pathological laboratory for solving infectious disease problems. Infantile paralysis was the ideal disease that would allow him to realize his goal - advancing the fields of bacteriology, pathology, and immunology and establish medicine on a sound scientific basis.

The dream that scientific medicine would conquer the disease seemed near realization.

Discovery of the polio virus, announced December 18th 1908, at a medical meeting in Vienna by immunologist Karl Landsteiner, M.D. and his assistant E. Popper, made that dream even more of a reality. As of that point in time, only a few viruses had been detected as agents of human or animal diseases - the viruses of smallpox and vaccinia, rabies and foot-and-mouth disease.

The use of tissue cultures for the growth of viruses was unknown until Landsteiner and Popper demonstrated microscopic slides of human and monkey spinal cords, all showing the histological picture of acute poliomyelitis and suggesting an invisible virus as the cause of poliomyelitis, an opinion soon confirmed by other experiments. By late 1909 the microbiological world accepted the viral etiology of poliomyelitis. Interestingly, experimental pathology on the polio virus established the fundamental clinical epidemiological truths Wickman earlier discovered.

Continuation of this "Poliomyelitis 'History' Summary" will be included in future newsletters.

Our thanks to Phyllis Hartke, President of San Francisco Bay Area Polio Survivors, who support the work we are doing by joining as a Life Member of the Lincolnshire Post Polio Network on behalf of her Support Group.

#### **Thursday, Sept. 27, 2001 Gaps Seen in Evacuation for Disabled**

NEW YORK (AP) It's one of the best-known stories of the World Trade Center disaster: Michael Benfante and a friend plucking a woman from her wheelchair in a 68th-floor office and bringing her to safety.

Benfante, 36, recalled that when he encountered the woman, there was a lightweight emergency chair folded up nearby that was designed for getting a disabled person down stairs.

But "nobody was doing anything," he said. So he unfolded the chair and strapped the woman in. While the chair was designed to be mobile, he said he and a friend decided to simply carry her in it because she was light.  
**end of excerpt.**

#### **The Fire Alarm sounded at 1.30 a.m. on 30th September at the IBIS Hotel in Lincoln.**

Members visiting from afar for our Annual General Meeting were staying at the IBIS Hotel in Lincoln. Mary who was in the disabled room nearest to the front doors with a sounder not only in her room but immediately outside was shocked into grabbing her crutches and was first out of the hotel struggling to walk without her calliper and shoes attired only in the lightweight shortie items she had been able to carry in her rucksack as she had travelled down from Lancaster by train.

The hotel provided sheets to those who needed to cover up a bit more and all were told to go across to the hotel next door. Luckily David had brought his car keys with him and was able to drive Mary across the car park to the other hotel. She could not have walked that distance without her calliper and shoes of carry them and use her crutches. The lighter side of Mary's arrival with Karen holding her 'sheet train' was the astonished look on the face of a still wedding dress attired very drunk bride.

Not only did our members have the problem of how do you move without your calipers and special shoes on, but one of our members did not leave the hotel. Denise had put earplugs in slept right through the whole episode. Despite the concern of the rest of our members the hotel were unable to help them specifically because no-one knew her last name or room number. I could not afford to stay this year and folks had booked direct and we had not made a list of members and room numbers this time. We have spoken to the Hotel  
continued on page 24.

**continued from page 19...** and in future we have agreed that all staying should be in adjacent ground floor rooms. That we make a list of names, room numbers and where help is needed and that the hotel and each person staying have a copy of this. Anyone needing help will be advised separately on booking in what to do if the Fire Alarm goes off.

Staying at two Travelodges in the last week we found not only a Do not Disturb sign but also a sign to put outside the room if you would need help in the event of an evacuation.

Before we retire at night we should think ahead. Can I quickly put on enough to keep me warm, are the aids that I might need easily accessible, and are my neighbours (or those with me, or where I am staying) aware that I need help and what that entails.

Contact your local Fire Service for advice for your

## REST, PACING AND TIMING

Grace R. Young, MA, OTR

<gryoung@bigfoot.com>

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<http://www.geocities.com/graceryoung/tip.htm>

Fatigue and pain must be respected. Overuse to muscles is not always apparent while it is occurring. Muscle pain is a warning signal that the muscles have been overused. The damage accumulates over a period of time and may not become obvious until you lose the ability to do an activity which was previously possible.

