



# POST - POLIO NETWORK (NSW) INC.

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## NEWSLETTER

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### Editor's Corner

This issue contains a lot of information on our first International Post-Polio Conference, *Living with the Late Effects of Polio*, to be held in New South Wales. For many of us it is the first opportunity to attend an international Conference about polio right on our doorstep. We are anticipating that the Conference will be a great success and hope that many people will be able to attend, if not for the whole week-end, then at least for part of it. If you can only make it to one polio seminar this year, make it this one.

On page 6 our hard-working Conference Co-ordinator, Jean Skuse, gives the answers to some commonly asked questions about transport to and from the Conference venue, and about the accommodation facilities. If after reading her article you still have any questions in this regard, please don't hesitate to give Jean a ring on (02) 810 7864. What she can't answer immediately will be passed onto the planning committee.

On pages 7 to 10 you will find details of the draft program. Speakers and topics are being rapidly finalised and the program is taking on its final form. Wherever possible brief details of the content of the sessions are given to whet your appetite. This information will be updated progressively and further reports given in the remaining Newsletters leading up to the Conference.

Registration Forms for the Conference were sent out to all members with their last Newsletter (Issue 27). Please return your Registration Form as soon as possible. We must have a very clear idea by 28 June 1996 of the numbers attending, to secure the venue. If you have misplaced your Registration Form, or want extra copies to distribute to people who you think would like to attend, please contact Jean as above, or Nola on (02) 636 6515.

On the fund-raising side, we have been very fortunate and extremely grateful to secure a one-off grant from the New South Wales Ageing and Disability Department towards the cost of staging the Conference. In her letter granting the funds, the Director-General of the Department, Jane Woodruff, wrote "I have taken the opportunity to look at the material you sent on the Conference and in particular about the Network and its achievements. I feel that this is a most worthwhile initiative. ... I wish you every success with the Conference".

We will shortly be organising a large fund-raising raffle with exciting prizes, to be drawn at the Conference. We hope all members will assist in making the raffle a success by selling tickets. Further details will be provided soon.

Our **Annual General Meeting, Conference Update, and Seminar on Pain Management** will be held on **Saturday 1 June 1996** at the Independent Living Centre in Ryde, commencing at **11:00 am**. Full details are given on page 2. Please be there if you can. We need your support to ensure the Network continues to grow. Please also give some thought to standing for the Management Committee. Some members are standing down this year and it is important that we get a full Committee to spread the workload of organising the Conference.

# *Annual General Meeting*

**Date:** Saturday, 1 June 1996  
**Time:** 11:00 am - 12:00 pm  
**Agenda:** As previously circulated  
**Venue:** The Independent Living Centre  
600 Victoria Road, Ryde

Parking is available on the premises. It would be appreciated if those who are more mobile would leave the closer parking for members who are only able to walk or wheel short distances.

**Lunch:** Bring a packed lunch to eat from 12:00 pm.  
As usual, fruit juice, tea and coffee will be provided.

At **12:30 pm** **Jean Skuse, Conference Co-ordinator**, will give an update on preparations for the Conference and answer any questions you might have.

## *Seminar : Pain Management*

The seminar will feature two viewpoints on pain management. First, we will hear from a PPN member who experiences pain related to the late effects of polio and find out how he controls and manages it. We will then hear from a professional in the field.

Commencing at **1:00 pm**, Blacktown Support Group convenor **Bernie O'Grady** will speak of his experiences in the search to find a way to manage his pain. He will tell us about the facilities at the Royal North Shore Pain Clinic and about the practical advice and assistance the Clinic provides.

At **2:00 pm** we will hear from **Joy Lyneham**. Joy has undertaken study at the Pain Research Institute, London. She currently lectures at Mitchell University in Bathurst. After speaking of her work in the field, Joy will be happy to talk to specific problems that people have.

There will be time for a question and answer session after the speakers finish.

As usual, afternoon tea will follow. We hope you will be able to stay and catch up with friends. If this is the first seminar you have attended, please introduce yourself to a Committee member.



# Rehabilitation Services in NSW for Post-Polios

## Merle Thompson (Management Committee)

During last year the Committee was concerned that many Network members in non-metropolitan areas could not readily attend the Post Polio Clinic at Prince Henry Hospital and/or were unaware of services within their own areas for assessment or ongoing assistance. I was asked to contact the Department of Health to ascertain what services are available in country areas for our members.

