



The LincPIN

The Lincolnshire Post-Polio Information Newsletter
Volume 3 - Issue 9 - February 2002

WebSite - <http://www.lincolnshirepostpolio.org.uk>
Celebrating its 5th birthday 14th February 2002.

A Personal Appeal—To Fight Polio

**GIVE A "LIFT" — ADD YOUR NAME
TO THE LONG LIST OF THOSE
WHO HELP THE CRIPPLED and MAIMED**

LANCASTER'S POSTER GIRL

GIVE
Voluntarily
Willingly
Generously
NOW!



**TO
PROTECT
Our
Children
It Takes
DOLLARS
And
DOLLARS**

Polio Won't Wait

JANCE EIGHY, 4 years old
Daughter of Mr. and Mrs. Glenn F. Knight, 111 N. Lincoln Avenue, Lancaster, Pa. was stricken September 1941, was at the level of Lancaster General Hospital for 18 weeks and had been a patient of the Massachusetts State Hospital for more than 3 months.

Polio Won't Wait

The Child You Help Could Well Be Your Own

When your fellow employee comes around and asks if you care to JOIN UP in this "FIGHT AGAINST POLIO", just think for a moment what our local chapter has actually done for more than 600 boys and girls and men and women right here in Lancaster when they were 'hit' with POLIO and needed HELP. Then, too, remember what is being done nationally to end this terrible scourge finally for all time. Support this plea -- substantially.

IT COULD BE TOO LATE, IF YOU HESITATE—SO GIVE NOW!

THE LANCASTER COUNTY CHAPTER FOR INFANTILE PARALYSIS

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Life Member Jann Hartman when she was six years old.

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I had Polio in the USA the year before the Salk Vaccine was approved for use. Field tests were being done in 1954, and soon the vaccine was ready for use in the schools. The "National Foundation for Infantile Paralysis" (NFIP) was responsible for this research. The NFIP was the forerunner of the "March of Dimes."

Franklin Delano Roosevelt, US president who had Polio as an adult, felt that no one should be denied treatment for Polio. He had the connections and influence to establish a foundation to raise funds. Starting in 1935, the "President's Birthday Ball" was given to raise funds nationwide. Thousands of dollars were raised. At first, they funded patient care at Warms Springs, Georgia, as well as research into preventing Polio. When the annual "birthday balls" outlived their usefulness and the Polio epidemics continued, other fundraising efforts were sought. continued page 3.

Lincolnshire Post-Polio Network - UK Registered Charity 1064177
Donations large and small towards our work are always welcome.

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12 Larch Ave, Allington Gardens, Allington, Grantham, NG32 2DR - [01400 282546]

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President Roosevelt used his friends and connections to get famous people to spread the word that money was needed to "fight Polio." Many of the actors and actresses were very willing to help. Helen Hayes, whose daughter died from Polio, was a volunteer. Rosalind Russell, was instrumental in getting the story of Sister Kenny on film. Entertainer, Eddie Cantor, coined the popular term "March of Dimes." This became a very successful fundraising campaign that appealed to everyone to give whatever they could... even just a dime... for such a worthy cause. Posters and handouts were printed and distributed. Radio spots were done by many entertainers. Many popular characters, like Howdy Doody (a marionette) and Buffalo Bob did public service announcements on TV. Movie stars, like Andy Rooney and Judy Garland made pleas for funds to "fight Polio." Collections were taken at movie theatres. Pictures were even taken of singer Elvis Presley getting his Polio shot.

The old March of Dimes was founded in 1938. It was created to fund the care of new and old patients; to give scholarships to nurses, doctors, and physical therapists to learn Polio treatments; to print publications that explained new treatments; and to provide money for research on a Polio vaccine. The costs continued to grow with each epidemic. Many of these fundraising ideas were so successful they are used today.

The Polio Poster Child program was begun in 1946 and ran through about 1955. I remember pictures being taken of me before I left the hospital in 1954. I was wearing a nice dress that my mother made just for the occasion. They distributed my posters to businesses in our area to help collection of funds. My mother had been active with the "March of Dimes and Dollars" joining the "Mother March on Polio" as chairman for our town. She was in charge of recruiting volunteers, distributing the collection canisters and buttons, and collecting and distributing the "dimes" collected to the MOD chairman. She and the other volunteers did a tremendous job! At the time, I was not aware of any controversy with the Poster Children idea. But, now some feel it was "exploitative and manipulative." However, it was also recognized as a worthy cause to "fight Polio" with a campaign that really worked. The MOD was successful even though it was founded after we came through a depression, and even during World War II. Without the money that was raised, many more people would have suffered, needlessly.

My parents allowed me to be photographed to help repay the March of Dimes for all they did for us and many other families. While my Dad had insurance from where he worked, they often did not pay for items needed like a brace and physical therapy. Other families had no insurance, and since we don't have a national health care system (even now) the MOD was able to make sure all who needed treatment got it. [Note: Those of us in the US with PPS are keenly aware that the MOD has moved on to other worthwhile projects, but those working or retired without personal health insurance have little in the way of funds for necessary treatments, drugs, and equipment.]

I felt that being a Poster Child was a positive experience for me. I really thought that being photographed was just one more step in getting to go home from the State Hospital. I only remember appearing on a local TV show for a few minutes. I didn't even meet any famous people. While my poster was used all over the county, I was only "famous" for a very short time, in my own neighborhood, for which I am eternally grateful. Much nicer was being "Queen of the Neighborhood" for the day when I got home. It was an impromptu party by friends complete with a paper crown.

"The modern era of polio rehabilitation started in 1940, with the arrival in the United States of an eccentric Australian nursing sister named Elizabeth Kenny." (p.103, *A Paralyzing Fear*) But, that's another story....

Recommended Books:

Patenting the Sun, Jane S. Smith

A Paralyzing Fear, The Triumph Over Polio in America;

Nina Golden Seavey, Jane S. Smith, Paul Wagner

Jann Hartman, Life Member

Baltimore, Maryland,

<jann@home.com>

Editors Note. I have just obtained and read a copy of 'Patenting the Sun' and will be bringing this back to the UK with me. In the UK we have a copy of the video 'A Paralyzing Fear', this is in NCTS Format. Many video players now play both PAL and NCTS formats. Donations of books or videos mentioning polio or pps are always welcome.

Editorial by Hilary Hallam, Chair

The first printed, instead of photocopied, issue of our newsletter had some hiccoughs in it for which I apologise. This was my first try at emailing the newsletter to the Printer and we had some technical problems which we hope we have corrected with this issue.

Over the next few issues we hope to improve on and standardise the format. Permanent features will be **Editorial, Articles, Letters to the Editor** - which can be questions or comments you wish to make. **Reports** - notification and reports on discussions with various agencies, meetings and get-togethers. **Hints, Tips and Bits from PPSers** - anything that you think might help or be of interest to our readers from a line or two to a page or more. Where space permits some **Musings** - including short puzzle or word items. We look forward to receiving your items for our Newsletters.

This newsletter contains a long article called the **Fine Art of Breathing by Larry Kahout**. He wrote this in three sections but I have taken the decision to print this in full in this newsletter. My reasons are that anyone who is having any problems, or even just thoughts about possible future problems, has some excellent information in one newsletter to pass on to any health professional they are consulting. Larry offered us this article via Judy, a member and Polio Survivor from Minnesota that I met at a PPS Conference and been friends with for four years. Larry thank you for taking the time to write this and share it with us.

My thanks to two Presidents of PPS groups that I met at the GINI Conference in St. Louis, Linda Donahue from Connecticut and Phyllis Hartke from San Francisco for the other articles.

Reading technical articles or being told technical facts can be difficult to absorb and often we shy away from them. If we have like problems then we know we are not alone and the writers are happy for you to contact them to talk about your problems. This is not intended as an 'instead of going to health professionals' but 'in addition' where there is more time to talk in a relaxed manner rather than the most often short stressful time of a hospital consult.

Richard and I are at his home in Florida at the moment as he continues to recover from his Rotator Cuff surgery. Remember recovery from operations for Polio Survivors can be 4 to 5 times as long as for non polios. Rotator Cuff Surgery recovery can take a year or more.

We have just spent ten days at a living re-enactment

pre 1840 camp. The Alafia River Rendezvous at the Florida Frontiersman Inc new home in Homeland, Florida. This was Richards 10th Alafia and my first. The camp was a mile long with over 1200 adults plus children in tents and tepees. Attendees were dressed from all walks of life from the 18th and early 19th Century. Everything visible outside the tent had to be in period. With help with the tent, chopping wood, fetching water, charging our wheels and cooking, we managed. The atmosphere, the friendliness, the feeling of belonging to a family tied in with the most wonderful and varied music, crafts, and events that were organised made it a lifetime experience. Indian ceremonies - making a circle of land sacred, giving indian names and hoop and other dancing - the School, the Court, the Country dancing, the Scottish ceilidh, Pot Luck Supper, Hat decorating, games for all from the era, the muzzle loading shooting, the archery, the hawk and knife contests, food and drink, and much much more. I had a hobby horse head made for my scooter and covered the rest with a blanket, made a mane and tail and so many folks stopped me to talk it was incredible. Thankyou to all who helped us.

We left there, with me with insect bitten arms and lower legs, both desperate for a shower, absolutely exhausted. I felt at peace with myself, refreshed and realising that living life other than polio and pps is more important than I had realised. I phoned my daughter and she said 'Mum do you realise this is the first time in years you have something to tell me other than polio!!!' [Since I found PPS existed six years ago I have been immersed in it almost daily.] It's now five days since we got back home and we have been pacing our resting! Doing little else. Was it worth it? Do it again? Yes, this was living not just existing.

I met three Polio Survivors whilst there, Bonita Bow, Raquel Fruchter and Louella Harris who with her husband Richard are Founders of the National Awareness Campaign for Upper Cervical Care. In 1958, in Kenya, East Africa, Louella Harris contracted polio. She was 3 years old. More from Louella next newsletter. <www.uppercervical.org> <info@uppercervical.org>

NACUCC, 5215 Colbert Road, Lakeland, Florida 33813, U.S.A. Tel. 1-888-622-8221

Jann and John Hartman visited with us a few days before the Rendezvous and we had a great time chatting and looking at her old polio items. Soon we are travelling north to near Athens in Georgia to meet with another Life Member Sue Karnes. Tommy Lynn, Lili, Jo and other polio survivors and their families are also joining us. We will be back in the UK in a few weeks time.

Since taking over as Secretary in 2000 I have never

Report from Wendy Grimmitt - Secretary

explained via the Newsletter who I am or what I am doing. I will try and redress that now.

