JULY 2011
Volume 7
Issue 5

POST POLIO MATTERS

The Polio Survivors Network Newsletter - Volume 7, Issue 5
n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk

READ CODES FOR POST POLIO SYNDROME ISSUED IN APRIL 2011

Version 2
F29y1

Version 3
X0002p
Page 8

GET PHYSICAL PAGE 5

WE'RE STILL HERE!
October 9-15, 2011
www.post-polio.org

SUPPORTING PHI'S YEARLY CAMPAIGN

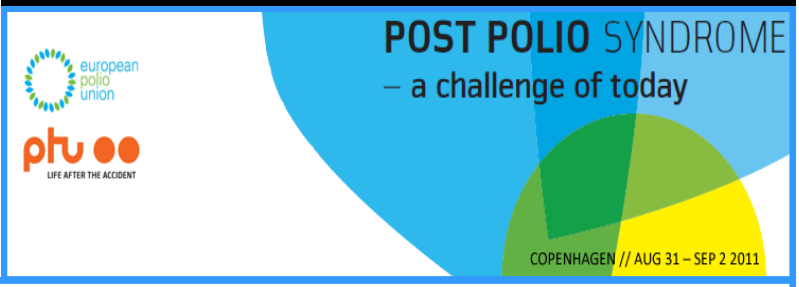
Polio World Photo Poster Competition 2011
Page 11

european polio union

Polio Survivors Network Joins the European Polio Union

August 31st to September 2nd 2011 in Cøpenhagen, Denmark.

EUROPEAN CONFERENCE ON POLIO - Page 10



Full Conference Program now available at

www.polioconference.com/pdf/Program.pdf

Printed by Elpeeko Ltd., Lincoln 01522 512111

Thank you Wickes for donating £750.00 towards improving our new website

Scottish Post Polio Network AGM/ Conference 2011

Saturday, 1st October 2011

10 am – 5pm at Hilton Strathclyde Hotel, Strathclyde Scotland.

NAIDEX

GLASGOW

14/15 Sep 2011

LONDON EXCEL

19/20 Oct 2011

www.naidex.co.uk

Contents

New Members and Donations received.

We welcome new member John Lloyd

Thank you to the following for donations given towards our work.
Wickes donated £750.00 towards improving our new website.

Donations from members from the date of the last newsletter will be included in the October Post Polio Matters.
Total since last newsletter is **£ 750.00**

We have no paid employees. We would like to recognise and thank the following for so generously donating their time. The Trustees, Dave Eate, and Bob Price

Donations & offers of time towards our work are always welcome.

Editorial by Hilary Boone

Members regularly raise the issue of lack of knowledge and experience by health professionals of polio and the hugely various ways it affected our bodies. The success of the 1955 vaccine led to less and less facts being taught in Medical schools as the decades passed. Another major point is that as we recovered and left the health system what and how we managed was not recorded. We were all affected in a different way to a variety of levels with different treatments. We have achieved highly in our professional, and family lives. So NO set pattern for health professionals to work to must make their work more difficult.

We are still working hard to see an improvement for polio survivors and thank the members who responded to the PSN survey. The report will be finalised in the next few months. In the meantime if you have respiratory and sleep issues I would refer you to the PatientPlus article for health professionals on Post Polio Syndrome [1] the 28 page June 2006 issue of the LincPIN [2] and watching the presentations from the 2009 and 2010 Breathing Symposia in San Diego.[3]

Other issues raised have been problems with bloated stomachs and difficulty with evacuating waste products so I have added the Lincolnshire Post Polio Library article - Gastrointestinal Involvement of the Post Polio Syndrome [4] pages 12 to 17. The article does contain fairly technical terminology but would be informative for any health professional you consult who has minimal knowledge of Polio. Personal experience of eighteen months of reporting constipation getting worse with two health professionals just got us the standard responses. We did what was advised but we still had the problems. Now we realise that they were most probably unaware that our prior polio could have any bearing on our problems. If you have similar issues we recommend seeing your GP and going back again till you get the problems resolved. A Prescription of Macrogol eased our problems and had it been prescribed earlier would have saved the NHS the cost of 5 days in hospital and us a lot of stress.

The Scottish Post Polio Network (SPPN) have had some success for Scotland. They too have been campaigning (since 2001) for greater recognition of the needs of individuals with new or continuing problems due to polio. Following their representations to Scottish Ministers, the Scottish Medical and Scientific Advisory Committee [SMASAC] set up a Working Group in 2008 to consider the issues. The 62 page report produced for the Scottish Government by APS Group Scotland. [DPPAS11404 (04/11)] was published by the Scottish Government April 2011. [5]

The main messages from the report are ones raised in every country:-

- There is still a significant number of individuals in Scotland affected by PPS/LEOP who will require services for up to another 40 years.
- Many of the difficulties faced by PPS/LEOP individuals are the same as for individuals with other chronic neurological conditions.
- PPS is a diagnosis of exclusion and other possible causes of the new features must be excluded before it can be accepted.
- Many healthcare professionals who will encounter individuals with PPS have, understandably, little or no knowledge of this newly recognised and relatively rare condition. Even many polio survivors are unaware of PPS.
- Services are patchy and poorly coordinated.

1. www.patient.co.uk/doctor/Post-Polio-Syndrome.htm
2. http://poliotoday.org/?page_id=761 and http://poliotoday.org/?page_id=766
3. www.poliosurvivorsnetwork.org.uk/images/lincpin/lincpin5-9.pdf
4. www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/usa/gi.html
5. www.show.scot.nhs.uk/

Members not on the internet who would like more information please ring or write to us.

Polio Survivors Network - Meeting information

The next Trustees Meeting is being held in Rugby on October 12th 2011
If you have any matters for our attention at our meetings please get in touch via
info@poliosurvivorsnetwork.org.uk
or Tel: 01522 888601 or write to us at Polio Survivors Network PO Box 954, Lincoln LN5 5ER

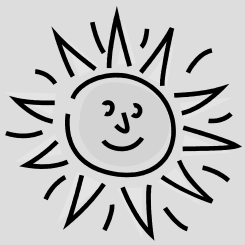
"The best measure of a man's honesty isn't his Income tax return.
It's the zero adjust on his bathroom scale."
Arthur C. Clarke
Polio 1959

A bear, however hard he tries, grows tubby without exercise.

A.A. Milne

Wonderful
Wonderful
Cøpenhagen

Friendly
old girl
of a town



Message from the Chair

Dear Members and Friends,

Thank you to all who came to our AGM in Birmingham and although we were small in number it was a friendly and successful meeting. If you would like a copy of the Information Pack that attendees received, please let Hilary know and one will be sent to you.

Gillian Bryan, our new Trustee and Treasurer presented her suggestions for our financial future, which is critical to our future. The main change we are making forthwith is that our financial year will now run from January to December instead of April to March. This means that the current year will only be nine months from March to December 2011.