The reply from the Department indicated that there was no centralised information on specific services offered in various areas. I was sent three documents:

- ***1995-1999 Disability Plan for the NSW Health System***

This sets out the policy framework and aims for services for people with a disability in NSW. It has been provided to the NSW Office on Disability in accordance with NSW Government requirements for departments to prepare disability service plans and will be filed with HREOC in accordance with the federal Disability Discrimination Act.

One activity undertaken in accordance with the plan has been the development of guidelines for the preparation of disability service plans within area and district health services.

- ***A Policy Framework for Medical Rehabilitation in NSW***

This paper was prepared "in recognition of the need to improve planning for the provision of medical rehabilitation services in NSW and to provide guidelines on the delivery of those services". It "directs Area and District Health Services to develop a written plan for the provision of rehabilitation services to meet the needs of the community".

- ***A list of the Area and District Health Services in NSW***

It was recommended that I contact each Area and District Health Service for information on their services. The following are extracts from my letter which was sent to each Area and District Health Service.

"The members of this organisation have all suffered from poliomyelitis. Most experience considerable difficulties from the effects of the original illness and its resultant paralysis. Many also experience the late effects which can develop at a much later stage, possibly even decades after the original illness."

"Rehabilitation services can be of great benefit in the management of the varied disabilities which members have. The only specialised service for those with post-polio disabilities is at the Prince Henry hospital for which there is an extensive waiting list and on-going treatment is not generally possible. It is predominantly an assessment service. This service is not available to those members who are in country areas or suburban areas without ready access to Prince Henry and all members would benefit from access to on-going rehabilitation services."

"The complex nature of the problems mean that it is often necessary for people to consult with rehabilitation, orthopaedic and respiratory specialists, physiotherapists, occupational therapists, orthotists and podiatrists without any co-ordinated service and frequently they see only one of these people because of the difficulties in having multiple referrals and conflicting advice."

There were 10 Area Health Services listed. Two have since been amalgamated. These are all in the Sydney/Newcastle/Wollongong area. A response was received from 8 of the 9 Areas.

There are 23 District Health Services for the remainder of NSW. To date responses have been received from 16 of these.

Several have indicated that they will provide me with a copy of their Rehabilitation Plan when it is prepared and some have said that they would like to consult us in the development of their plan. We have responded to these requests as a Committee and, where appropriate, put them in touch with Support Groups in their areas.

A copy of the relevant response has been sent to each Support Group convener to enable the convener to inform their members of the services in their area, and to enable the convener to make contact for consultation purposes.

A summary of the information provided by each area/district will given in the next Newsletter. Unfortunately space does not permit its inclusion this issue. In the meantime, members are welcome to contact me for further details, by writing to PO Box 38, Woodford 2778 or by phone or facsimile to (047) 58 6637.

## Poet's Corner

*Member Gary Buchanan, Revesby, NSW, writes:*

*After suffering the after effects of polio for the past 45 years I was able to understand the difficulty and trauma suffered by Debbie, a close neighbour of mine, when she was diagnosed as having MS a few months ago.*

*One of the things I did to try and cheer her up was to write a little poem which she keeps stuck to the fridge door.*

*I thought you may like to include the poem as it does refer to both MS and polio.*

### HEROES OF ANNE STREET

Polio and MS are neighbours in our street  
Two greater living legends you'd never wish to meet

They conquer pain their enemy  
Though not an easy feat  
For one is helpless in the cold  
The other in the heat

One sometimes finds it hard to walk  
The other hard to see  
But two with greater courage  
There is as yet to be

But sometimes sadly in the night  
Behind closed doors it's said  
One curses all his handicaps  
One softly cries in bed

These downers though they never last  
And after each we're told  
Their strength and sense of humour  
Increases by twofold

So when they rise and take a stand  
We know they can't be beat  
No pain will ever conquer  
The Heroes of Anne Street

# WHEN A POST-POLIO PATIENT HAS ANESTHESIA

*This article was prepared for the North Central Florida Post-Polio Support Group by **Selma Calmes, MD, Chief of Anesthesiology at Olive View-UCLA Medical Center, California.** Dr Calmes is a polio survivor with PPS. The article is reproduced here with thanks to "Polio Post News", Florida, September 1995.*