Like the Chair and Vice-Chair, I am also a survivor having been 'blest' with the virus in 1939 at the age of 4 together with my sister aged 14 who was severely handicapped. I managed to make a virtual complete recovery and due to a brilliant surgeon when I was 7 operating to make my foot grow straight rather than clubbed I was only left with one leg shorter than the other. Which in my case was fortunate as I grew up to be a sports maniac, dabbling in all major sports - good at all, superior in none! Although my weaker leg did give me problems at times, an example being that I was unable to take the tests in ice-skating as there were certain turns I had to fake although I was dancing to gold standards.

My sister, although severely handicapped was the most go-ahead fighting person I have ever met right up until her passing on in 1992. Some of you may remember her story in the Newsletter back in early 2000, I only wish we had both been aware of post-polio syndrome at that time. Hilary has on more than one occasion asked me to continue her story from my point of view but I have never got around to doing it.

Can I now make a few comments about my post as Secretary. In the first place can I say many thanks to the people that have sent donations ranging from £2.00 to £50 and to Christine and Myra for their selling of wheatbags which has also raised monies. As most of you are aware we are a self-funded group, all working from our own homes and your membership monies and donations are so very much needed to enable us to continue support and the bringing of as much information as possible.

With regard to your membership, with the exception of new members you should all have received a membership card. If not, can you please let me know. I am now sending out a reminder letter and renewal form with the last Newsletter of your membership and am also going to enclose a Standing Order form for the UK members (and self addressed envelope whereby you will only have to complete the form and stamp the envelope), as I feel some members either forget or lose their forms and this may be an easier way for them to pay. If you do pay this way could I ask that you let me know when returning the renewal form. Your membership number shows the month of renewal in its first number, i.e. 4/AM - life members will start LM which is why some people have received two cards as they are sent a new one when they change from annual to life.

Please note that our bank account details have

changed from National Westminster Bank to HSBC. All people paying by Standing Order should have received a new sheet to take to their bank. The details are as follows:-

HSBC plc., P.O.Box No 6, 88 Westgate,
Grantham, Lincs NG31 6LF.
Sort Code 40-22-19
Account No 21637827

Can you also take into consideration that if your membership is not renewed your name will be removed from the Members Discussion List on the Internet as this is for members only.

If you do not wish to re-join I would appreciate a note of your reasons as we would like to know if we are not meeting your needs. I am always available by 'phone/e-mail/post to talk if required - contact details page 2.

Can I wish you all a Happy 2002 and in the least a solution to some of your problems.

Wendy

Reports from Janice Eary - Vice Chair

Report on the PAGB debate Redefining Access to Primary Care

This was held at the House of Commons, not a very disability friendly environment, but they did serve good cream cakes!

The debate was hosted by Dr Howard Stoa MP, chairman of the All Parliamentary Group on Primary Care and Public Health. Speakers were Dr Ian Spencer Director of Primary Care Newcastle & North Tyneside Health Authority, Dr John Chisolm, Chair General Practitioners Committee, Ms Sara Richards Chair Royal College Of Nursing, Practice Nurse Association and Mr Peter Lapsley Trustee of The Long Term Medical Conditions Alliance.

In the audience were politicians, health care professionals and representatives of various patient organisations.

The main focus of the debate was how to give more choice to users of public services. The challenge: how to reconcile maintenance of equitable access for all with greater choice for the individual. Introducing the debate, Dr Stoa said that the traditional role of the GP as the gatekeeper, to accessing health care was changing, and many more access points to the NHS were in place or being developed. Particular stress was placed on the role of self care. "People do look

after their minor conditions themselves and are becoming more expert in their own long-term medical condition but we have not in the past made use of this behaviour in the context of the NHS. The wish to give people power and wider choices means that we now need to include the whole spectrum of possible options of care"

"What can we do to empower patients, what can we do to get them more involved in their treatment, and what can we do to enhance the services available in primary care while making sure that patients can access good quality treatment, and good quality information?" These were the challenges for primary care, he said.

Dr Ian Spencer talked about an innovative project in a socially deprived area of Tyne and Wear which was assessing whether patients with minor ailments could be better dealt with more quickly and conveniently by a pharmacist than by a G.P.

Dr John Chisolm told us that Improved accessibility was a key target of the NHS Plan for England, which stated that by 2004 a patient should be able to see a primary care professional within 24 hours and a G.P. within 48 hours. Research had shown that patients 2 top priorities, were for GPs to provide a quick service in an emergency and for the GP to have enough time to listen and explain. Patients had greater satisfaction if they were given more time to talk about their problems. Other research had found that patients valued a personal relationship with their GP, and that personal continuous care provided the highest levels of satisfaction for the patient. It was pointed out that in a recent survey of all UK GPs said they valued continuity of care as a important aspect of the care they would like to give. However he went on to argue that as the service was under strain, too few GPs, not enough nurses etc. there may have to be a trade off between greater accessibility and continuity of care and longer consultations.

Dr Chisolm went on to point out the benefits to GPs of initiatives such as NHS Direct and various self help programmes, in reducing their workload. I was a little disappointed that the benefits to us as service users/consumers/patients [whatever the current pc term is] of becoming the "Expert" in our own condition were not spelled out, and as many of you have told us getting a GP to listen and accept that you may actually know more about your condition is no easy task.

Putting the nurses point of view was Ms Sara Richards who said that there were many new ways that patients could access nurses in primary care. She quoted many of the new roles for nurses such as nurse practitioners, advanced practice nurses, specialist nurses, NHS Direct nurses, and walk in

centres. However the present shortage of qualified nurses meant that the distribution of specialist nurses in primary care was very patchy.

Traditionally patients had gone to their GP as the first port of call, but with falling numbers of GPs it made sense to use appropriately trained nurses to relieve some of "*burden*" [my italics]

Representing patients was Peter Lapsley, from The Long Term Medical Conditions Alliance [of which LPPN is a member]. He said that there was increasing confusion about the different methods of accessing health care. There was a series of new initiatives - NHS Direct, NHS Direct Online, walk in centres, talk of nurse and pharmacist prescribing, plus increasing diversity of specialist clinics in primary care and 'special interest GPs' and this was causing confusion." We need a map to find our way through the NHS maze" he said. It should be practical, usable, and designed to meet patients' needs, rather than simply to be convenient for health professionals. Mr Lapsley said he had often heard government representatives saying that doctors and nurses knew best what patients' needed; this was not the case and there was for example, an imperative on health professionals to recognise the expertise of patients with long term conditions. Given that 60% of all illness was long term illness, self management was useful in empowering patients and taking pressure off health professionals.

He also felt it was important to inform and educate people about their responsibilities as users of the NHS. Basically what was needed, was a simple leaflet giving clear advice and guidance on access to health services, plus a persuasive explanation of peoples responsibilities towards the NHS. [I should have jumped up there and then and said that perhaps a similar leaflet giving guidance to health professionals on how to treat patients with long term medical conditions as responsible adults who know more about their condition than they do, plus a "persuasive" explanation of their responsibilities in supporting these patients, and in how to adopt a non patronising manner. However I didn't as my polio-fogged brain didn't think of it until I was on the train home. I promise to pass that message on when I get an opportunity.]

The discussion that followed raised a number of points. Representatives from patient groups highlighted the problems of developing links with Primary Care Trusts and GPs to help empower patients. There were difficulties in getting GPs to attend meetings as they did not have the time. However it was pointed out that the difficulties for primary care teams was that there were so many specialist patient organisations. However many organisations had much in common and by getting

together they might engage the interest of GPs and primary care teams. Everyone was singing from the same hymn sheet as regards patient empowerment [if only to pay lip service to it, now then mustn't get cynical in my old age] and the relative and extended roles of professionals. There was a feeling that we needed to move on from pilots and to see funding of these on a much wider basis so that more people may benefit. Ministers were seen as the catalyst for this change to occur.

All this could be seen as a sign that at last those with the power to bring about change and actually improve access to health care for those unable or unwilling to opt out of the NHS, were listening and prepared to act. However a word of caution. In my pre pps life I was a nurse/midwife and health visitor, & during the discussion little bells of recognition were ringing, I was sure I had heard some of this before. When I got home I trawled through some of my old lecture notes from my health visiting course going back to 1987. Surprise surprise, I found details of reports going back to the 1970s, These were even then, showing that many had major problems accessing appropriate health care and that many were paying for this with higher infant mortality rates, higher rates of illness in childhood and adulthood and premature death. Some of you may have heard of The Black Report published in 1980 which showed that "Despite strong support for the NHS and **especially for the principle of equal access to health care irrespective of income**, on which the service is based, inequalities in health between classes remained disturbingly wide" We do not tend to talk much about class these days, but replace class with, disability, social deprivation, low income etc. and it can be seen that the language may have changed but, we haven't come very far in 20 years. In spite of pilot projects, NHS Direct, etc. etc. access to health care is still a "problem" prompting discussions in high places such as this one. Think after over 20 years we have enough information, isn't it time for some ACTION.

Thanks to Ms Gopa Mitra MBE, for allowing me to quote from her discussion report on the debate. The views expressed are my own and do not necessarily reflect those of other members of the committee. I hope to present a report from another conference I attended in November which dealt with how quality of life can be measured and the subsequent data used to, guess what? Answers on a post card please.

Janice Eary
Vice Chair

Changes to our Constitution.

Every registered charity has by law to have a constitution approved by members and the charity

commission which circumscribes the charities work.

Our constitution served LincsPPN well when the organisation was formed. However we have now outgrown it. The existing constitution only permits us to work within Lincolnshire. As we now have members in all parts of the UK and abroad it is obvious that this needs to be changed.

The committee also feels that other changes are needed. We have come to realise that the best way to bring about greater recognition of the problems faced by those with PPS, and to fight for improvements in research and holistic treatment options, is to work together with other similar organisations and to facilitate the formation of local support networks throughout the country.

This is a tall order. The majority of committee members have PPS, we are all volunteers, however we feel strongly that this is the only way we can gain credibility with "the powers that be" as an organisation that speaks for those with PPS.

At the present time the only organisation that is seen as representing polio survivors is The British Polio Fellowship. I think even they would not dispute that they have not been exactly pro-active in bringing the problems of those with PPS to the fore. This is not meant as a criticism of the BPF we have many members in common and we should be able to work together to improve the lot of all survivors of polio.

Nothing can happen without your agreement and we propose the following timetable. We have drafted the changes we think necessary and submitted these to the charity commission. When we get their approval an extraordinary meeting will be called for you to vote on the changes. In order that as many members as possible have their say, the charity commission has permitted the use of proxy votes for this meeting only. We will enclose a new clause in the revised constitution which will permit the use of both postal and proxy votes for all future meetings. Details of how you can use your proxy vote will be in the next issue as will the exact wording of the proposed new constitution.