Gillian is also taking on the position of Membership Secretary, see short article on the bottom of the next page.

Verité Reily-Collins, Polio Survivor and PSN member gave an interesting talk about her activities and Professor Catherine Sackley from Birmingham University gave a talk around the findings of the RESULT Study, which some of you participated in. This study was commissioned by the Department of Health's Policy Research Programme. The Study is written up and currently going through the formal pre-publication process at the Department of Health. As soon as we can we will let you know how to obtain a copy.

I am also pleased to tell you that we are now full members of the European Polio Union (EPU) and looking forward to working with the EPU to raise not only issues of concern but the many positive experiences in the lives of Polio Survivors in Europe. Although we cannot afford to send anyone to the conference in Cøpenhagen from 31st August to 2nd September this year, we will be working hard to improve our financial situation so that we can delegate attendance at the next conference. If you would like to go details are available at www.polioconference.com, and is featured once again on page 10 of this copy of Post Polio Matters.

The next Trustees meeting is on 12th October, 2011 and if you have anything to bring to our attention, please do let us know.

On behalf of the Trustees I wish you a good summer, albeit a bit rainy at the moment, fingers crossed for the hazy, lazy days.

Sandra Paget Chairperson
sandra.paget@poliosurvivorsnetwork.org.uk
Tel: 01494 729373
Mob: 0777 294 0905

Get physical.

Physical activity, exercise, moving, whatever we call it, is good for everyone. Some of the health benefits can help to reduce blood pressure, control diabetes, improve heart health and circulation and help to reduce depression. The Department of Health recommends exercising for 30 minutes 5 times per week. For some this is easier said than done. Even so, it is probably worth considering how you can increase your daily physical activity levels.

Two reviews published last year, ('Update on current and emerging treatment options for post polio syndrome by Elisabeth Farbu, at Stavanger University in Norway' and 'Management of post polio syndrome by Henrik Gonzalez and others from Karolinksa Institute of Sweden, published in the Lancet, September 2010) suggested that individually tailored exercise programmes can be beneficial to people with post polio syndrome.

One option you could consider is a consultation with the Clinical and Exercise and Rehabilitation (CLEAR) Unit at Oxford Brookes University, which provides individually tailored exercise programmes. The CLEAR Unit is staffed by qualified exercise and fitness scientists and is part of the Movement Science Research Group at Oxford Brookes.

For those of you living in and around Oxford your GP may be able to refer you but you **can refer yourself.** Those of you living further away **can also self-refer.** The staff will help you create an exercise programme tailored to your needs and wishes to use at your local gym or home.

This is not about getting fit to run the marathon, swim the channel or to become a champion weightlifter ready for the next year's Olympics! It is about learning how to increase your physical activity levels beginning with you and what you do now, what you would like to do and in the context of PPS.

For a consultation you can contact James Bateman at the CLEAR Unit on Tel:- 01865 484293

http://www.brookes.ac.uk/lifesci/clea

Free to download publication. Physical Activity for Neurological Conditions.

http://www.brookes.ac.uk/schools/lifesci/lifepass/

A note from your new Membership Secretary, Gillian Bryan.

Renewing Yearly membership.

In future all renewal notices will be sent separately from the newsletter with a stamped addressed envelope enclosed.

We also receive donations from members usually as an addition to their annual subscription. For all of these we are very grateful.

It is worth pointing out that it costs us just over £1 per member to send renewal reminders and it would help our finances somewhat if as many members as possible paid by standing order. A Standing Order form will be included with your Renewal Reminder if you are able to pay this way.

All emails relating to membership to:- membership@poliosurvivorsnetwork.org.uk

Gillian Bryan, Treasurer and Membership Secretary

Polio Biology XIV
A Review of the current state of knowledge of Post Polio Syndrome
By Professor Eddie Bollenbach

An article was written in Lancet Neurology in 2010 on the management of Post-Polio syndrome. Two of the authors previously published articles on an antibody mixture called IVIg in treating PPS from the Karolinska Institute in Sweden. There were two or three small research studies which showed such treatment relieved some muscle pain due to PPS. The authors suggested the fact that different formulations of IVIg could have been investigated for PPS but as far as I can tell no new work has been done with the IVIg preparations. Indeed, Professor Borg, one of the authors, indicated that there needed to be a screening of antibodies in the mixture to see if one or another formulation was more effective in treating PPS.

I came across the article mentioned above on-line in Lancet Neurology and decided to take a closer look to see what these authors had to say about the state of our knowledge of PPS in 2010. The article comes to us from Danderyd Hospital and the Karolinska Institute. Henrik Gonzalez, as a graduate student of Kristian Borg, at the Karolinska Institute, first introduced the PPS world to the possibility of using IVIg (an antibody mixture) to treat PPS and is now on the staff of Danderyd Hospital. The authors make the case that although the polio vaccine was introduced in the USA and Europe in the mid-50's, infectious polio slowly diminished through the 60's as a result of vaccination programs. That was acute infectious polio. Now the most common motor neuron disease in the United States are the problems survivors of infectious polio are suffering, including the Post-Polio Syndrome.

Post-Polio Syndrome has diagnostic criteria, a major one is the elimination of other causes of progressive weakness: According to the authors the following diagnostic criteria are used:

1. Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neurological examination, and signs of loss of nerve to muscle connections with electromyography.

2. A period of partial or complete functional recovery after acute poliomyelitis, followed by an interval (usually 15 years or more) of stable neurological function.

3. Gradual or sudden onset of progressive and persistent new muscle weakness or abnormal fatigability (decreased endurance), with or without generalised fatigue, muscle atrophy, or muscle and joint pain. (Sudden onset may follow a period of inactivity, or trauma or surgery.) Less commonly, symptoms attributed to post-polio syndrome include new problems with breathing or swallowing.

4. Symptoms persist for at least a year.

5. Exclusion of other neurological, medical, and orthopaedic causes of abnormality.

ALS [Amyotrophic Lateral Sclerosis also known as MND - Motor Neuron Disease] which affects upper motor neurons in the brain, and is fatal, can be distinguished from polio by distinct signs. Other neurological diseases, and toxicity due to drugs or poisons, as in statin muscle damage can also be eliminated from PPS by lab work. It is reported that between 20% and 85% of people who have a history of polio will develop the Post-Polio Syndrome.

There is a distinction made between;- sequelae of polio (no progressive decrease in function but with overuse damage and/or neuromuscular damage from stress and strain) compared to slow or abrupt progressive weakness, with plateaus, due to a loss of nerve end connected to muscle fibers as the loss of nerve fibers outpaces the replacement of them, typically, in PPS.