There are three types of anesthesia: **general anesthesia** (being put completely to sleep, usually used for major operations), **regional anesthesia** (the part of the body where surgery will take place is made "numb" by injecting local anesthesia in various places; this can not be used for some operations. "Spinal" is a common regional anesthesia), and **monitored anesthesia care (MAC)** in which the anesthesiologist gives intravenous (IV) medicines to make the patient sleepy while the surgeon injects local anesthesia at the site of the surgery. Cataract surgery is usually done using MAC. No one has studied how well post-polio patients do during anesthesia, but we do know that anesthesia today is extremely safe. Post-polio patients' most likely anesthesia risks occur with general anesthesia. Because post-polio patients have lost motor nerves, they are very sensitive to muscle relaxants. In essence, they can have an "overdose" to what might be a usual dose for a normal patient. This should not be a problem if the anesthesiologist is told about your post-polio weakness (the anesthesiologist should interview you before surgery, to find out your history) and measures how you respond to muscle relaxants. Measuring response to muscle relaxants is easy and is usually done routinely, using an instrument known as a nerve stimulator. This device allows anesthesiologists to check each patient's response to muscle relaxants. With cautious use of muscle relaxant drugs, usually at half the normal dose, and with careful monitoring of each patient, problems should not occur in the average post-polio patient.

If a problem did occur, there would be continued muscle paralysis. Anesthesiologists are used to dealing with paralyzed patients and should identify the problem and treat you appropriately by breathing for you until you can breathe by yourself. That might take as long as an hour. But, it is best to try to prevent the problem from occurring at all. So, be sure your anesthesiologist sees you before surgery and discuss this problem with him/her. Common muscle relaxant drugs are vecuronium, pancuronium, mivcurium, rocuronium and atracurium. There are theoretical reasons to prefer mivcurium or atracurium to the others. Curare, the first muscle relaxant drug, is not often used today, as the newer drugs are better.

Another short-acting muscle relaxant often used in anesthesia is succinylcholine. This works differently than the drugs listed above; it makes muscles contract first, before paralysis occurs. It is often used at the start of general anesthesia to help place a breathing tube. Succinylcholine can cause severe muscle pain in post-polios, especially if they will be up and about soon after surgery. It's best to avoid succinylcholine, if possible.

Other problems might occur in post-polio patients during anesthesia. Sleep apnea might get worse immediately after surgery. Many post-polios don't have normal stomach emptying and could be at risk for vomiting as anesthesia begins. Low blood pressure might occur with normal doses of common anesthesia medications. Those with ventilation problems, especially those needing respirators, can expect increased need for ventilation for at least 48 hours after surgery. These are all common problems that anesthesiologists face every day and should be able to deal with.

Previously it was thought there might still be a chronic viral infection going on in the spinal fluid in post-polios. We now know this is not the case, so regional anesthesia, which has many benefits, can be used on post-polio patients. MAC is generally not a problem if you are watched carefully while you are sedated.

Post-polio patients should be in the best shape possible for elective surgery. You should not have a cold, asthma or bronchitis. Smoking should be stopped as soon as you know about surgery. Weight control is extremely helpful. A high protein diet post-op helps your muscles stay in the best condition possible.

Finally, it is essential you inform the anesthesiologist of your post-polio problems, the chance of being very sensitive to muscle relaxants and the need to monitor your response to these drugs. Many community hospitals have concerned and knowledgeable anesthesiologists and can provide this type of care. Large university hospitals with teaching programs always have a high standard of anesthesia care. If you are not satisfied with your anesthesiologist's response to your concerns, it is possible to ask for another one. With attention to all these details, post-polios can have needed surgery safely and keep in the best health possible.



# **International Post-Polio Conference 8-10 November 1996**

## ***Living with the Late Effects of Polio***

### **You Were Asking ???**

Some people who have been considering attending the Conference have been seeking assurance on two main areas - transport and accommodation facilities. I've set out further details about these below, but if you still have any queries please don't hesitate to contact me on (02) 810 7864 or Nola on (02) 636 6515. If your Registration Form indicates that you have special needs, we will be following this up with you to confirm your exact requirements.

### ***Transport***

We have been able to make arrangements for transport to and from a limited number of railway stations, and to and from accommodation at the nearby towns of Richmond and Windsor. The railway stations will be designated once we have a good idea of the total number of people attending the Conference and how they are travelling.

Transport will also be co-ordinated from the overseas and domestic airport terminals. This will include transport capable of carrying people using wheelchairs.

There will be a charge of approximately \$20 each way to and from the airport, and a small charge for local transport.