If anyone who did not attend the AGM [or those who did and could not follow my garbled explanation] would like to discuss this further then please contact me by phone 01663 743870, or e-mail janice.eary@lincolnshirepostpolio.org.uk

The Fine Art of Breathing *By Larry Kohout - Polio Survivor.*

This is the first of a three part article in which I have documented my experience with breathing problems. I have tried to explain the technical information that, in order to understand the problems I was dealing with, I had to learn. My purpose in writing this was to seek the therapy that writing always provides me, but it is also my hope that what I have learned will be a help to someone else.

BACKGROUND I was 13 years old in 1953 and ready to start eighth grade. It had not been a typical summer, since my family stayed in town that year. My father, a school teacher, always took a summer job to make ends meet. Typically, he would move the whole family to my mother's home town, then find a job somewhere in that vicinity. Because of summertime polio epidemics, people avoided crowds and we were lucky to be in the country where we could avoid the crowds.

For reasons I've forgotten, or never knew, we stayed in town that summer. I have no idea where I picked up the virus; people rarely do know. I had been playing sandlot football late in that hot August and thought it had brought on a migraine headache. I also mistook the back and neck ache for the results of playing football.

I was admitted to Sister Kenny Institute on September 1st, the same day that Dr. Salk decided he had a safe and effective polio vaccine, the same day he inoculated his wife and sons. My diagnosis was spinal / bulbar polio. By the time I was admitted to the hospital, I was having great difficulty swallowing. My own saliva would build up in my throat until I was choking on it. They started suctioning me by passing a thin tube through my nose and down into my throat. I was moved into a room full of iron lungs and transferred to one of the machines. They placed me on the "tray," that narrow bed portion of the machine, and put my head through the rubber collar, but they never closed the machine nor turned it on. I was not aware of breathing problems, and was sure they had confused my swallowing problems for breathing problems.

I stayed on the tray for about three days. The morning of the last day I overheard the doctor and the head nurse talking. He said, "If he doesn't start to improve soon, I'm going to have to do a tracheotomy." That was the encouragement I needed, the next morning they put me back in a regular bed. At my worst, both legs and my lower trunk muscles were paralyzed, but my breathing – in my mind – was not affected and my swallowing problems had cleared up.

After lots of rehab I finally went home in the late winter or early spring, I don't remember for sure. At home my mother and grandmother continued the therapy and by spring I returned to school on a half-time basis. How I managed to matriculate is beyond me. Only recently did I recall that I had to drop out of band because I did not have sufficient breath control to continue playing the trombone – lucky for Tommy Dorsey. But remember, I didn't have any breathing problems.

DENIAL Somehow I managed to stuff and deny any memories of the breathing issues. I did remember the swallowing problems because they scared me green. Forty-two years passed and even the swallowing problems were now a distant memory. In the early to mid '80s, however, I started suffering from overwhelming fatigue, increasing muscle pain. Because of these symptoms, and the evidence of denervation seen by the EMG, my doctors diagnosed PPS. But breathing or swallowing problems were still miles away in my mind. About 1995 I began to realize that I became short of breath after consuming an alcoholic beverage. The realization came slowly, and when I did make the connection the solution was simple: I quit drinking. It was hardly a sacrifice since Cathy, my wife, is allergic to alcohol: the two of us rarely drank. And remember, I didn't have any breathing problems.

DETERIORATION In the late fall of 1999 I became aware, again slowly, that when I was talking I'd often run out of breath before I came to the end of a sentence. Other things began to filter into my consciousness. When I'd exert myself in the slightest, I'd start to pant. I'd feel breathless when I'd read aloud. I was breathless after meals. At the same time I was aware that I was waking up at night on an almost hourly basis. When I did wake I'd often have to go to the bathroom, and so I became concerned about a possible prostate problem, but I didn't connect this to a breathing problem.

SEEKING MEDICAL ADVICE Finally I connected enough of these things and decided that it was time to see a doctor. Because I was suspicious that what I was experiencing was a post polio related breathing problem, I made an appointment with my physiatrist. When I described my symptoms, her first thought was about heart problems, and her second thought was that my back brace might be obstructing my breathing. In either case I was in the wrong place. She sent me to my primary care physician (PCP) and asked him to run a pulmonary screening both sitting up and lying down and with and without my back brace on.

My PCP sent me to the office of pulmonary medicine where they had the tools to run a proper screening. The pulmonary screening test was a fairly simply process. The technician had a rather large machine and I was asked to put my mouth around a large pipe

and breath in as fully as possible. Next to breathe in and then out as fully as possible. Some of the tests were run with a clamp on my nose, all of the tests were timed. From this series of tests they were able to gain the following information.

Spirometry: Spirometry is the study of the volume of air entering and leaving the lungs.

- § FVC or Forced Vital Capacity, this is a measure of the total amount of air you are able to expel from your lungs. The quantity of air is measured in liters and I expelled 1.18 liters. They also provide a prediction based on my age, size, and sex. The prediction for FVC was 5.32 liters. That meant that my FVC was at 22 percent of what was predicted.
- § FEV1 or Forced Expiratory Volume in 1 second, this is also measured in liters. This is a measure of the total amount of air you are able to expel from your lungs in the first second of exhaling.
- § FEF or Forced Expiratory Flow and is measured in liters per second. The machine calculates what the rate of flow is at the 25, 50, and 75% points of total flow.
- § MEP or Maximal Expiratory Pressure where the pressure is measured in centimeters of water. This is the greatest pressure you produce when breathing out.
- § MIP or Maximal Inspiratory Pressure, like the expiratory pressure, it is measured in centimeters of water. This test represents the greatest pressure you can produce while breathing in.

Diffusion: In the lungs, diffusion is the transfer of gas between the alveoli (A tiny, thin-walled, capillary-rich sac in the lungs where the exchange of oxygen and carbon dioxide takes place.) and the pulmonary capillary blood.

- § DLCO Diffusion Lung Carbon Monoxide – this test uses a gas mixture containing both carbon monoxide and helium to study the time it takes to exchange the gases between your lungs and your blood cells.
- § VA Alveolar Volume - during the DLCO test the space in your body occupied by the gas mixture, but not contributing to the exchange of gas between your lungs and your blood cells is measured and is known as anatomical dead space. The dead space of the machine is a known entity. These two dead space volumes are then subtracted from the inspired volume to yield the Alveolar Volume.
- § DL/VA Diffusion Lung / Alveolar Volume – This is the ratio of the Diffusion Lung Carbon Monoxide to the Alveolar Volume. This ratio is useful in evaluating the causes of a reduced

DLCO.

Blood Gases: Blood is drawn from an artery (Remember the arteries carry the oxygenated blood from the heart to the remainder of the body. The veins then return the de-oxygenated blood to the heart.) and analyzed for the amount of oxygen and carbon dioxide in the blood to determine how well oxygenated you are. They also analyze a number of other things including the pH of the blood.

WHAT DOES IT ALL MEAN Now we get to one of the very interesting points of this whole episode. When I went in to see my PCP to discuss the outcome of the tests, he told me that the tests were entirely consistent with neuromuscular disease, and there was nothing to be done for it. He did say if things got bad enough, he would put me on oxygen. That's when the bells went off in my head. I had read an article that talked about the fact that oxygen was a no-no (well - only in very special cases) for people with neuromuscular problems. I went home and dug out the article *Oxygen is NOT for Hypoventilation in Neuromuscular Disease* by E.A. Oppenheimer, MD, FCCP. Here it said quite clearly that "Patients with neuromuscular diseases who are developing progressive respiratory failure due to respiratory muscle weakness will die unless mechanical ventilation is used." Opps! Did he say die? Yes, that is exactly what he said. I'd best do some more looking.

AN EMPHATIC ASIDE Before I get too far, I want to point out an important issue. My PCP had told me that there was nothing to be done for this. That is exactly what he believed. He is not dumb, under-educated, or out-of-touch. He is just like so many other people who work in a particular field; he doesn't know everything. I later came back to him and told him the results of my search. He nodded quietly and said, "And again, I've learned something new." This is precisely why I believe I must take responsibility for my care, and why I spend so much time reading all I can regarding my condition.

STILL SEEKING So where do I turn now? My most trusted medical advisor, my PCP, has just told me there is nothing to be done for it. I need to talk to someone familiar with polio. I called and talked to one of my polio buddies who had breathing problems, Leah Welch (now departed), and she told me I needed to find a pulmonologist, and not just any pulmonologist but someone with a familiarity with polio. She put me in touch with another of her friends, someone who had the same symptoms I had. This man asked me to read him the results of my pulmonary study. He confirmed that our profiles were very much alike and told me that he used a volume ventilator at night and after meals. Why at night? Because when I lie down all my internal organs push up against my diaphragm muscle making it more difficult to breathe.

In further conversation I found that both he and I went to the same clinic. I asked for the name of his pulmonologist, only to find out that this doctor wasn't taking new patients. At this point I called my physiatrist to tell her the results of the pulmonary study and to ask her help in getting in to see this pulmonologist. As luck would have it, she had already seen the results of the study and saw a note saying "This study is consistent with neuromuscular weakness and restrictive physiology.. .." She particularly focused on the restrictive physiology. We struck a bargain, she asked me to exercise for two weeks using an inspiration spirometer, a device that you inhale through to raise a little ball on a scale. Her theory was that my back brace might well have allowed my trunk muscles to weaken, and some exercise might just bring them back. She said if it didn't work, she'd get me the appointment with the pulmonologist, who just happened to be a buddy of hers. She set up a regimen for me to follow and I was off sucking on my machine.

After a week and a half of working on the inspiration spirometer I was sure it was doing no good, and in fact might be making things worse. I called her to let her know. She told me to stop immediately. One day later her secretary called me with an appointment to the pulmonologist for the following Tuesday. That's keeping a bargain in spades.

HELP IS FOUND On the appointed Tuesday I met with the pulmonologist. He asked that I give him a history of my difficulties. When I told him about the doctors at Sister Kenny confusing my choking problems with breathing problems he smiled and suggested that they could see breathing problems also and were afraid they'd get worse. Hence, the time on the tray of the iron lung. When I explained my experience with my PCP and physiatrist both saying that there was nothing to be done for it, he reached across and patted my knee and said "Larry, there is something to be done for it."

He prescribed a sleep study to see if we were also dealing with any form of sleep apnea, and he also had me take a pulse oximeter home to use overnight. A pulse oximeter is the machine that uses an infrared clip over the tip of your finger to magically deduce the oxygenation level of your blood. It also maintains a record of your blood oxygen level over time and plays that back out for the doctor to review. My blood oxygen level, though low, was certainly not into the danger zone.

The doctor also prescribed a machine called a BiPAP for me. A BiPAP is a Bilevel Positive Airway Pressure ventilator. The machine is small and quiet and, in the machine I got, ran on either 110 volt house power or a 12 volt battery. It connects to a mask that fits over your nose and supplies a volume of air that is forced in at a prescribed pressure for the inspiration cycle. It then drops the pressure but still blows air

into your nose during the exhalation cycle. The reason for the constant flow of positive pressure is to make sure your nasal passages do not close down, obstructing your breathing.