The cause, or etiology of PPS would be an answer to the question of why end fibers cannot be replaced as fast as they are lost, which occurs in post-polio syndrome after a long stable period. The Lancet article is a comprehensive review of the damaging changes and clinical characteristics of post -polio syndrome, current diagnostic and treatment options, as well as suggestions for future research.

This is a welcome review since such review papers are in our past 20 years of research on PPS but a 2010 paper update to the polio literature helps us know where we stand now. In this overview I will stick to what we know now as a result of the previous studies reviewed in the 2010 paper.

Early studies by several researchers on post-polio syndrome have shown a process of loss of nerve sprouts to muscles and resprouting new connections by other healthier nerve cells nearby. This process is continuous and the healthy sprouting neurons get larger and larger with respect to the muscle fibers they connect to. These "giant motor units" continue to grow until they can no longer provide the needed stimulus to such a large number of muscle fibers. They eventually fail and the result is new weakness in the affected muscles. The reason why this happens to some people but not others is still unclear.

Many researchers have looked at a purely mechanical approach (stressed fibers affected by polio die out over time to be replaced by more sprouts from healthy fibers, which become overburdened and eventually fail). Perry, as early as 1988 suggested this, while Hubbel and Weichers championed this approach. Nevertheless, the authors point out that longitudinal studies have not implicated overuse as the cause of muscle weakness. Indeed, in an unpublished survey done by Marcia Falconer and myself, there was evidence that people who had more exercise prior to PPS seemed protected somewhat and developed PPS a bit later.

A longer time period since acute polio infection is a risk factor for PPS, but again, not all those with polio damage can be classified with PPS at any age, and loss of motor neurons increases with age. So, this loss can be a confounding factor making it difficult for a clinician to pick out true clear cases of PPS.

Persistent viral infection has been suggested as a cause of PPS, and one paper found that mutated polio virus is present in all patients with the post-polio Syndrome, while other papers have not shown this in clear cases of PPS. But, since during polio virus infection the virus mutates frequently, even people who had polio but do not develop the post-polio syndrome should have mutated virus within many of their cells.

Others have looked at immune system explanations including inflammation and antibodies, which weaken overtaxed neurons. Several authors have demonstrated antibodies unique to individuals with PPS that do not appear in people with a history of polio without PPS. These antibodies and inflammatory chemicals of the immune system may instigate an exaggerated immune reaction which would include chemicals like cytokines, interferons, and Tumor Necrosis Factor, (TNF), which can damage nerve tissue and which have all been found in PPS. This could possibly explain why in PPS there is an inability to regenerate nerve connections to muscle. Further, a paper in 2009 showed that in those with PPS there are always small foreign proteins not found in those without PPS. This would explain why there is inflammation in those with PPS.

Clearly, inflammation in the already damaged spinal tissue could tip the balance into PPS. Apparently there is always inflammation and the presence of inflammatory chemicals and processes entwined within the process of PPS.

If nerve inflammation is the cause of PPS there should clearly be a way to treat it with IVIg or drugs which interfere with the inflammatory process. As of today there is no clear approach that will result in the abatement of PPS by these means although a notable handful of people have benefited treatment with antibodies, the majority have not.

Studies with regard to genes within those with PPS have been done with mixed results. There is clearly a need to pursue such studies comparing the genes of those with PPS to those without PPS. As developments in genetic analysis proceeds at a rapid pace such work could show genes which predispose polio survivors to PPS.

Currently there aren't any drug treatments that have shown promise in the arrest of PPS. Amantadine and high dose Prednisone have been ineffective. Pyridostigmine showed a slight improvement in walking with one study but in another study the drug showed no benefit. In contrast to this, the mood stabilizer lamotrigine had promising results on pain, fatigue, and quality of life in a small study of 30

patients (15 controls). More studies are clearly needed with lamotrigine. A larger number of patients will validate the statistical significance which was assessed as positive in this small study. The reference is listed at the end of this article.

At the present time treatment of symptoms is the mainstay of the management of PPS. Appropriate physical activity for appropriate muscles is also used as rehabilitative treatment of PPS.

From the review by Lygren et al it was noted that patients with postpolio syndrome who reported doing regular physical activity had fewer symptoms and a higher level of functioning than those who were not often physically active. No prospective data show that increased physical activity leads to muscle weakness as long as weak muscles are not overused and damaged. Unfortunately we continue with symptoms we can only minimize by lifestyle modifications. Whether something will happen which will change this for us at this time is unknown. Although there is rapid progress in biomedicine and there have been discoveries of chemicals which can spur new growth of neurons and end-fibers, the time, if ever, to an effective treatment with these agents is unknown and fraught with problems and expense. On the other hand many in the community of people with disabilities urge us to do what we can now to manage our lives.

We should do our best to help ourselves and Live! I think this is the best advice for now. I have seen "high profile" individuals who suffered disability orient their entire lives with the hope of a cure on the horizon only to pass away before any cure materialized. I don't believe this is a good posture for us, although hope is always present.

REFERENCES

Lancet Neurol 2010; 9: 634–42 Henrik Gonzalez, Tomas Olsson, Kristian Borg) Gonzalez H, Ottervald J, Nilsson KC, et al. Identification of novel candidate protein biomarkers for the post-polio syndrome - implications for diagnosis, neuro-degeneration and neuro-inflammation. J Proteomics 2009; 71: 670–81)

Farbu E, Gilhus NE, Barnes MP, et al. EFNS guideline on diagnosis and management of postpolio syndrome: report of an EFNS task force. Eur J Neurol 2006; 13: 795–801.

Lygren H, Jones K, Grenstad T, Dreyer V, Farbu E, Rekand T.Perceived disability, fatigue, pain and measured isometric muscle strength in patients with post-polio symptoms. Physiother Res Int 2007; 12: 39 –49.)

On AY, Oncu J, Uludag B, Ertekin C. Effects of lamotrigine on the symptoms and life qualities of patients with post polio syndrome: a randomized, controlled study 2005;20(4):245-51

READ CODES are the current standard clinical terminology system used in Primary Care (by GP's) in the UK

Read codes have traditionally been used to record clinical summary information as they allow some standardisation of the way that information is recorded. They were developed within a framework of disease areas or 'chapters', e.g. surgical, etc. The first character of the code indicates which chapter it is representing: e.g. **F** Nervous system and sense organ disease. There are two major systems in use in the UK at the moment, Version 2 (5 bite) and Version 3

.

APRIL 2011 NEW CODES ISSUED FOR Post-Polio Syndrome

	Version 2	Version 3
Poliomyelitis encephalitis	F 0302	
Late effects of acute poliomyelitis	AE1	
Acute Poliomyelitis	A40	
Polio		Xa97c
Post Polio Syndrome	**F29y1**	**X0002p**

Laughter is the shortest distance
between two people.
Victor Borge

ACRONYMS FOR SENIORS.