Every effort will be made to make your travel as congenial as possible. This is why it is important that you give a clear indication of your travel plans and specific needs as early as possible.

### ***Accommodation***

Accessible bathroom facilities are available in each accommodation block. They are only a short distance from any room. Although those requiring wheelchair access to toilets and showers, and those in the non-ensuite rooms, will have to use the communal bathrooms, the passage is level, well lit and under cover.

If anyone wishes to have arrangements made for a commode to be available in their room, it may be hired at an extra cost. Again, just let us know your specific requirements.

In the rooms which have bunk beds, only the bottom bed of the bunk will be used. There is a clearance of 82 cm between the top and bottom bunks.

To date, many registrants have opted for the rooms with ensuite facilities. If you wish to have such a room, you are advised to get your registration in soon.

If you know someone who would like to volunteer to help out at the Conference, please let us know and we will send you out a volunteer's form.

The planning committee wishes to do everything possible to make your participation in the Conference comfortable, enjoyable and reasonably priced. The surroundings at Merroo are beautiful. The auditorium, dining area, meeting rooms and sleeping accommodation are either on the same level or connected by accessible ramps. We believe the Centre is a preferable option to expensive hotels and a scattered community.

If you have further questions or specific needs which you think have not been addressed please contact us.

**Jean Skuse, Conference Co-ordinator**

# ***Living with the Late Effects of Polio***

## **DRAFT PROGRAM**

### **Thursday 7 November 1996**

<b><i>After Lunch</i></b>	<b>Registration</b> <b>Meetings of <i>Polio Australasia</i> delegates</b> <b>Support Group activities</b>
<b><i>Evening</i></b>	<b>Free time</b>

### **Friday 8 November 1996**

<b><i>Before Lunch</i></b>	<b>Registration</b>
<b><i>2:00 pm - 2:30 pm</i></b>	<b>Welcome and Opening Actions</b>
<b><i>2:30 pm - 3:30 pm</i></b>	<b>Plenary 1</b> <b>The State of Knowledge of Post Polio Syndrome To-day</b> Dr Stanley Yarnell, Director of Physical Medicine and Rehabilitation, St Mary's Hospital and Medical Centre, San Francisco
<b><i>4:00 pm - 5:00 pm</i></b>	<b>Plenary 2</b> <b>Latest Research Findings on Polio</b> Dr Elizabeth Dean, Associate Professor of the School of Rehabilitation Medicine, University of British Columbia
<b><i>Evening</i></b>	<b>Informal mix and mingle</b>

### **Saturday 9 November 1996**

#### **9:30 am to 10:45 am                      Parallel Sessions**

##### **1.      Technical Solutions to Assist with the Late Effects of Polio**

Keith Olds, Coordinating Engineer (professional engineer), and Winsome Baker, Client Service Coordinator (physiotherapist), Technical Aid to the Disabled

*Keith and Winsome will demonstrate either by slide, overhead or actual device, special solutions to help compensate for the difficulties caused by weakness associated with the late effects of polio. These devices are custom designed for each person with the specific aim of helping people live as independently as possible.*

##### **2.      Orthopaedic Surgery - Is it Right for Me?**

Nola Buck, Post-Polio Network (NSW), and Dr Michael Neil (St Vincent's Clinic)

*Facing orthopaedic surgery to replace a failing hip joint, 50 years after what Nola had hoped was her last polio-associated operation, brought back long-forgotten memories and many questions, such as, would the success of the surgery outweigh the trauma.*

*Dr Neil will discuss how he views surgery for someone with the late effects of polio. He will speak of the type of prosthesis to be used, the rehabilitation period, and the pain-free and enhanced lifestyle that can be expected.*



**9:30 am to 10:45 am**

**Parallel Sessions (continued)**

**3. Overcoming Isolation**

Edith Morris, Counsellor and Teacher, Osaka, Japan

*Does the experience of isolation and separation continue to effect us emotionally and psychologically today? Long periods of hospitalisation and separation from family may have left deep-seated inner wounds. Fear of abandonment and rejection, the inability to maintain intimacy are some of the topics to be examined and discussed.*

**4. What I have Found Helpful**

*Short presentations by people who have had polio - details for this session not yet finalised*