The very first night I used the machine I only woke up once. My waking problems were not caused by a need to go to the bathroom but by my breathing problems. The doctor had recognized my wakefulness as a symptom of the breathing problem. From that night on I slept through the night with only one or two waking episodes. But I had a sleep study scheduled and I had to discontinue use of the BiPAP for 48 hours prior to my sleep study. Apparently, use of the BiPAP (or any other mechanical ventilator) throws off the data that is gathered in the sleep study.

SLEEP STUDY A sleep study is done in a hospital or clinic. You spend the night in a room very much like a motel room. There is a normal bed, a bathroom, and a television. There is also a camera that keeps constant watch on you and you are wired like an astronaut. Transducers, little electrical connections, are fastened to your scalp with a spot of cement, to record your brain waves. Other transducers monitor your eye lid movement, your breath flow, your breath rate, your pulse rate, and your jaw tension, and I think, the color of your socks.

With all your wires in place, the technician hands you the remote control for the television and says "sleep well." I didn't and I suspect most people don't sleep all that well. Just being in a different bed is enough to disturb my sleep. But apparently you sleep well enough so that the studies are meaningful. They found that I only stop breathing (apnea) about 10 times per hour. Neither the number, nor the lengths, of these apnea episodes were out of the normal range. My breathing, however, was shallow and labored.

THE FINE ART After the sleep study I went back to using the BiPAP whenever I slept and for an hour to an hour and a half following my meals. My intercostal muscles are essentially useless and my breathing is being done by the diaphragm muscle alone. As previously stated, lying down allows your intestines to push up against the diaphragm muscle, making it more difficult for that muscle to perform its function. Likewise, eating fills your stomach, which again pushes up against the diaphragm muscle with the same result. Therefore, using the BiPAP while sleeping or after eating provided the assist to the diaphragm muscle to get its job done. For the next 15 months my breathing was not a problem.

The only minor difficulty I had was that when I used the nasal pillow mask for both night-time and daytime ventilation my nose got sore. So at night I used a nasal shell mask called an Ultra Mirage, made by ResMed, and during the day a nasal pillow mask called a Breeze, made by Mallinckrodt. Actually, the Breeze has both a nasal pillow and a nasal shell mask,

but I could not get a nasal shell that fit me and was comfortable. Finding comfortable mask(s) is essential to using non invasive ventilation.

One other problem developed after two or three weeks. My nose started to run as though I had a bad cold. It seems that when you push air up your nose the process of pressurizing the air also dries it, and the dry air pushing through your nasal membranes dries them also. Your body reacts by forming the missing moisture. By adding a simple humidifier to the mix, the problem goes away. I found that a non-heated humidifier, the Oasis made by Respirationics, worked just fine for me and for the next 15 months my breathing was not a problem at all.

The story continues.....

Breathing suddenly changes, necessitating a change in both the machine and the interface.

SATURDAY SURPRISE Have you ever noticed that medical problems don't ever occur in the middle of the week? Nor do they occur during the day when it would be relatively easy to consult the medical professionals. Medical problems, at least for me, occur at 1:00 o'clock Saturday morning. That was when my next experience surfaced. I was wakened by the sense of smothering. I couldn't exhale. I pulled the mask off my face and was surprised to find a small elephant sitting on my chest, at least that was the way it felt. My first assumption was that I had somehow mis-set the exhalation pressure on the BiPAP. I immediately checked the machine, and when I found the pressure to be what it should have been, decided to drop the pressure another pound. I put the mask back on and tried to go back to sleep.

I was no more than beginning to drop off to sleep when the experience recurred. Again, I pulled the mask off and again found the elephant there. When I was conscious of my breathing I could inhale and exhale acceptably, but as soon as I forgot about it I would end up being blocked and unable to transition from inhale to exhale or the opposite. At this point I decided that I was just psyching myself. My ruckus had wakened Cathy, my wife, so she got up and put an old movie into the VCR to help me just forget about things and let this silliness pass. I enjoyed the movie but was never able to drop off to sleep.

Every so often my breathing would just stop and it required a significant kick start to get it going again. I drew the analogy of trying to walk through a deep mud puddle, each step of the way requiring that extra effort to pull the foot up out of the mud. By morning it seemed to be happening on a regular basis. Thinking about breathing kept things going, forgetting about it, my breathing stopped.

By six o'clock I'd had enough. I got up and called my pulmonologist's office. I explained the problem to the answering service, and the woman told me that

a doctor would be calling me back within 15 minutes. He did, but he was a doctor that I had no experience with. I had to explain the polio connection and all of the breathing problems leading to this episode, before I could tell to tell him about the new situation. He approved of the change that I had already made in the BiPAP setting and suggested that I also increase the inspiration pressure. He also told me to call the Durable Medical Equipment company and have them come out and check the BiPAP. By 8:00 I had someone at my door with the equipment to check my machine and with a loaner BiPAP. Even though my machine checked out all right, he took it back to the shop to be checked more thoroughly, and left me with the loaner machine. The on-call physician had also told me to call back if anything changed and to get in to see my regular pulmonologist first thing Monday.

DIAGNOSIS TIME On Monday my pulmonologist fit me into his schedule. He started with the requisite chest x-ray. It was clear, normal, showed nothing, nada, zip. On the theory that I could have an infection that didn't show up on the chest film, he started me on a week's worth of antibiotics. I agreed with the approach. It is perfectly possible to have an invisible infection. However, through all of this, I was still having to work at breathing. At the end of the seven days, I called the pulmonologist and told him that nothing had changed and that it was getting more and more difficult to get any sleep at all. He suggested that I needed to go on to a volume ventilator.

The difference between a BiPAP and a volume ventilator is that the BiPAP breathes with you and the volume vent breathes for you. The first machine my medical provider brought out was 16 inches wide, 14 deep, and 12 high; it weighed 35 pounds and, luckily, wouldn't work with the non invasive interfaces. A machine that size would have made it virtually impossible for me to get around my own house since they make them "portable" by mounting them on a little trailer behind your wheelchair. I can just get into my bathroom now without a trailer.

The next machine was the Pulmonetic Systems LTV 950. LTV stands for Lap Top Ventilator. The machine is 10 inches wide, 12 inches high, 2 inches thick, and weighs 11-½ pounds. It also has a built in non-invasive positive pressure mode. What a relief, within minutes of being connected to this machine I was able to relax and let it do the work. That isn't to say I just forgot about it. Periodically I would start breathing on my own and – invariably – out of synch with the machine. But it was a simple matter to get back in synch and very easy to just let the machine do the work.

NON-INVASIVE POSITIVE PRESSURE VENTILATION – NPPV There is a great push within the medical community to use non-invasive ventilation. If it works it avoids a packet of

problems. The non-invasive term refers to the fact that this ventilation is accomplished by way of some sort of mask or mouth piece that connects some form of mechanical ventilator to the user. This as apposed to using a tracheal tube or a tracheostomy. It can connect to the nose, the mouth, or both. There are several lines of masks and mouth pieces available off the shelf, and there are also custom-made masks available. Finding a device that seals and is comfortable for you is the trick for making NPPV work.

The positive pressure term in the NPPV equation refers to the fact that most ventilators available today use positive pressure. This was not the case in the original ventilator, the iron lung. Philip Drinker, a Harvard engineer, who at first was looking for a way to sustain artificial respiration, designed the iron lung. Drinker used electrically driven bellows to create negative and positive pressures in an airtight tank. When negative pressure was applied the patient's chest was expanded causing inhalation, and when positive pressure pressed against the chest the patient exhaled.

This same principle also applied to the chest shell, or cuirass, that was developed a little later and allowed people to move around with the ventilation attached. While this negative pressure method of ventilation was very dependable, it was also very restrictive. With the end of the polio epidemics in the middle 1950s, invasive positive pressure ventilation came into vogue. This ventilation connected to the patient via a tracheal tube or tracheostomy. It became popular largely because of its reliability and provision of direct access to the airway.

In this method a machine develops a positive pressure to blow air into the lungs for the inhalation cycle. The positive pressure is then stopped to allow the air to flow back out of the lungs under the force of the atmospheric pressure on the body. With this form of ventilation people could be ventilated with comparatively small machines, small enough to allow people to move around more or less on their own. Non-invasive positive pressure ventilation administered via lip seal was tried during the 1960s and 1970s. In the early 1980s nasal Continuous Positive Pressure Ventilation (CPAP) was developed to treat obstructive sleep apnea. In 1987, several reports appeared describing improvements in symptoms and daytime gas exchange in patients using nocturnal NPPV for chronic respiratory failure, and the thrust toward NPPV was started.

NPPV PROBLEMS By this time I had used the BiPAP on a part time basis for 15 months, and on a full time basis for another month and a half. I then switched to the volume ventilator. I was in hopes that I'd be able to return to something less than the 24 / 7 schedule, but when I took the mask off and stopped the ventilator, I would only last about a half hour

before I was feeling very breathless and very fatigued.

While it was clear that the volume ventilator was keeping me much better ventilated, my nose and face were getting very sore. Using the two different masks, one during the day and one at night had worked fine while I was using the BiPAP but when I went to full time use I began to develop soreness in and on my nose. The volume ventilator was supplying air at a higher pressure than what I was getting from the BiPAP and probably exacerbated things. Even the cartilage of the nose was sore when using the nasal pillow mask. When I used the shell mask the skin around my nose and particularly the area under my nose became sore. Also, I had no way of adding moisture during the day and the air was drying out my nasal passages to the point that I was having occasional nose bleeds.

I discussed these problems with my pulmonologist on a couple of different occasions and looked at the Internet news groups that cater to breathing problems (Vent Users and TrachVentList). While I'm sure that there are people in this wide world who use 24/7 non-invasive ventilation, I was not able to find anyone. I was hoping to be able to pick the brain of someone who was using 24 hour ventilation. I did hear from a number of people who were using NPPV for up to half a day but I hadn't had problems while I was in the half day range. I also heard from one woman who suggested trying a lip seal interface. A lip seal is a non-invasive interface that you hold in your mouth. I must confess, I didn't even give this idea a try. I am an habitual nose breather and just couldn't conceive of breathing through my mouth.

In a final attempt to find some way to make breathing comfortable, my doctor referred me to the head respiratory therapist at the hospital. According to my pulmonologist, she was the most experienced therapist and the one that knew the most about fitting a patient with the various non-invasive interfaces. When I met with her she started by asking what I was currently using. I told her that I was using two different masks, the nasal shell, and the nasal pillow interfaces. When I named them she simply threw up her hands. She said that those were the best interfaces available.