BTW - Bring the Wheelchair
BYOT - Bring Your Own Teeth
FWIW - Forgot Where I Was
FYI - Found Your Insulin
GGPBL - Gotta Go, Pacemaker Battery Low
GHA - Got Heartburn Again
HGBM - Had Good Bowel Movement
IMHO - Is My Hearing-Aid On?
LMDO - Laughing My Dentures Out
OMRR - On My Riser Recliner
OMSG - Oh My! Sorry, Gas
ROFL-CGU - Rolling on the Floor Laughing...Can't get Up
WTP - Where's the Prunes
GGLKI - Gotta Go, Laxative Kicking in

Yes the urinal has a fly in it.
Research proved that
if a man saw a fly in the urinal
he would aim at it
and reduce spillage by 80%.
Some makers now
etch a fly into the porcelain.

The National Health Service Proposed Cuts.

The Allergists voted to scratch them, but the
Dermatologists advised not to make any rash moves.
The Gastroenterologists had a sort of a gut feeling about it, but the
Neurologists thought the Administration had a lot of nerve.
The Obstetricians felt they were all labouring under a misconception and
Opthalmologsts considered the ideas short sighted.
Pathologists yelled, "Over my dead body!" while the Paediatricians said, "Oh, Grow up!"
The Psychiatrists thought the whole idea was madness, while the
Radiologists could see right through it.
The Surgeons were fed up with the cuts and decided to wash their hands of the whole thing.
The ENT specialists didn't swallow it, and just wouldn't hear of it..
The Pharmacologists thought it was a bitter pill to swallow, and the
Plastic Surgeons said, "This puts a whole new face on the matter...."
The Podiatrists thought it was a step forward, but the
Urologists were Pi***d off at the whole idea.
The Anaesthetists thought the whole idea was a gas, but the
Cardiologists didn't have the heart to say "No!"
In the end, the Proctologists won out, leaving the entire decision up to the A******es in London.

Post Polio Syndrome - a challenge of today
European Conference, Copenhagen, Denmark, August 31st to September 2nd, 2011
European Polio Union [EPU} and the Danish Society of Polio and Accident Victims [PTU]

AIM
The European Polio Union wishes with this conference:

- To give medical and social professionals a possibility to exchange new research results and to debate relevant topics on a professional level
- To give polio survivors a possibility to achieve and exchange new knowledge on assessment, treatment and coping
- To achieve awareness on post-polio issues in the health sector and social services

Congress language will be English. Online registration.**www.polioconference.com**

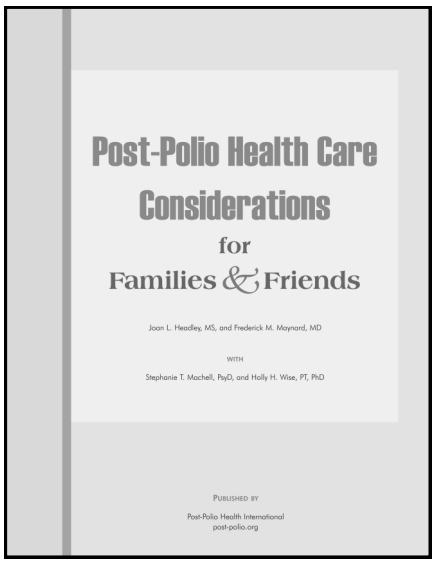
REGISTRATION FEE

	After April 1st 2011
Professionals	3500 DKK / 470 Euro
Polio Survivors	950 DKK / 260 Euro [£220.13]

Registration fee includes participation of the sessions and catering during the conference & free admission for the Welcome reception. Conference Dinner must be paid separately.

VENUE
Hotel Crowne Plaza Copenhagen Towers
Ørestads Boulevard 114—188
DK 2300 København S, Denmark
+45 88 77 66 55
www.cpcopenhagentowers.dk [rooms from £104 a night]

CONFERENCE SECRETARIAT
Merete Bertelsen
PTU, Fjeldhammervej 8
2610 Rødovre, Denmark
+45 3673 9044
mbe@ptu.dk



Booklet Featured in April 2011 Post Polio Matters.

Post-Polio Health Care Considerations For Families & Friends

Joan L. Headley, MS - Post-Polio Health International, St. Louis, Missouri
Frederick M. Maynard, MD - Physical Medicine and Rehabilitation, Marquette, Michigan
With
Stephanie T. Machell, PsyD - International Rehabilitation Center for Polio, Framingham, Massachusetts
Holly H. Wise, PT, PhD, Associate Professor, Division of Physical Therapy, College of Health Professions, Medical University of South Carolina, Charleston, South Carolina

PUBLISHED BY Post-Polio Health International www.post-polio.org

An interactive copy is available on the Internet.

Anyone who would like a printed copy of this document please get in touch before the end of August when we will be ordering from PHI. Cost £7.50 inc. post and packing.

Three pictures and a few words can tell the Post Polio Story.

.1952 - Waist down paralytic polio age 5.
1953 - Hiding thin left leg
1969 - Policewoman 1969 to 1973
1987 - Working 60+ hours a week.
1988 - Slipped on wet floor, new problems for seven years with nothing found.
1995 - I said. 'I had polio as a child' and at last my prior polio is in the equation.
1997 - Second hospital and opinion and diagnosed with PPS.

WE'RE STILL HERE

2011 POLIO-WORLD POSTER COMPETITION

Organiser Micki Minner.

You are invited to send us photographs to show your individual history of Polio.

We are looking for three photos:

the first showing Polio,

the second depicting Living with Polio

and the third Adapting to Post-polio.

We will use the photographs to create an awareness of Post-polio and to show the world that WE'RE STILL HERE!.

PLEASE ENTER AND

send your submission to Mickiminner@msn.com

Three photos and with a description of 50 words of less.

Please put Polio-World in the subject line, your description in the email and attach your photographs.

You can design the whole poster yourself if you wish.

Deadline is September 1st 2011.

Create your own smiley at www.smileycreator.com

GASTROINTESTINAL INVOLVEMENT IN THE POST-POLIO SYNDROME (PPS)

Sinn Anuras, M.D.

A LINCOLNSHIRE POST POLIO LIBRARY ARTICLE

www.poliosurvivorsnetwork.org.uk/archive/Lincolnshire/library/usa/gi.html

This study has not been published by a peer-reviewed Journal -- or on the Internet until now, except for America Online. Tom Walter put together this article from talks the Dr. gave about it in the early '90's, plus feedback he gave to some local participants.

BACKGROUND - During the late 1980's to early 1990's, Dr. Anuras was Director, Division of Gastroenterology, Department of Internal Medicine at Texas Tech University in Lubbock. Along with Terri Bozeman, R.N., they surveyed over 750 post-polio patients regarding their gastrointestinal symptoms. Following report is from a paper they delivered at The Second Texas-Oklahoma Post-Polio Symposium, September 21-22, 1991, at the Ramada Inn of Wichita Falls, TX. (To that point, they had included 500 patients in the results; Table 3 below has been updated to reflect the symptoms of the first 754 participants in the study.)