### REST

Try to rest at least one hour during the day. If you work and resting at lunchtime is not possible, take a one-hour rest immediately after work. This will make your evening activities more productive and enjoyable.

Lie down to rest so your back doesn't have to support your body weight. Sitting takes 1/3 more energy than reclining. If you want to read use an overhead book holder so your hand and arm muscles won't stay tense. You can listen to music, practice visualization, or meditate; the point is to allow all the muscles in your body to relax.

### PACING

Have you had days when you felt so good that you took on an ambitious project and kept pushing yourself so you wouldn't lose momentum? Were you incapacitated for a few days after that? It is tempting to overdo on your good days. However, you'll be more productive over-all if you plan your activities for a balanced lifestyle.

Prolonged activities such as cleaning house or gardening, can leave you exhausted for the rest of the day unless you break them up into short segments with rest breaks in between. Before starting an extended activity, decide how long you will work at it and allow a 15-minute rest break every 30 minutes. Use a kitchen timer to let you know when to stop working and when to start up again.

Alternate light and heavy tasks throughout the week. Split your ambitious projects into daily segments throughout the week, and stick to your plan no matter how good you feel on any particular day. Plan fewer activities for the days when evening activities are on the agenda.

### TIMING

You may have different levels of pain and fatigue at

various times of the day. Activities which are simple to perform in the morning may be difficult later in the day, or vice versa. For example, if cooking supper in the late afternoon is too stressful, prepare most of it in the morning, to be reheated later.

### HOW CAN YOU JUDGE IF AN ACTIVITY IS TOO STRESSFUL?

The easiest sign is a feeling of fatigue while you are in the midst of the activity. This seems obvious but many of us do not pay attention to our body. If the level of fatigue is out of proportion to the level of activity, the activity may be too stressful even if your mind says it should not be.

If there is a change in the quality of movement. For example, you develop a tremor or "jerkiness" in your motions while performing the activity.

If there is a change in the quantity of movement; that is, decreased range of motion. For example, you can usually lift your arm to a certain height but that height lessens as you continue the activity.

If you start to use compensatory movements. For example, you "hunch" your shoulder in order to raise your arm, or you swing your leg out to the side instead of flexing at the hip.

#### LETTERS TO THE EDITOR... -

The main subject of this letter is to congratulate all members of the Lincolnshire Post Polio Network for yet another of the amazing meetings I have had the luck to attend this year.

Your AGM was so positive in every aspect. It was a real inspiration to those of us who have been struggling for years against insurmountable odds, including widespread disbelief, medical arrogance and degrading financial status.

It was a wonderful lesson in observation of the difference (if any) between the so-called 'ME' and 'PPS' peoples ability to remain 'Active and Independent.

I woke this morning with renewed hope for the future - can't say when I last experienced that. Thanks a million! Betty.

[with permission excerpt from a long letter from Dr. E. G. Dowsett - A Life Member.]

[Editors note - The following two articles are taken from other Post Polio Support Group Newsletters. Sharing information across the world.] The following two articles deal with pain. This one is being answered by Dr. Jacqueline Perry, a pioneer researcher in Post-Polio Syndrome from Ranchos Los Amigos, California.

#### **QUESTION:-**

#### **WHAT TREATMENT DO YOU RECOMMEND FOR MUSCLE PAIN?**

**ANSWER:-** Every time a muscle contracts it must then repair itself and refuel. When people with PPS are tired but continue to push themselves, the muscles fatigue more quickly so the system gets overused. Following fatigue is pain, which is also a sign of overuse. I recommend cutting back on activities to a low enough level so there is no pain. If needed, PPS people may have to rest for ten minutes every hour.

Pain is a sign of injury. The first reaction to injury is inflammation, so I suggest the use of anti-inflammatory drugs (NSAIDs) to reduce the inflammation. I do not order other pain medications because they mask the pain. Patients are also warned to avoid using muscle relaxants. (NSAID: non-steroid anti-inflammatory drugs.)