WHERE DO WE GO FROM HERE I was getting breathing support and felt a lot better than I had on the BiPAP, but it was making my face miserable. In the process of getting to this point, a couple of people had alluded to my considering a tracheostomy. Forty-eight years ago that suggestion had kicked my recovery into high gear, or so I thought. The idea of a tracheostomy had been raised by my family during the previous weeks and I had given it a little thought. I had even come to the point of saying that a trach was better than putting up with the sore face all the time. Now I had to look at that idea squarely and

make some serious decisions.

It was time to go back to the Internet. I was aware of two people who had made the statements that they chose the tracheostomy and that after significant periods of time they were still happy with their decisions. I wrote to each of them privately and asked a number of questions about the care and feeding of a tracheostomy. In both cases I got the personal response that was essentially the same as what I'd heard from them before: they were very comfortable with their decisions and weren't interested in changing. In one case the man was a Ph. D. who was still teaching on a part time basis. He was not ventilated 24 hours a day and still favored the tracheostomy to the masks.

Other people who knew that I was struggling with these problems put me in touch with still other people who have trachs. In every case people who had trachs said that they were very comfortable with the decision (though not all of them had a choice). Several of these people had struggled with ventilation and had ended up in the hospital with respiratory arrest several times before they switched to the trach.

We then had one of those happy coincidences that come up in our lives every now and then. Cathy and I had met a man a year before and we'd gotten to be good friends in a short time, a good deal of it over the Internet. As it happened he and his wife were going to be driving across northern Minnesota and wanted to know if it would be possible for us all to get together while they were this close. We made arrangements to meet them in Duluth. This man had spent his career as an emergency room physician/surgeon.

We all met on a Monday afternoon and were sitting on the patio overlooking Lake Superior when they asked about the use of the vent. I wanted to tap his brain on a tracheostomy anyway and I sure wasn't going to miss this opportunity. I gave him the summary of where things were and asked for his thoughts. He said he probably wasn't the right person to ask because while he had performed hundreds if not thousands of tracheotomies, he never followed these cases up to see the long term results. He suggested that the best advice could be obtained by asking someone who owned one. He also made arrangements for my doctor to consult with the neuromuscular specialist at the National Jewish Medical and Research Center in Denver, Colorado, the pre-eminent facility on breathing in the country.

PROS AND CONS Non-invasive ventilation avoids the problems associated with breaching the body's normal mechanisms for protecting itself. When we breathe we inhale air through our nose and or through our mouth. In both cases the body has ways to filter out things like dust and other impurities in the air that don't belong in our lungs. The routines

associated with caring for non-invasive equipment of masks, hoses, humidifiers, and so forth is straight forward. You put it in a sink full of hot soapy water, wash it, drain it, and put it back in service. Once you go to a tracheostomy you are putting things directly into the trachea and the cleaning routines require you to wash things in hydrogen peroxide and rinse them in saline solution. Everything has to be taken care of with a higher degree of vigilance.

On the other hand, you don't have anything pressing into your face and you don't have to seal leaky masks. The trach tube is inserted directly into the trachea through a small hole in your throat and is held in place by a little collar, or necklace if you chose to spend the money. While I had not experienced one, everyone I talked with who had a tracheostomy was happy and comfortable with the result.

On the other hand putting a trach tube into your body gives the body something to reject. In the process the body forms secretions that have to be removed. Sometimes you can cough them out, sometimes you have to suction them out. Either way these secretions have to get out. So if you go with a tracheostomy you are going to have, yet again, one more piece of equipment.

On the other hand you don't have to live in fear of what will happen if you develop a respiratory infection (and this had worried me a great deal). With a trach you are delivering air directly into the trachea right above the point the airway branches to go into your two lungs. There isn't a more direct method of ventilating a person than this. And since you will need a suction machine anyway you will have all the tools you need to deal with a cold.

On the other hand oh come on Tevye, it's time to make a decision. After looking at all the alternatives I could find, I opted to undergo a tracheotomy (in case you're interested the tracheotomy is the operation, the tracheostomy is the result of the operation – that hole in the throat).

Just a little after mid July of 2001 I consulted one last time with my pulmonologist and when there didn't seem any more to talk about I asked if he'd consider recommending me for a tracheostomy. I think he'd been on that page for a long time and was waiting for me to catch up. He called and set up a pre-operative visit with the surgeon. Before I had time to take a deep breath (well, you know what I mean) I was in the surgeon's office with his hands on my windpipe.

The surgeon was aware of the complications of surgery on a polio survivor, but wanted me to be sure to talk to the anesthesiologist on the day of surgery.

The story continues.....

Tracheotomy, breathing, and speaking.

WHAT I THOUGHT I KNEW Before deciding to

undergo surgery I had tried to gather all the information I could on what life with a trach would be like. I had asked a lot of people a lot of questions and now realize that a lot of my questions didn't get answered. I did know that for up to a year after the surgery your body tries to rid itself of this foreign invader, the trach tube. In the process it forms secretions that need to be either coughed out or suctioned out of you.

I don't think that everyone experiences the same things in the same way and things that are important to one person may not be at all important to someone else. But I'm getting ahead of myself. I arrived at the hospital on the appointed day. I knew that I would be hospitalized about four days, most of which was needed to teach Cathy, my wife, and me how to take care of a tracheostomy. Some of the people we met seemed to be a little thrown by the fact that I had my own ventilator along with me, but we worked through that and without too many delays, I was in the land of nod and not at all aware of what was going on. For this I am always totally grateful. When I came around, I was in the intensive care unit, a routine procedure for people with ventilators or trachs. I was also told that I should expect to be put into IC if I ever go back into the hospital.

With my first real awareness of my surroundings I realized that I was very hot. My head and chest felt like a radiator. I found out that they had me on a hospital ventilator and a heated humidifier. I thought the problem was the humidifier and I asked that they turn it down. Well you can only turn it so low. There is a minimum beyond which it won't do the job intended.

As is typical for me, I floated in and out of consciousness the rest of that day, always aware that Cathy was right there. But when I saw her unpacking a new fan, I realized she must have left for a while. My darling wife firmly believes in solving problems as quickly as possible. She also doesn't suffer petty-minded bureaucrats lightly. No sooner had she set up the fan and made me comfortable than someone there wanted us to know that was not an "authorized" piece of equipment. Well, when Cathy solves a problem she intends that it stay solved so she simply said, "get it authorized." Her tone made it clear to the bureaucrat that another step toward the fan might be unwise.

Before long we had a man in the room who inspected the fan and asserted that it did meet all the requirements and so our fan was authorized. I knew it met the requirements because I was once again comfortable. I was surprised how comfortable. I had expected that there would be soreness in my throat from the surgery. The amount of pain was minuscule, but of course they were administering medications, and I wasn't paying all that much attention to what I was taking.

I had known that I wouldn't be able to speak for several days following the surgery, and we had prepared by buying a small white board and some erasable markers. We also worked out a code: Cathy would ask questions designed to be answered either yes or no. For reasons that neither of us can remember, I was to tap twice for yes and once for no. That system seems strange to me now but it worked; it's still working.

SOME THINGS ARE SURPRISING I no longer know when this occurred but at some point I was wakened and I was choking. Something was blocking my ability to breath and I couldn't get air in. I'm sure I came to with my eyes the size of dinner plates. But my nurse (one advantage of being in IC is that you have your own nurse) was by my side in a flash and very calmly connecting me to something and sliding something else right into my trach. As suddenly as it had started, my choking stopped.

These were the secretions I'd been told about. But now, rather than being a 61-year-old man I'd turned into the 13-year-old boy I'd been when this whole strange story started. Mucus had built up in my airways then also, and in order to get it cleared, they had run a fire hose through my nose and down into those airways and then turned on some kind of motor that pulled it out. It had been frightening and it was, at its best, uncomfortable. Now I was right back to the same place. While I knew that my breathing was much more comfortable than it had been in a very long time, I wasn't at all sure I had made a good trade off.

Along with my fear of the choking episodes, there was a sense of vulnerability that I had never experienced. Even at the points I was the sickest during the initial polio bout I always believed that I would make it. Only at one small point did I wonder if I might die. I had never felt helpless. But now I was feeling what I can only describe as vulnerable. Webster defines vulnerable as: 1) capable of being physically wounded 2) open to attack: assailable. That was how I was feeling. For the first time in my life I didn't really know what to do. While the nurses were around and Cathy was there, I knew that I would be okay, but what about my future?

Over the next few days these choking spells would sneak up on me while I was sleeping, watching television, talking with someone, or eating. They were devilishly clever and never seemed to reveal themselves in the same way twice. While I knew there was adequate medical help around, and they always seemed to be able to put the fire to this devil's tail, I still lived in fear of his revealing himself.

THE MECHANICS OF IT ALL Time moves on and hospitals don't want to keep you for more than the appointed time. I soon had someone from the speech pathology department at my door, and they

had a present for me. I was given my own Passé Muir valve. This is a little plastic device that is essentially a one way valve. It allows the ventilator to pump air into your chest, but it cannot flow back out the same way it came in.

Let's back up and start at the beginning. When I went from the BiPAP to the volume ventilator, a new level of complexity was added. In addition to just breathing for you, the volume vent also keeps track of the parameters of your breathing process. In order to do this, one of the things that changes is the breathing circuit (that set of hoses used to connect you and the ventilator together). I was connected to the BiPAP with a simple single hose (which they also called a circuit) between the machine and the mask. When I went to the volume vent the circuit became more complex. From the mask, and now from the trach, there was a very short hose that connected to a Y fitting. I was connected to the bottom arm of the Y and the other two arms connected to longer hoses. One of those longer hoses went to the ventilator's air outlet, the other one ended in what I learned was a PEEP valve, a small plastic device with slots at the end and a rubber stopper that moves to open or close the valve.

PEEP is the acronym that stands for peak exhalation pressure in the airway. It turns out that we need to have a small positive pressure remain after we are done exhaling. Without it we have too little carbon dioxide left in our lungs and it screws up the acid-base balance. The PEEP valve regulates the pressure left in the lungs at the end of the exhalation cycle.

To recap, air from the ventilator flows through one of the hoses connected to the Y and into your lungs. Here it swaps out its load of oxygen and picks up a load of carbon dioxide and now we exhale. Here the function of the Y pops up because it magically turns the exhaled air down the short little hose and out the PEEP valve. That wasn't too bad, was it? But what about the air you need in order to talk? Oh yes, that was where we started.

By placing a Passé Muir valve (PMV) in the circuit, your exhaled air can't get back to flow out through the PEEP valve. When you put the PMV in place, you have to let the ventilator know that it won't be seeing any more air flow out through the PEEP valve, otherwise it starts signalling alarms. However, when you get everything connected correctly, you will have enough air to flow up past the trach tube and past your vocal cords which can now vibrate away in this air flow and you have speech.