ABSTRACT - Gastrointestinal involvement is common in the post-polio syndrome, and it appears to affect the entire gastrointestinal tract. Unfortunately, there are only a few studies in this fascinating area. More extensive studies are needed to understand the pathologic and pathophysiologic processes in this problem, so that patients can be treated properly.

We report our survey of gastrointestinal symptoms that could affect up to 50 per cent of the post-polio syndrome patients in this review. We also propose the underlying pathophysiologic changes, outline the diagnosis and treatment for difficulties of various parts of the gastrointestinal tract.

INTRODUCTION - Normal gastrointestinal motility is a function of the gastrointestinal smooth muscle and is regulated by both the intrinsic (myenteric plexus) and extrinsic nerves of the gastrointestinal tracts. Extrinsic nerves from the central nervous system (brain and spinal cord) connect the enteric nervous system (submucosal plexus and myenteric plexus) with the central nervous system. Therefore, any functional or structural abnormality of either the smooth muscles or the intrinsic or extrinsic nerves will result in gastrointestinal dysmotility causing gastrointestinal symptoms.

The symptoms produced depend on areas of involvement. This abnormality may either involve the entire gastrointestinal tract or be limited only to certain parts depending on the underlying disease. Table 1 lists various causes of neuromuscular disease of the gastrointestinal tract that can cause gastrointestinal dysmotility by extrinsic denervation to certain parts of the gastrointestinal tract.

TABLE 1 - CAUSES OF NEUROMUSCULAR DISEASE OF THE GASTROINTESTINAL TRACT [excluded purely to save space - see full article online]

Results from our survey suggest that PPS may also cause damage to the intrinsic nerve (myenteric plexus) of the gastrointestinal tract. Future physiologic and pathologic studies of the gastrointestinal tract in PPS will elucidate these abnormalities.

Symptoms produced by gastrointestinal dysmotility are variable depending on the part of the gastrointestinal tract involved. Table 2 lists symptoms produced by dysmotility of certain parts of the gastrointestinal tract. We can see that there are a variety of symptoms that can be caused by gastrointestinal dysmotility. Thus, patients with the same disease may have different complaints

that may appear to be unrelated. Patients with PPS may have difficulty with swallowing and constipation, and both symptoms can be caused by PPS.

TABLE 2 - SYMPTOMS PRODUCED BY DYSMOTILITY OF VARIOUS PARTS OF THE GASTROINTESTINAL TRACT

	ORGANS	SYMPTOMS
1	Oropharynx	Difficulty initiating swallows, food pooling in the pharynx, choking when swallowing, aspiration and aspirated pneumonia in severe cases
2	Esophagus	Difficult swallowing (dysphagia), food sticking in the mid sternum area, occasional substernal pain with swallows (odynophagia)
3	Stomach	Nausea, vomiting, abdominal fullness long after meal, recurrent symptoms of stomach outlet obstruction (gastroparesis)
4	Small intestine	Abdominal pain and bloating after a meal, nausea, vomiting, diarrhea, recurrent symptoms of small bowel obstruction in severe cases (intestinal pseudoobstruction)
5	Colon	Constipation, abdominal pain and bloating, recurrent symptoms of colonic obstruction in severe cases (colonic pseudoobstruction)
6	Anus	Constipation

GASTROINTESTINAL INVOLVEMENT IN PPS - There are only a few studies of gastrointestinal involvement in polio survivors, and all are limited to oropharyngeal dysphagia. Gastrointestinal involvement has been virtually neglected by physicians who take care of PPS patients. We surveyed the nature and incidence of gastrointestinal symptoms in PPS patients by sending out questionnaires to 3,000 PPS patients.

Table 3 lists the symptoms that we analyzed from the first 754 PPS patients who responded to our survey.

TABLE 3 - GASTROINTESTINAL SYMPTOMS OF 754 PATIENTS

Incidence	Symptoms	Organs Involved
24%	Difficulty initiating swallow	Oropharynx
32%	Choking with swallowing	
32%	Difficulty swallowing (dysphagia)	Esophagus
51%	Heartburn	
28%	Nausea	Stomach, Small Intestine
12%	Vomiting	
53%	Abdominal bloating	Stomach, Small Intestine, Colon
40%	Abdominal pain	Small Intestine, Colon
32%	Diarrhea	
48%	Constipation	Colon, Anorectum
0.7%	Intestinal pseudoobstruction	Small Intestine.

The results from our survey suggested that gastrointestinal symptoms are common and extensive in PPS patients. These gastrointestinal symptoms may be caused by extensive gastrointestinal dysmotility from the oropharynx to the colon. To understand the pathophysiology and pathology, we need to study the motility and histology of the esophagus, stomach, small intestine and the colon of PPS patients. Full thickness biopsies of bowel wall from surgical or

autopsy specimens will enable us to examine the neuromuscular apparatus of the gastrointestinal tract in these patients.

DIAGNOSTIC WORK-UPS FOR GASTROINTESTINAL SYMPTOMS IN PPS PATIENTS

Since our survey showed extensive involvement of the gastrointestinal symptoms, the diagnostic work-ups must be directed to the patients' complaints (see Table 3 next page). Table 4 next page lists the work-ups for various parts of the gastrointestinal tract.

TABLE 4 - DIAGNOSTIC WORK-UPS FOR GASTROINTESTINAL ORGANS IN PPS PATIENTS

ORGANS	DIAGNOSTIC TESTS	
Oropharynx	(1) Video esophagram	(2) Upper esophageal sphincter manometry
Esophagus	(1) Barium esophagram	(2) Esophageal manometry
Stomach	(1) Upper gastrointestinal x-rays	(2) Radionucline gastric emptying study
Small Intestine	(1) Plain abdominal x-rays	(2) small bowel x-rays (3) small intestinal manometry
Colon	(1) Plain abdominal x-rays	(2) Barium enema (3) Radio-opaque manometry
Anus	(1) Anorectal manometric study	

If the complaints are oropharyngeal symptoms, video or cine-esophagram is useful to evaluate the swallowing mechanism of the patients. The abnormalities include unilateral bolus transport through the pharynx, pooling in the valleculae or pyriform sinuses, delayed pharyngeal contraction, and impaired tongue movements. Upper esophageal sphincter manometry may show incoordination between upper esophageal sphincter relaxation and pharyngeal contraction during swallowing.

Work-up for esophageal dysmotility includes barium esophagram and esophageal manometric study. Barium esophagram will rule out esophageal obstruction as a cause of dysphagia, and it will enable us to evaluate the diameter of the esophagus, gastroesophageal reflux and contractile activities of the esophagus. Esophageal manometric study will detect any motility disorder of the esophagus. The standard esophageal manometric technique uses low compliance water perfusion system through an esophageal manometric tube.