**11:15 am - 12:45 pm Plenary 3**

**Experiences in Treating People with Post Polio**

**Syndrome - Practical Implications of Clinical Research**

Dr Yarnell and Dr Dean, followed by questions and discussion

**2:15 pm - 3:45 pm**

**Plenary 4**

**A Panel Discussion of the Australian Experience and Research into Post Polio Syndrome**

Dr Robert Adler, Westmead Specialist Medical Centre

A/Prof. Simon Gandevia, Prince of Wales Medical Research Inst

Dr Jill Middleton, Post-Polio Clinic, Prince Henry Hospital

Amanda Piper, Sleep Clinic, Royal Prince Alfred Hospital

**4:15 pm - 5:30 pm**

**Parallel Sessions**

**1. Polio Memories and Stories - Early memories of having polio: Survivors' memories versus official myths**

Dr Mary Westbrook, Associate Professor of Psychology, Faculty of Health Sciences, The University of Sydney

*What was it like to contract polio? The themes in the memories of 176 polio survivors are compared with writings at the time of the epidemics. The importance of sharing our history and understanding its effects on our lives is discussed.*

**2. A Focus on Breathing**

Elizabeth Ellis

*Details for this session are not yet finalised*

**3. Polio and the Experience of Indigenous People**

Gail Kennedy

*Details for this session are not yet finalised*

**4. Equipment to Assist Independent Living**

Two Occupational Therapists from the Independent Living Centre NSW (Inc)

*Equipment in the following areas will be discussed and demonstrated: Mobility aids, bathroom equipment, home modification, personal care, food preparation, feeding, continence, seating, pressure care and recreation. There will be an opportunity for participants to trial the equipment.*

**Evening**

**Banquet and Entertainment**



**9:45 am - 11:00 am**

**Parallel Sessions**

**1. Freedom Bound**

Terry Fletcher

*Do our callipers and other orthoses give us freedom and independence or do they bind and imprison us? Setting it Straight, a survey of consumers' views on the quality and availability of orthoses in New South Wales (copies available at the workshop) made a number of recommendations that have been forwarded to the state government. This workshop is an opportunity for you to discuss your problems and make suggestions for improvement which we will pass on to relevant authorities. We would be interested in hearing about developments in orthoses from overseas and interstate participants.*

**2. Carnitine and other WA Research Success - a Simple Basic Self-Help Look at the Late Effects of Polio**

Tessa Jupp RN, Nurse/Coordinator, Western Australian Polio Network Clinic

*Signs and symptoms of Carnitine deficiency are fatigue, pain, muscle weakness and lack of endurance. The basic theory and research undertaken in WA looks at the relevance of carnitine and other food chemical substances in the late effects of polio. A lot of little annoying problems found amongst polios at the WA Polio Clinic like cramps, tingling, sweats, chest pain, have been found to diminish once basic general health has been addressed by simply looking at individual eating tendencies and signs and symptoms given out by the body. Allergies amongst post polios appear to run at 50%. WA research on successful dietary management using blood group and ancestral origin as a guideline, is showing an improvement in ability to function.*

**3. Footloose and Fancy Free**

Jill Fogarty OAM, Senior Podiatrist, Podiatry Education and Training,  
Sydney Institute of Technology

*This presentation is designed to refresh your knowledge about your feet and how they can control your life. Our feet are our main contact with the ground and are in constant communication with the brain to adjust our standing, walking pattern and speed and help us prevent those slips, trips and falls.*

*If you have problems with your feet, this session will give you some answers. Aspects that will be included are footcare, foot hazards and what to look for when purchasing or being measured for footwear.*

**4. Wellbeing for Polio People**

Reverend John Smith, Western Australia

*Details for this session are not yet finalised*

**11:30 am - 12:45 pm Parallel Sessions**

**1. Women and Disability**

**2. Men and Disability**

**3. Dysphasia and Other Swallowing Difficulties**

**4. The Disability Rights Movement**

*Details for the above sessions are not yet finalised*

**2.00 pm - 3:30 pm**

**Plenary 5**

**Where Do We Go From Here?**

In company with Drs Yarnell and Dean and other presenters, this session aims to draw together the strands of the weekend and provide a forum for debate on the way ahead.

# FAMILY REFLECTIONS: A DIALOGUE WITH MY MOTHER

Sunny Roller MA

*Sunny Roller is Diversity Coordinator, University of Michigan Medical Center. This paper was presented at the 1995 Polio Update Conference, 1-2 April 1995.*

On the 12th of this month our nation is going to commemorate the 40th anniversary of the 1955 announcement that the Salk vaccine was safe and effective. Jonas Salk will travel to the University of Michigan to be honored as the scientist who conquered the deadly polio virus. The world will be asked to stop and reflect for a moment on this historic event. We will be invited to visualize Salk's intellectual and interpersonal struggles, the dedication and tenacity that led him to the completion of his goal and then the formal proclamation that the field trials on over 1 million school children had finally proven his vaccine's power over polio.