Well there is another piece of the mechanics that needs to be explained, the trach tube. Trach tubes are made either cuffed or cuffless, the cuff being a little doughnut-like device that surrounds the end of the tube and is capable of being inflated or deflated. Also, if you have a cuffed tube it can be plain or it

can be fenestrated – have holes in it.

The inflatable cuff on the end of the tube seals the system as it were. When it is inflated, all the air has to go down into the lungs and all exhaled air has to go up through the trach tube and out the breathing circuit. That means no speech, but you have a closed system that makes it easy to keep track of what's happening and make any necessary adjustments. If you need to speak, you can deflate the cuff and allow some air to go twang over your vocal cords. But that's all you get, some air, since most of it flows back out the circuit. You can get a word or two out on each breath, and that is the reason that the PMV was invented. With the PMV in place the air can't get back through the circuit and has to go up where it can rattle your vocal cords.

GOING HOME TIME By the end of four days they were ready to throw me out even if I didn't feel like it was going to be all right. If I hadn't had such faith in Cathy, I think I would have found some way to stay. But home we went. Our going was coordinated by the hospital with our home care provider. Within an hour of our arriving home, the home care provider showed up with a home suction pump, a back-up ventilator (just in case), an ambubag (the mask with a big rubber ball attached that you see the ambulance personnel using on the TV medico shows) just in case, just in case, and a box of dressings and trach collars, and cleaning solutions, a heated humidifier, and ... a lot of other stuff.

My little devils didn't stay at the hospital; they came along home. But Cathy would be on top of things every bit as well as the nurses were, and she'd hook up the suction pump and clear me out. My sense of vulnerability was alive and well and living in Edina, MN. So with all the supplies I could need and my vulnerability intact, I got transferred into bed in my own bedroom. Just to keep things exciting, I was no more than into bed when the low pressure alarm on the ventilator started to scream. We could get it to stop for a minute or two, but, every time I spoke or moved, the alarm would go off again.

Cathy got out the back up machine and set it up and tried it but we had the same experience. Of course the alarms did a lot to make me less vulnerable. We got the home care provider on the phone, and he made a couple of suggestions that didn't help a bit. Then he said we should call the doctor. After a few useless suggestions from the doctor, he said we'd better come into the emergency room and let them take a look. So not more the six hours after leaving the hospital we were back. As I was checking in at the desk I heard someone say "I thought I recognized that voice." One of the respiratory therapists that had taken care of me during my hospital stay just happened to be walking by. I explained to him what had happened and he stuck around, worked with the doctor, and finally decided that my neck was too big

for the trach I had installed. Any little movement between my trachea and the trach tube would cause it to dislodge, which resulted in the tube sitting at an angle in my trachea, creating a big leak.

I kept saying that the trach was too small for my neck but they saw it the other way around. It was my neck that was at fault. No matter the semantics, the solution was the same; I needed a longer trach. The ER doctor and the RT got in touch with the surgeon and after lengthy discussions, everyone agreed I needed a longer trach. But this wasn't going to happen right away. In the mean time they jury-rigged an elastic band around my middle to hold the weight of the breathing circuit so that it wouldn't pull on the trach and cause it to dislodge. When this happened the return air would blow right past the cuff and up through my throat causing the vent to panic and sound the alarm. So go home, keep the belly band on, stay in bed as much as possible, and wait for Monday. Then call and tell the whole story to the surgeon and have him order a new trach. Of course, in the mean time, in order to help stabilize the trach tube we should keep the cuff inflated. With the cuff inflated we were back to the white board communication process.

The original trach that was installed was fenestrated. That means that in addition to being able to deflate the cuff to let air go past the vocal cords, there were also the fenestrations to which enabled air to pass up and over the vocal cords. With this I was able to speak quite well, at least until I had to put the cuff up. On Monday we called the surgeon's office, explained the whole story, got them to get the new trach on a rush order. It should be in by the end of the week.

On Thursday we were called and told to come in Friday at about noon. At the appointed time we arrived in the surgeon's office. When he came in I indicated that I wanted to know what to expect. In my mind this question was supposed to yield an answer that would let me know how the procedure would be done and whether or not to expect any pain. Apparently this was not what the surgeon understood because he said: "What to expect? I'm going to take this trach out and put in this new one." At which point he disconnected the ventilator, undid the trach collar, yanked the existing trach out of my neck, jammed the new one in, inflated the cuff, attached the collar, and walked out of the room. The trach was longer, which had the cuff hitting in a new spot within my trachea, and I was gagging and gasping and coughing and fighting to get air in.

It was probably a good thing he did walk out, because if he had stuck around either Cathy or I would have happily strangled him. After several minutes of fighting with the new trach I got the idea to deflate the cuff. This did make things better. With the cuff up, the trach was pressing against my trachea in a new place and my over-developed gag response was

trying to throw it right out of my throat. By the time we got home, my body had settled in to the new trach tube and things were better but somehow not quite right. Sometime later that evening I decided that since I now had a stable trach, I should once again put the speaking valve back in place.

POP GOES THE SPEAKING VALVE I had no more than put the valve in when there was a loud pop or bang followed by the realization that the speaking valve was not doing its job. The new trach tube that they had put in was not fenestrated and apparently there was not enough room between the outer tube and the walls of the trachea. As soon as the first breath had been pushed in and the exhale cycle was started, the back pressure blew the membrane out of the speaking valve. With no fenestrations in the tube, all the air had to flow back around the outside of the deflated cuff and up through the space between the trach tube and the trachea.

So with my second trach tube in we still didn't have the right combination of equipment so that I could both talk and breathe. Breathing was much more comfortable than it had been in a very long time, but what's the purpose of breathing if you can't talk. Actually, that needs to be clarified: I could talk in that I could get out a word or two, but the words were squeaks at best and within just a few words I needed to stop and allow the ventilator to push in more air or – since I still have enough muscle power to initiate breaths on my own – take what the doctor calls volunteer breaths.

AND THE HEAT GOES ON From my first consciousness following surgery, I have been aware that my head and chest seem to be radiating heat. Cathy had gotten me the fan and that kept me comfortable as long as the air was blowing over me. Whenever I was out of reach of power, however, I couldn't use the fan, and got uncomfortable. Once again my ingenious wife was off to solve a problem. She purchased a small fan that ran on four D-cell batteries. Whenever I left the house, that fan went along with me in order to keep me comfortable.

Two weeks after the surgery and about a week after I had been back to the surgeons to have the trach tube swapped out, I had an appointment with my pulmonologist. Before the doctor came into the office, one of the respiratory therapists (RT) came in and drew some arterial blood for the Arterial Blood Gas (ABG) test. Then the doctor came in and checked me over, listened to my lungs and generally behaved like a doctor. When he had completed his routine I asked him if he had any idea why, ever since the surgery, I had been fighting with what felt like a huge heat build up in my body, making my head and chest feel like radiators. He immediately looked at the settings on my ventilator and said: "you have to be hyperventilating." At about that point the RT came back into the room with a strip of paper reading

out the results of the ABG test. Before she opened her mouth the doctor said "his oxygen is too high, his carbon dioxide is too low, and his acid base is out of balance."

"And why is it you bother to have me run this test?" she said, presenting him with the strip of paper that proved him right. She never did ask him how it was that he knew these things, but it was obvious to me that hyperventilation would throw these parameters out of whack. He had the RT decrease both the number of breaths per minute and the tidal volume that the machine was producing. They also changed the mode in which the machine was operating, from Assist Control to something called SIMV (Synchronized Intermittent Mandatory Ventilation). In the Assist Control mode the machine delivers a set number of breaths at the full set tidal volume. If I initiate a breath on my own the machine jumps in and delivers that additional breath, again at the full set tidal volume. By putting the machine in SIMV mode I get the set rate and volume as long as I'm not breathing on my own, but when I take volunteer breaths I only get as much air as I work for. In this mode I'm not going to over-ventilate myself.

My first reaction to this was to feel like I wasn't getting enough air. The doctor assured me that I was getting enough air and that I needed to wean myself from this over-ventilation over a period of weeks. He also assured me that when I got to where I belonged I wouldn't feel like I was a radiator. Two weeks later I was back in his office feeling better, but still a little hot. He rechecked my blood gases and showed me I was still hyperventilating. This time he gave me a target to try to reach over the next two weeks. Even before I reached the target rate and volume he had established I was able to turn the fans down and finally off.

VULNERABILITY My feelings of vulnerability had been so intense that I had not wanted Cathy to leave the room, let alone leave the house. But as the days turned to weeks I started to realize that I was beginning to take back control of my life. Even the last two days at the hospital had been sleepless. I was afraid that if I went to sleep I'd end up choking. At least when I was awake those first signs warned me and I would begin the suctioning process. When I got home I simply couldn't fall asleep. For the week and a half I slept for 45 minutes to an hour at a time. If I did wake up choking it made it all the harder to fall asleep the next time.

Eventually it became clear that Cathy would have me hooked up and suctioned almost before I was awake. As time passed I began to wake myself and suction myself. Then I started waking up without choking but aware of needing to suction.

Also at this time we were approaching the opening of the Minnesota State Fair. Cathy and I have been Fair

freaks all our married lives. We always go to the Fair and usually go several times during its run. When Cathy mentioned the upcoming Fair to me it was clear that she didn't want to miss it. I said - in a weenie voice, I'm sure - that I intended to go to the Fair with her; I wouldn't miss it. My speech was braver than I felt.

But as the time got closer I was feeling better and more able to handle things on my own. As the day arrived I sucked up my courage and we loaded Larry, ventilator, suction machine, and all the other spare parts and dressings we'd need into the van and were on the Fair grounds by 6:00 AM as has always been our practice. The weather was perfect in that it dawned bright and clear, but was threatening rain enough to keep the amateurs off the grounds. We had our usual foot-long hot-dog breakfast, saw the animals in the barns and were at the Creative Activities Building by 9:00 for its opening. While we surveyed the exhibits, the weather poured rain all over the grounds. By the time we'd finished, the weather had cleared and we did the rest of the day in dry comfort without too many people needing to be run over.

As the day progressed I would feel the need to be suctioned from time to time. We'd find as quiet a spot as possible, out of the way of traffic, and connect up the suction machine. I'd been harboring a secret fear that if people saw me shoving this tube into the hole in my throat they would be horrified or repulsed. For the most part the people never paid me any attention at all. Those that did glance my way simply noticed me and kept right on about their own business.

My day at the Fair had been the confidence booster I needed. My vulnerability didn't evaporate but diminished slowly but surely over the next month. It took a total of three and a half months to get a trach that worked for me and allowed me to use the speaking valve. I have been told by several other trach users that this isn't all that unusual. It takes time to find the right size and configuration that works for you and suits all your needs.