To evaluate gastric dysmotility, we obtain upper gastrointestinal (UGI) x-rays and radionuclide gastric emptying study. UGI x-rays will enable us to detect any ulcer or outlet obstruction that may mimic gastric dysmotility. Radionuclide gastric emptying study using technetium-labelled scrambled egg will quantitate the emptying function of the stomach. In normal subjects, half of the solid contents will empty from the stomach in 45-90 minutes. If there is a delay in gastric emptying, it will take longer than 90 minutes for half of the solid contents to empty from the stomach. Radionuclide gastric emptying study is an excellent objective method to measure the stomach emptying function.

Abdominal bloating and distention may develop in patients with intestinal and colonic dysmotility. Plain abdominal x-rays are useful to detect gaseous distention of the dysfunctional organs. The patients may have ileus of the small intestine or colon due to severe dysmotility causing symptoms and signs of bowel obstruction without any evidence of mechanical obstruction. (It is called intestinal pseudoobstruction or colonic pseudoobstruction depending on the organ involved.)

Small intestinal dysmotility can be evaluated by small bowel x-rays and small intestinal manometric study. Small bowel x-rays enable us to rule out organic disease, to evaluate the size and contractility of the small bowel, and to measure the barium transit time of the small bowel.

Small intestinal manometric study will detect any abnormal motility of the small intestine. During fasting, the small intestine has a unique pattern of motility called migrating motor complex (MMC).

MMC has three phases. Phase 1 is a quiescent period lasting for 10-15 minutes. It is followed by phase 2 which shows intermittent contractions that last for 60-90 minutes. The contractions will intensify with time and will reach phase 3 when the small intestine contracts intensely at approximately 11-13 times per minute. Phase 3 lasts for 5-8 minutes, and the small intestine becomes quiescent again, i.e., it returns to phase 1.

This cyclical motor activity will go on until the subjects are fed. After feeding, the subjects will have fed activity which resembles active phase 2. The fed activity does not have any cyclical motor activities. Fed activity usually lasts for 4-5 hours and the small intestine will return to fast pattern after that. Any small intestinal dysmotility will cause alteration of the above activities. Small intestinal manometry is very sensitive to detect abnormality in patients with small bowel dysmotility.

To evaluate colonic dysmotility, we use barium enema, radio-opaque markers study and colonic manometric study. Barium enema will enable us to rule out any organic lesion and to evaluate the size and length of the colon. Radio-opaque markers study will determine if colonic dysmotility is caused by colonic inertia or functional colonic outlet obstruction. Colonic manometric study will detect colonic dysmotility.

Function of the anorectal area can be evaluated by anorectal manometry. In normal subjects, the internal anal sphincter relaxes when the rectum is distended. If the patients lose this reflex, they will have constipation.

As we can see from the above discussion, there are specific diagnostic work-ups for certain parts of the gastrointestinal tract. A careful history will direct us to study the appropriate organs. From the survey, it appears that gastrointestinal dysmotility in PPS patients can affect the entire gastrointestinal tract. Therefore, taking a good history from the patients is important to direct us to give appropriate diagnostic work-ups.

TREATMENT - Treatment must be directed to the patients' problems. We will discuss the treatment of dysmotility of each organ separately.

(1) oropharyngeal dysmotility.

The most serious complication of oropharyngeal dysmotility is aspiration during swallowing. The treatment must focus on the prevention of aspiration that may lead to aspiration pneumonia. Pharmacologic treatment has not been very effective. In patients who are less symptomatic, taking the time to eat or drink will reduce the incidence and severity of choking and aspiration. Dilatation of the cricopharyngeus muscle with bougies can be tried in more symptomatic patients. However, the effectiveness of the dilatation is not proven. It might be worthwhile to try before embarking on more invasive therapy.

In patients who have severe aspiration and recurrent aspiration pneumonia, cricopharyngeal myotomy should be considered. The technique involves sectioning the fibers of the cricopharygeus down to the submucosa; and it can even be done under local anesthesia in poor-risk patients. Two-thirds of the patients operated upon have been relieved of dysphagia. There are a small number of patients who develop massive aspiration after cricopharyngeal myotomy. We strongly believe that any patients who undergo cricopharyngeal myotomy require esophageal manometric study and gastric emptying study.

Esophageal manometric study will allow us to evaluate the competency of the lower esophageal sphincter; the competency will help to prevent gastroesophageal reflux. Gastric emptying study will allow us to detect any delay in gastric emptying that may promote gastroesophageal reflux

and aspiration. Abnormality of any of these two tests may exclude the patients from having cricopharyngeal myotomy.

(2) Esophageal dysmotility.

The treatment for dysphagia due to abnormal motility has not been effective. Calcium channel blockers (such as nifedipine), nitroglycerine and balloon dilatation of the lower esophageal sphincter may be useful in some patients with diffuse esophageal spasm due to intrinsic nerve dysfunction of the esophagus. At least half of the patients with diffuse esophageal spasm do not respond to the above regimens.

In patients with gastroesophageal reflux and heartburn, antireflux regimen must be used to prevent complications of reflux esophagitis and stricture formation. We give a dose of H2 receptor antagonists such as Tagamet, Zantac, or Pepcid before bedtime, and elevate the head of the bed approximately 6 inches.

(3) Gastric dysmotility.

Delayed gastric emptying usually occurs with gastric dysmotility. Metoclopramide has been used to treat this problem with variable results. A liquid and low fat meal empties faster from the stomach than a solid meal. Therefore, we advise the patients to take a low fat and liquid meal. Feeding formula such as Ensure, Vivonex, Isocal and so on can be used to supplement the calories.

A new prokinetic drug, cisapride, is being studied for delayed gastric emptying. Early results are encouraging. When this drug is available in the market, it will be useful for this group of patients.

(4) Small intestinal dysmotility.

Small intestinal dysmotility may cause postprandial (after eating) abdominal pain and bloating. In severe cases, the patients may have intestinal obstructive symptoms and signs. There has been no effective prokinetic drug available yet for this problem. An ideal prokinetic drug should either enhance the contraction of a damaged muscle or normalize the coordination of a damaged myenteric plexus. No drug has, as yet, lived up to this expectation.

The symptoms in most patients occur intermittently, and only a small number of patients may have persistent symptoms. Since the symptoms are directly related to meals, manipulating the amount, the nature and the frequency of meals may help some patients. The patients should consume 25 calories/kg of ideal body weight per day divided into 3-4 equal amounts. Half of the calories may come from feeding formulas. The patients must avoid carbonated beverages to prevent adding excessive gas in the digestive tract.

Occasionally, nasogastric suction and intravenous fluid are needed when the patients have intestinal obstructive symptoms. When the obstructive symptoms are persistent or occur several times a week, a long term parenteral nutrition is the only treatment that will improve the patient's symptoms and nutritional status.