Heat is good for muscle pain because it increases circulation. However, I prefer a two minute ice massage because it not only increases circulation but it also relaxes the tissues. The immediate reaction to ice is blood vessel constriction. There is a second reaction of small vessel dilation, which increases the local circulation.

Since pain is a sign of injury, I tell patients to adjust their lifestyle until there is no pain. I follow the same rules myself. I am no longer at Rancho Los Amigos Med Center 48 hours per week. When I get tired I go home and rest. Then I may return later in the day.

In order to keep on doing things, polio survivors must not do so much. They need to reduce strain on their muscles by modifying their lifestyle and use mechanical assistance when appropriate.

Reprinted from Rancho Los Amigos Post-Polio Support Group, May 2000; reprinted from Polio Heroes of TN, June 2001

The following is also reprinted from Polio

Heroes of TN, June 2001; reprinted from Echo News, May/June 2001

#### **A REAL PAIN IN THE NECK An Editorial By Charles N. Beaton**

My daughter works for a major trauma center here in the valley. She tells me they have done some surgery on four polio survivors within the last month or so.

These people had developed problems in their necks, osteophytes, etc.

When they had an MRI, they were found to have developed a syrinx (pronounced seer inx), which is a false Ventricle or pocket of Cerebral Spinal Fluid (CSF) within the spinal column.

The question was if the syrinx had led to many of the problems of weakness or sensory changes in the upper extremities.

The four patients on which they did the shunting procedure have all had improvements in their upper body strength.

One of my daughter's neuro-surgeons asked her if I had had an MRI, because it had been found that many polio survivors had developed a syrinx. This neurosurgeon recommended that polio survivors consult with their primary care physicians to see if an MRI would be advisable.

My daughter cautioned me about unwanted surgery, but thought our membership would be interested in knowing about the possibility of polio patients developing a syrinx and the possibility of alleviating the upper torso weakness with a shunt surgical procedure.

If any of you have found evidence of a syrinx, we would appreciate hearing from you and having the opportunity to share information with you.

I can be reached at Polio Echo,

or directly at my home address:-

Charles Beaton,

3208 West Cactus Road,  
Phoenix, AZ 85029-2327.

My email address is:- cnbeaton@juno.com.





specific needs. Also Vol. 1 - Issue 9 - January 1998.

## MEETINGS.

### **LINCOLN AREA - OCTOBER 27th.**

**Saturday October 27th 2001** - 1.30 to 4.00

Ruston Marconi Sports Ground, Lincoln on A1434.  
MESH (ME Self Help Group) Lincoln invite members to attend a talk by Dr. Michael Midgley author of booklet A Practical Guide to Living with ME - the adventure of a doctor living with ME for 30 years. £1.

### **BRISTOL AREA - NOVEMBER 8/9th.**

Meet with Hilary and Richard and other local members.

We will be in Bristol from about 2.00 on Friday the 9th November till 1.00 p.m. on the 10th November.

If you would like to meet up, watch a presentation on PPS from a Polio Survivors Point of View then please get in touch so that firm arrangements can be made. If enough members are interested there is a possibility of a talk by at least one other speaker.

Advertise your meetings/get-togethers here.

**Lincolnshire Post-Polio Network - UK Registered Charity 1064177**  
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**Membership** - <membership@lincolnshirepostpolio.org.uk>  
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**Hon. Sec. Wendy Grimmitt** <Hon.Sec@lincolnshirepostpolio.org.uk>  
**12 Larch Ave, Allington Gardens, Allington, Grantham, NG32 2DR**

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

**Please make cheques payable to 'Lincolnshire Post-Polio Network'**

**European Membership** - LM £125 - Member £12.50 a year - Newsletters by airmail.

**USA/Canada Membership** - LM US\$250 - Member US\$25 a year - Newsletters by airmail.

(US\$ checks to Lincs PPN. c/o 4212 Blanding Blvd, Jacksonville FL 32210, USA)

Other Countries please contact for details.

All other correspondence and enquiries - items for newsletters - to  
enquires@ or newsletter@ - lincolnshirepostpolio.org.uk

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**Next LincPIN Newsletter - December 2001**

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