It took two months for my nose to heal so that I was able to touch it without flinching. My family is happy to be able to see my face out from behind the masks and I am now breathing easier and more comfortably than I have since before this whole thing reared its ugly head. For the most part I am handling things on my own. Cathy still does my trach care for me, morning and evening. This consists of cleaning the site with a peroxide/saline solution and changing the drain sponge that sits under the face plate of the trach tube. She also has to help me with all the things I forget to gather before I get into bed at night, but that isn't something new. I get myself up in the morning, disconnect the humidifier, put an artificial nose (a device that traps your exhaled humidity and

returns it to the next breath) in the circuit, and get the day under way. I wish I had known about those devils that rise up to choke you before I had started this process but I learned to defeat them anyway. I think I've mastered the fine art of breathing.

Larry Kahout <lkohout@mn.rr.com>

Letters to the Editor

Dear Mrs. Hallam,

We thank you for renting from ScootAround in the past and look forward to serving you again in the future.

ScootAround Inc.
1-888-441-7575
info@scootaround.com
www.scootaround.com

[A firm in America that arranges hire of scooters and wheelchairs from local dealers for your travels round the States. I now travel with my scooter and so far - touch wood - have not had too many problems once I obtained the correct charging equipment. Remember to check with your dealer before you leave for details of who to contact in the event you do get a problem. I get requests for rental and travelling information for the U.K. and Europe. If anyone has any information regarding travelling in any country in your own, rented or public transport and reasonably priced disabled friendly accommodation, do tell us]

Jann Hartman has just emailed me the following information regarding an online newsletter about Travel. I found it interesting reading.

ACCESS-ABLE/TRAVELIN'TALK
NEWSLETTER
VOLUME V NUMBER 1 (January)
<http://www.access-able.com>
<http://www.travelintalk.net>

Dear LincPIN,

My name is Mrs Julia Squire, 14 Kitchener Street, Martinborough, South Wairarapa. New Zealand. Email address julia@infogen.net.nz.

I caught polio in the 1948 epidemic and lived in the Barnsley area of Yorkshire where I was living at the time. I spent 12 months in a hospital called Rivelyn Valley which I think is either in Yorkshire or just over the border of Sheffield. I would love to correspond with anyone who caught Polio when I did and even more delighted if you lived in the same area. I work with our National PPS Society.

Julie Squire <julia@infogen.net.nz>

Musings

Kangaroo Words - A word that has within it a perfect synonym for itself, e.g. Blossoms and Blooms. 12 right is good. 13 or more is excellent.

Answers page 21.

1. Evacuate
2. Encourage
3. Prosecute
4. Calumnies
5. Rapsallion
6. Indolent
7. Prattle
8. Diversified
9. Rampage
10. Matches
11. Perambulate
12. Pinioned
13. Joviality
14. Container
15. Regulates

A deep sea fishing boat is lying in the harbour. Over its side hangs a rope ladder, with its end just touching the water. Rungs of the ladder are one foot apart. The tide rises at eight inches an hour. At the end of six hours how many rungs will be covered?

Answer. page 23.

Transitioning To A Wheelchair: An Exploration of our Fundamental Fears

You were paralyzed by polio; do not be paralyzed by society!

When actor Christopher Reeve sustained his spinal cord injury in a horse riding accident, he went immediately from Superman to Man in Wheelchair. In contrast, we polio survivors usually go through a lengthy, angst-ridden decision making process before we plunk ourselves down in a wheelchair.

We listen to the recommendation of our physicians and we sheepishly explore the idea with our loved ones. We recognize that using a wheelchair would keep us from tripping and falling. It would help us conserve our limited energy and sure would make daily life a lot easier. Why, then, is this decision so emotionally intricate and agonizing?

Let's go all the way back to the beginning. Does this sound like you? You contracted polio as a baby, child, or young adult and endured a long hospitalization. You were separated from your family at a tender age and probably still have some psychological wounds from that trauma. You may have emerged using braces and crutches for mobility. However, in many cases, your medical professionals gradually eliminated these aids.

You made an impressive recovery, walking unaided for many decades. Then approximately 30 years after onset, you began to experience weakness, fatigue, and pain. You may have been diagnosed with post-polio syndrome.

You now use a cane for support in walking; possibly, you were fitted for a brace and/or forearm crutches. You may find that motorized shopping carts at the grocery store are a colossal help to you. But life is still much more difficult with PPS.

You may be declining activities that involve walking. You sit back and reluctantly stay home, unable to do some of the activities you once enjoyed due to increased weakness, pain, fatigue, fear of falling, and lack of endurance?

Did you once adore pops concerts in the park? Now you decline to go because the walking on that uneven grass is far too difficult for you. *You stay home.*

Did you once savor the fun of cruising the mall with your daughter-in-law? Now you decline to go because that much weight-bearing and walking is far

too painful. *You stay home.*

Did you once thrill to walking the boardwalk at the beach absorbing the sights and sounds of the ocean atmosphere? Now you decline because the length of that long, winding boardwalk is too much to manage without pain and fatigue. *You stay home.*

You and your polio medical professionals recognize that the time has come for you to use a wheelchair for most of your mobility needs. However, the thought of ***appearing in public*** in a wheelchair fills you with dread. The key phrase there is "appearing in public." Alone in your home, you love the way you can move smoothly, gracefully, and without pain and fatigue. But the image that most terrifies you is the thought of using your wheelchair out in public. Your emotions overflow with panic and anxiety. Why? You realize on a rational level that using a wheelchair would be very liberating. But that rational base is overpowered, indeed almost buried, by the negative emotional overtones that shout: "No! No! No wheelchair for me!"

Let's examine the underlying origin for this resistance.

- ◆ As a child, you received considerable praise for your attempts to walk unaided.
- ◆ Society places an inordinately high value on walking.
- ◆ The wheelchair makes it virtually impossible to be a "passer," that is, to pretend you are able-bodied.
- ◆ Indeed, it is the image of a wheelchair that is the universal symbol of disability.
- ◆ Much of your self-esteem is wrapped up in the fact that you are still able to walk.

These are some of the contributing factors in your resistance to using a wheelchair. However, we have only examined the surface reasons.

The deeper, overriding reasons for your reluctance stem from a negative association of ideas. Think of that statement as an algebraic equation: YOU are on one side of the equation and DISABLED is on the other side. That association of ideas is laden with shameful emotional overtones. Why? Because historically people with disabilities are stigmatized. They occupy a low rung on society's "A List."

I remember the various social cliques in high school. Teenagers were ranked in hierarchal order as "Preppies," "Jocks," "Greasers," and "Nerds." The most popular kids were the Preppies and the least popular were the Nerds. Very few handicapped kids

landed in the popular crowd. We absorbed that message like water into a sponge. Although those classifications have undergone various transformations over the years, I have a sense that we still long to belong to the "popular crowd."

Our resistance to using a wheelchair is intimately connected to our unwanted view of ourselves as disabled. We are influenced by a deep-rooted prejudice in the society that it must be better to be ambulatory than to be in a chair. For example, there could hardly be a greater medical triumph than getting someone "up out of a chair." Consider the hidden negatives in our language: "wheelchair bound," "confined to a wheelchair."

Almost universally, people who are not totally wheelchair dependent, make too little use of the wheelchair, if they are willing to use it at all. Likewise, people who are gait impaired but not crutch dependent, make far too little use of crutches, if they are willing to use them at all. "I'm not THAT disabled. I don't need it/them," are considered sufficient reasons to forgo the enhanced function, ease, safety, and health benefits they could have from selective use of adaptive aids.

When a polio survivor chooses to use a wheelchair, he/she faces emotional, interpersonal, and social issues that can be deeply troubling and anxiety producing. How my heart pounded with dread and self-consciousness the first semester I wheeled into the faculty meeting. That wheelchair gets the credit for "outing" me. I now had to admit to the world that I was, indeed, a Person with a Disability. But ever since that day . . . oh, the liberation that has been mine!

It is an important healing step to act on the belief that is OK to be YOU. Know that the consumerist driven, stereotypical images of "attractive" and "popular" are oppressive falsehoods rather than the truth. Consider this thought: It is stunningly appealing for a person with a disability to exhibit confidence and self-acceptance. People are not used to seeing this in someone who is disabled. When you perceive others' positive responses and you realize these responses are to YOU, as you are, you will be freed. You will receive positive reaction to the real you, not despite your disability, nor because they are unaware of your disability, but to YOU. You will shed a burden you may have carried around since adolescence.

The good news is that the stigma is diminishing. Societal attitudes about people with disabilities are vastly more accepting today than they were in the doo-wop era. Are you still suffering from antiquated tapes playing incessantly on your internal tape recorder? If so, it is time to erase those old tapes. You can trade in

your negative thought patterns for powerful new positive beliefs. You can liberate yourself and claim your rightful place in society.

If you love the comfort and ease of using your chair in private but dread the thought of using it in public, you can use the power of your human consciousness to restructure your perceptions and free yourself. You were paralyzed by polio; don't be paralyzed by society!

Think about sitting proudly, head held high, in your sleek manual chair or perhaps zipping around in your sporty, power-chair. Visualize yourself maneuvering gracefully over the grass at the pops concert in the park. How lovely the grounds look when you are no longer fearful of tripping. How sweet the evening air as the melodic musical sounds touch your heart.

Picture yourself on a swift mobility scooter at the shopping mall with your favorite friend, scooping up bargains. You can shop 'till you drop and still have energy left over to go out to dinner at the end of your day.

Envisage yourself travelling the length of the boardwalk at the ocean. Your senses overflow with the ambience of the seashore. Since you have no pain or fatigue, you are much more free to hear the seagulls scream, to smell the salty sea breeze, and to celebrate the sheer joy of this outdoor experience.

I know that this is still a difficult decision. Generally speaking, I think we are in a climate where the mobility-impaired person has to swim upstream against self-imposed inner conflict, as well as from family and friends who are caught up in the "use it or lose it" mantra. If we are to make optimal advantage of wheelchair mobility, we need a lot more people willing to swim upstream, proudly and confidently, to change that climate. Won't you join me in the swim?

Dread of using a wheelchair is based on old emotional baggage. Toss that baggage out as you would a sack of old trash. Wheel with pride and flaunt your self-acceptance. You will be an inspiration to all who encounter you.

Linda Wheeler Donahue
Professor Emeritus of Humanities
President, The Polio Outreach of Connecticut

LinOnnLine@aol.com

Answers from page 19

1. Vacate. 2. Urge. 3. Sue. 4. Lies.
5. Rascal. 6. Idle. 7. Prate. 8. Divers.
9. Rage. 10. Mates. 11. Ramble. 12. Pinned.
13. Joy. 14. Can. 15. Rules.

Summary of San Francisco Bay Area
Polio Survivors November 17th meeting's
presentation by Neuropsychologist
Glenn Hammel, PhD, CRC**
SFBAPS Newsletter,
Volume 11, Issue 4, January 2002.

Finding Balance: Depression and PPS.