(5) Colonic dysmotility.

The most common complaint is chronic constipation. The patients must avoid using stimulant laxatives such as Senokot, Dulcolax, etc., on a long term basis because most of the stimulant laxatives can damage the myenteric plexus when using them long term. This effect will further compound the difficulty that the patient already has.

We usually try the patients on high fiber diets or fiber compounds such as Fibercon or Metamucil. More than half of the patients will respond to these regimens. If the patients do not respond to fiber, we next try to use saline laxatives such as milk of magnesia. We titrate the dose of milk of magnesia to obtain one bowel movement a day. In early stages, it is not uncommon to use milk of magnesia up to two ounces per day. Later on, we are usually able to maintain the patients on one tablespoon daily. Tap water enema can

be used if the patients have no bowel movement for three days while on fiber or milk of magnesia.

In patients with obstipation despite adequate dose of fibers or milk of magnesia, an ileostomy or subtotal colectomy with ileoproctostomy may be required to take care of the problem. We encounter very few patients with colonic dysmotility with severe obstipation that require such a drastic approach.

(6) Anorectal dysfunction.

At the present time, we are not certain if PPS patients have any anorectal dysfunction. Anorectal manometric study in these patients will enable us to better understand the anorectal function in this group of patients. The medical treatment of anorectal dysfunction is disappointing. Surgical treatment such as rectal myectomy may be beneficial to some patients with anorectal dysfuntion.

LPP Library article created 7th February 1997. Last modification 31st January 2010.

NEW BOOK A Rough Road by Patrick J Bird.

After contracting polio at age four in 1940, Paddy spends nineteen months in a "reconstruction home" far from his family. This is his story of that time, presented mainly from the child's point of view.

Enduring aching sadness and loneliness along with the pain and disappointments of rehabilitation, Paddy learns to prevail physically and emotionally through his interactions with a colorful cast of hospital staff—from a friendly giant orderly and a light hearted nurse to a no-nonsense physical therapist and an evangelical swimming instructor as well as an imposing and frightening physician and his unsympathetic nurse.

Perhaps most important to his "reconstruction," however, is the arrival of roommate Joey. An older, adventure loving youngster with spina bifida, Joey introduces Paddy to the joys and tomfoolery of boyhood and inspires him with his physical and mental toughness. Then there are the infrequent - but significant - visits of Paddy's mom, who is sure the Blessed Virgin will cure him, and his Pop, who fears in his heart that he will have a *cripple* for a son.

Also woven gently into the fabric of this deeply personal story are relevant aspects of the polio experience during the early 1940's including the painful immobilization in casts, the dreaded iron lung, the often unwise corrective surgery, and the stigma (feeble and likely retarded as well) associated with survivors - even President Roosevelt, for instance, stricken with polio in 1921, went to great lengths to hide his atrophied legs from the public.

A Rough Road is a testament to the capability of children to overcome the most difficult of times. It is a walk down memory lane for some, a lesson in history for others, and a moving experience for all.

ISBN-13: 9781452892955 $10.45 Trade Paperback

For sale at Amazon.com, Kindle eBooks, book stores & through other channels.

pbird@ufl.edu

Member Guido D'Isidoro recommends good travel website for the disabled.

Guido recommends us to have a look at the website, put together by Sean Gorman who has Multiple Sclerosis and is deteriorating, as it might be of interest to members.

Planning a trip, a holiday, or a day out? Come to Disabled Travel Guide first. Our travel community share reviews and information describing their best and worst experiences, so you can decide where to go and what to avoid. Hotels, locations, music venues, walks. It's all here on Disabled Travel Guide. Join our community, leave a review, and share your own expert information. The short video on the right explains where to start, and how to get the most out of our site
www.disabledtravelguide.co.uk/

Glycemic Load diet helped me lose weight then STRESS and CHOCOLATE snuck in.

Three requests for more information on the diet I started in 2009 in the last two weeks.

In 2009 I was told I had Type 2 diabetes, a huge shock! I remembered polio survivor Derek Paice article in a LincPIN on glycemic index and dieting and did some research. I found the Patrick Holford Low Glycemic Load [GL] Diet Bible which advised a weight loss meal plan of 40GL units per day. Three 10 GL meals and 2 x 5GL's for snacks. There were some ideas of meals and a few pages of charts of food groups. What excited me was the choice and taking fruit you could have one date, ten raisins or 600 grams of berries for the same 5GL unit amount. Berries here I come, the thought of not having to eat like a bird was great. We looked at what we ate and swapped the high GL foods for low ones and we were still eating food we liked. I did not expect to lose weight as easily as I did because living with PPS leaves Richard and I with little energy for exercise other than a few stretches. I reported in the June 2009 LincPIN that I had lost 48 lbs in three months and my blood sugar and cholesterol levels were now normal. I then started to add the odd treat and the weight loss slowed but I did very well for a year.

In the spring of 2010 Richards assessment for the new Personal Budget was started and it took eight months to get through the whole procedure. Eight months of STRESS where I would go looking for highs and bought CHOCOLATE AND GOOEY CAKES. I realise now that knowing this was making me gain weight I stopped weighing myself once a week.

On 12th July I looked in the mirror, winced and made the decision to stop being stupid and cut out the high GI stuff and weigh myself. I went back to eating 40GL units of food per day and today am 15 lbs lighter. I am eating a balanced diet with a reasonable plateful of food. I don't feel hungry between meals anymore.

To make up a 10GL meal you need a glycemic load index book and pick food items from that to end up with a balanced plateful protein, carbohydrate, vegetables, milk products. Here are just a few items at 5GL that show the lower the GL amount the more you can eat.

CEREALS 5GL units	DAIRY PRODUCTS 5 GL units	FRUIT 5 GL Units
7g of cornflakes	90 ml rice milk	7g One date
9g of puffed wheat	250ml full fat milk	19g One fig
11g of Special K™	**400ml semi skimmed milk**	75g Ten grapes
12g one Weetabix ™	100g low fruit yogurt	120g One orange
25g All Bran ™	150g soya yogurt	200g cherries
75g porridge oats	**333g plain yogurt**	**600g berries - 450g to the lb**!

Breakfast for me is a sachet of porridge with 200ml low fat milk, a level teaspoon of cinnamon because that helps lower cholesterol, a large helping of berries and a low cholesterol drink on top. Plus a Fat Free Actimel in a pint of water. Richard adds an egg to this because he needs the added protein.

Lunch is a medium portion of chicken, turkey, ham, egg or cottage cheese, good portion of salad items and a toasted slice of brown soya bread and some light mayonnaise [love the mustard one and just found a herb one in Lidl]

Evening meal is lean meat, salad or stir fry vegetables micro waved not fried, and a small sweet potato, or a small portion of brown rice or pasta. Pud is a low fat yogurt and more lovely berries.

- 28g portion of cornflakes and 200ml full fat milk **24GL**
- 25g sachet of porridge oats and 200ml skimmed milk and 300g of berries **6GL**. .

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]
Chair - Sandra Paget - sandra.paget@poliosurvivorsnetwork.org.uk
Secretary - **Hilary Boone** - hilary.boone@poliosurvivorsnetwork.org.uk
Treasurer - **Gillian Bryan** - gillian.bryan@poliosurvivorsnetwork.org.uk
Glenna Tomlin - Glenna.tomlin@poliosurvivorsnetwork.org.uk

Operations Team
Membership Secretary - Gillian Bryan - membership@poliosurvivorsnetwork.org.uk
Phone and Email Enquiries - Hilary Boone **-** info@poliosurvivorsnetwork.org.uk -
Administrative Support - Gillian Bryan - gillian.bryan@poliosurvivorsnetwork.org.uk
Website Administration - Dave Eate - webadmin@poliosurvivorsnetwork.org.uk

[Please contact us if you would like to help with our work]

Membership

Full membership includes voting rights and is available to polio survivors, their partners, families and friends.

Associate membership, no voting rights**,** is available to patient organisations, health and social care professionals working in the interests of polio survivors

Friend/Supporter. If you would like to support the Polio Survivors Network you can do so by making a yearly donation of your choice.
You will receive a yearly update of our activities and be invited to our AGM.

Membership Fees

Individual - £ 12.50 per year
Life membership - £ 150.00 or pay by Standing Order £ 5.00 x 30 mo.
Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

We welcome members living in other countries and details will be sent upon request.
Please note the majority of information will be sent via the Internet.
Email:- membership@poliosurvivorsnetwork.org.uk

All Forms are available on our Website, by phoning our helpline or writing to us.

Donations

giftaid it

Donations, small or large, towards our work will always be gratefully received.

NEW

Val Scrivener is supporting us by making photo greetings cards for you to purchase

- Some members send us a few postage stamps
- Some members take their newsletter via the internet saving us printing and posting costs.
- Others add a donation amount to their yearly cheque, or Standing Order amount.
- UK Taxpayers can Gift Aid their subscription and donated amounts.

The Gift Aid scheme. Charities can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. Between 6 April 2008 and 5 April 2011, the government will also give UK charities an extra 3% of all eligible donations. This 'transitional relief' does not affect your personal tax position. You must pay tax at least equal to the amount reclaimed on your donations in the current tax year.

If you pay tax at the higher rate, you can reclaim tax relief on your gross donation at 20% (i.e. the difference between the higher rate of tax at 40% and the basic rate at 20%).

Polio Survivors Network

what we have what we are what we do

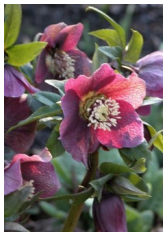
Registered Charity No. 1064177

Website - www.poliosurvivorsnetwork.org.uk

Email - info@poliosurvivorsnetwork.org.uk

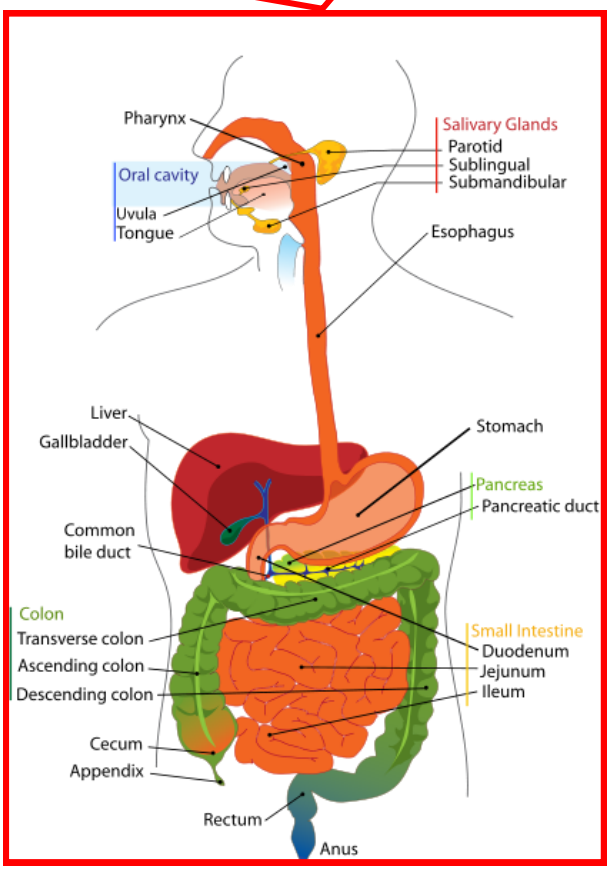
P.O. Box 954, Lincoln, LN5 5ER, U.K. ☎ 01522 888601

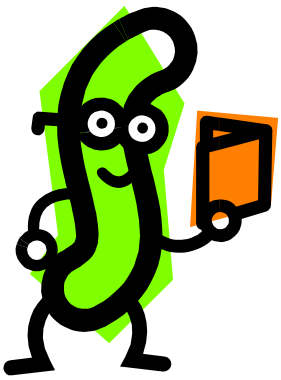
POST POLIO MATTERS because **WE'RE STILL HERE!**

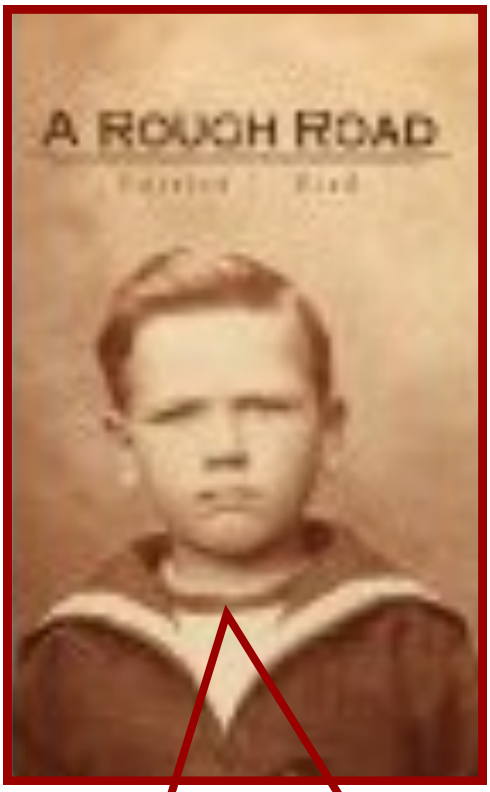


Gastrointestinal issues for Polio Survivors

Page 12 to 17







After contracting polio at age four in 1940, Paddy spends nineteen months….

Info on new book Page 16.