Neuropsychology is a branch of psychology. It deals with the relationship between the nervous system, particularly the brain, and the cerebral or mental functions such as language, memory, and perception.

The poliovirus affected the brain. This is important to know. The brain produces the energy needed to effectuate mental and physical functions. The virus destroyed a portion of the brain's energy production ability and blocked transmission of some of the energy produced.

The 'memory' function is fine and remains intact; the problem is *'retrieval'* of stored information. Over-learned information, like counting numbers 1 to 20 or saying the alphabet, are engrained in the brain's pathways and require little mental energy for recall.

Alternatively, processing new information and new tasks requires a lot of mental flexibility and energy. Examples of this are: sequencing numbers with alphabet letters (i.e. A1, B2, C3, etc); writing a check; and, processing emotions. The enormous amount of energy and mental flexibility required causes brain fatigue and sheer exhaustion if 'pacing' is not practiced.

Medical impairment strikes at the core of our value. We want to be of value to others but there is a general feeling of loss that others no longer need us. Impairment prevents the continuation of activities that showered us with the value we strived for and achieved. This can lead to feeling depressed, particularly at times of holidays when we really need our active social family life.

Always remember that an individual with brain function limits has merit. When we ask for help, accept that there will be negative and positive reactions. There will always be peaks and valleys when there is damage to the brain. The 'reality within us' must be validated, not what others think of us or what we think (our perception).

Joni Mitchells life exemplifies this aspect. She

overcame polio and became famous for her music (jazz singer and acoustic guitarist). She developed back problems and lost the strength needed to lift and play a guitar, even when adapted to meet the needs of her deteriorating physical abilities. As her physical malady progressed, her brain stopped sending signals for her to play her music. Her music evolved into what she couldn't do and social reality, resulting in depression. Her music shows the progression of post polio syndrome and her mental anguish about that. Her albums progressed from all music (vocal and guitar) being done solely by her to albums consisting mostly of other artists' music as well as hers, to albums consisting mostly of the music and lyrics of others with her providing few lyrics and no instrumentation. Likewise, as time passed her lyrics changed from being intricately creative and upbeat to being angered and sad and much less sophisticated or complex. She no longer does music, vocal or instrumental.

We are social creatures, having learned during the first five years of our lives to become social. We go through life having to navigate a medical condition that is a social disease. The medical problem later effects psychological consequence that is made worse by the frustrating need to teach doctors about our condition before symptoms and treatment issues can be addressed.

Only a small percentage of polio survivors experiencing the late effects of polio are clinically depressed. The majority are not depressed, but instead suffer a 'depressed mood' relating to post-traumatic stress disorder. For instance, when you feel tired often weakness results and this creates a sad mood. It all becomes clinical.

The question becomes how best to cope. Suggested methods are:-

1) Definitely leave a doctor who does not believe your medical condition exists. Find a doctor who knows of its existence and is willing to learn about its nuances;

2) Anti-depressant and anti-anxiety medications really help. Your brain needs this because a biological disorder exists. Find a drug that works for you if the prescribed drug turns out not to meet your special needs. Many new drugs are on the market, and more kinds are continually being added;

3) Undertake psychotherapy with a professional who believes you and practices cognitive

behaviour methods;

4) Pace. Pace. Pace. This impacts on your mood and works with your natural limits.

5) Accept the physical changes taking place rather than denying those changes. Go with the flow; fit the cycle instead of fighting it and causing more damage.

**Dr. Hammel is a licenced Clinical Psychologist with Post-Doctoral Fellowship training in Neuropsychological Rehabilitation. In addition, Dr. Hammel is a Certified Vocational Rehabilitation Counselor, and holds Diplomate status with the American Board of Forensic Examiners; the American Board of Psychological Specialities, Forensic Neuropsychology; and with the American Board of Disability Analysts. He has two offices; 1) San Rafael, CA (415) 485-1939 and 2) Kaiser Occupational Health Dept, Richmond CA, (510) 307-1560

Helpful Tips for Wellness

SFBAPS member Monica Dupont and Alta Bakes Herrick Campus Registered Dietician Nancy Pancoast have devised these methods that Monica finds quite helpful for:

- maintaining proper nutrition with weight loss;
- providing muscle/joint flexibility when confined to a wheelchair; and,
- increasing energy and stamina.

The nutrition advice is particularly helpful for polio survivors who suffer from neurogenic stomach or other illnesses that do not tolerate ingesting solid foods, and folks who are bed-bound with the flu or whatever or are immobile. The shake provides daily nutritional needs if taken twice daily.

FLEXIBILITY.

Think of your body as a car. It needs to warm up, and it needs lubrication. So do you!

Don't stretch or do exercises when you first wake up in the morning; your body's not yet ready for that.

Drink a glass of water, relax and shake like a dog for a minute or two. This will start your circulation in every part of your body and prepare you for the day ahead.

After a meal, pace around your apartment for several minutes. If you don't walk well, just sit, rock and bounce. You'll be amazed at how much this helps your digestive process!

Now, here are some passive exercises to help

keep you flexible. (No, we can't be Jack LaLanne, but we can stop our muscles atrophying, even if we're chairbound or bedbound.)

Remember, gauge your own strength and stamina and do only what feels comfortable to you. Never strain yourself. Your goal is flexibility, not muscle mass. Repeat these as many times as you want;

- 1) Lie down, get up, lie down, get up....
- 2) Sit down, sit up.....
- 3) Put on your coat, take it off.....
- 4) Put on your shoes, take them off..
- 5) Unscrew a jar lid, screw it back on..
- 6) Open and close doors, sliding doors, or windows.....
- 7) Lying on the bed, hug your pillow and roll back and forth.
- 8) While standing, drop an item and pick it up.
- 9) While sitting, throw a coin just beyond your reach and very slowly reach for it and pick it up.
- 10) Wash out a dishcloth or anything small in warm water. (Kneading your hands in water is exercise).

You've just pretty much used all your muscles and it's so easy.

TIP. Even a simple thing like lifting a telephone receiver to your ear, is exercise. Any movement, no matter how minimal, uses some muscle group. Learn to exaggerate every motion.

INSTANT NUTRITION

To make this shake, you will need a blender and

- Trader Joe's Chocolate Flavored Whey Protein Powder Dietary Supplement. This is Low Fat with all the needed vitamins and minerals - \$8.99 per 18oz can. The nutritionist states it is an excellent balanced drink. If taken twice daily, you do not need vitamin supplements. This comes in different flavors, but the nutritionist advises the chocolate tastes best). [Editors note - check with your local pharmacist/dietician for a UK alternative to the one suggested].

- Olive oil
- Frozen berries (Strawberries work best)
- Bananas (small)
- Apples (small)
- Lowfat milk or Lactaid or Rice Milk.
- Gatorade (I recommend red). [Sports Drink]

Breakfast menu-

Pour 1½ tblsp of oil into the blender.

Add: 1/3 package of frozen berries,
1 banana,
1 peeled and sliced apple,
1 cup of milk,
1/3 cup Gatorade,
2 heaped scoops of protein powder (use
scoop from can).

Blend until thick and smooth, adding a lettuce
leaf after starting. If the mixture is too thick, add a
bit of water. Makes the exact right amount for one
person (2 glasses per meal).

Lunch Menu (4 hours after breakfast)

Pour 1½ tblsp of oil into blender

Add: 1/4 package of frozen berries,
2 heaped scoops of protein powder,
1 cup of milk

Blend until smooth, again add a bit of water if too
thick.

Dinner Menu (4 hours after lunch)

Eat your regular dinner; or if you prefer, repeat
the lunch recipe for dinner. DO NOT repeat the
breakfast recipe.

President Phyllis Hartke of the SFBAPS became a Life
Member of the LincSPN on behalf of her Organisation in
support of the work we are doing.
SFBAPS, P.O. Box 272175, Concord, CA 94527-2175
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sfbaps@aol.com

Hints, Tips and Bits from PPSers

From Anne Wood
<Anne87@BTINTERNET.COM>

DON'T CREAM YOUR FEET

Here's a tip.....don't cream your feet at 1 o'clock in
the morning, get into bed, realise you forgot to take
your sleeping pill, and try to get off the bed - your
greasy foot will shoot over the carpet, you fall off the
bed bending your other leg under you, you slam your
knee joint into the furniture and your sliding foot hits
the door which bangs shut.

If you do all this, you will need to take 10 minutes to
work your leg from under you, inch towards your
bedside cabinet, find the little china bell, edge
towards the door, just about reach up to open it, ring
the bell like fury to call your husband who is still in
the lounge with the door shut, watching a film . The
tears will be flowing.

He will come out, gasp, and neither of you will have
any idea how to get you up. You make a start with
the electric cushion lift, once you have been able to
wiggle your backside on to it, not using your arms as
they are too weak to support you. Now you are just
12" off the floor, and the only option is for your
husband to link his arms round your body and heave
you up. "Don't stop!" you cry, "Don't stop until my
legs are straight! Up, up! Keep going!"

At last you are standing, except you would rather sit
down. You find, yet again, that no bones are broken,
but your knee is seriously aching, your big toe is not
too happy and your shoulder feels a tad wrenched.
After 2 cups of tea, a pain killer, a sleeping tablet,

and 20 minutes with the ice pack it's now 2 o'clock in
the morning and you have learned a very useful
lesson - after creaming your feet put on a pair of
socks. It saves so much time.

Cheers, Anne

From Patty in the USA.
<puffdragon20@EARTHLINK.NET>

EXERCISE PROGRAM:

We never seem to have the time to keep up a serious
exercise regimen. I have devised a simple workout
that I think will fit everyone. I thought I would let
you, my friends, in on a little secret I've found for
building my arm and shoulder muscles. You might
wish to adopt this regimen. 3 days a week works
well.

I start by standing outside behind the house and, with
a 5-pound potato sack in each hand, extend my arms
straight out to my sides and hold them there as long
as I can.

After a few weeks I moved up to 10 pound potato
sacks, then 50 pound potato sacks and finally I got to
where I could lift a 100 pound potato sack in each
hand and hold my arms straight out for more than a
full minute!

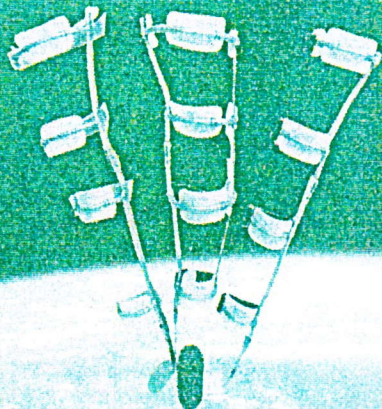
Next, I started putting a few potatoes in the sacks, but
I would caution you not to overdo it at this level.



Answer - None, because the boat rises with the tide.

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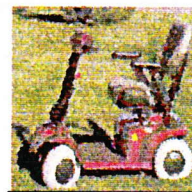
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