Being involved with the March of Dimes in planning this event has provided me with a new opportunity to reflect on the significance of this celebration for me as a polio survivor. What good does looking back really do? 1955 is long-gone. What can be learned from this sanctioned time of reflection? I got polio. I wasn't saved from it by the vaccine. It came 3 years too late for me! Am I supposed to thank Dr Salk for annihilating people like me from occupying a place in our global society? I can't and won't do that.

And I've realized recently that that's not the point. As part of the ceremony, polio survivors from around the country have been asked not only to attend, but to share their personal family stories for publication in the commemorative book that will honor us, along with Dr Salk. You see, we too, have conquered this deadly virus in our own right -- in our own very complex and private ways. We have set goals, fought, struggled, worked hard to compete and live well in a culture organized for its non-disabled members. And we have become productive members of that society. Even today, as we gather in these rooms, we continue our historic work as we pioneer to conquer the late effects of polio.

Looking back to discover how we have, as a group, established a place for ourselves in American history is a great opportunity that this 40th anniversary ceremony offers. It's a time to acclaim the 1.6 million of us who are still living in America for how we have lived and what we have achieved. We have important lessons to teach generations to come about growing old gracefully, physical and social adaptation, personal empowerment, spirituality, independence versus interdependence, and civil rights, to name a few.

The 40th anniversary of the Salk victory also can prompt us into a time of individual introspection. It invites an opportunity for each of us to review our private lifecourse with polio -- to open our own personal histories for a time of recollection and perhaps a little reconstruction.

My personal way of glancing back to reflect on past events this winter has been to begin a new dialogue with my mother. I asked if she would be willing to capture some of our history on paper. She was surprised and pleased to be of help, so we have begun to write letters to each other. Lincoln Schuster, the American publisher once said "letters remind us that history was once real life". As we write back and forth, Mom and I are taking time to re-examine our "once real life" polio experience together. It's giving us an opportunity to re-confirm and slightly re-order our lifelong views. It's helped me to see more clearly from my mid-life vantage point, our roles as mother and daughter, our personal strengths and human limitations. I've learned that Mom was the one who made things work. She



provided the family with emotional strength through the polio crises. She was solution-oriented and spent very little time dwelling on the problem. There were times though, when she felt helpless. Like the time when she was forced to abandon her paralyzed 4-year-old child at the hospital. She writes to me in one letter "all we could do was leave you there and face what was yet to come. Before we left you said 'will you give me a kiss?' Of course we did, but we thought of the danger to ourselves because polio was so contagious. We believed that the kiss was more important than our fear."

My curiosity about the past and her recounting have driven home the notion that this disability also intimately affected and permanently shaped all of the people around me -- my brother and sisters, my father, my teachers, my employers, my doctors and therapists, my close friends, but especially my parents. It is true that so many people who touched our lives should also be admired and honored on April 12 along with Dr. Salk.

What good does looking back 40 years really do? I didn't know until I started this mid-life journey into my past. Then the insights began to emerge in a new way. In our dialogue, Mom and I both have come to agree that its good to talk about our past and validate how its been for each other so we can move into the new phases of our lives that are waiting to open up for each of us. Some things are ugly and scary and too private to share publicly. Some things are more heartwarming than I had remembered. With the hope that you may be encouraged to take some time to talk with those you love the most about your experience together with polio, Mom and I would like to share our first 2 letters with you today. We hope that our starting to dialogue may encourage each of you to use history to your advantage as you ask: "What was it really like? What can the past 40 years teach us? Where are we right now?"



January 27, 1995

Dear Mom,

Here we are in 1995. I'm a successful professional woman -- single, creative and well-travelled. You and Dad are in your 70s, successful, retired with 4 kids and 2 grandchildren. As I take this moment to reflect on our 47 years together as a family, I'm wondering if you'd help me understand what it was really like having me for a daughter. How was it for you to have a child -- a healthy, pretty firstborn -- who at the age of 4 was suddenly devastated, almost killed, by polio?

Remember the doctors only gave me ten days to live? They almost put me in an iron lung. I could only move one finger. In the hospital for nine months right after the acute attack, I recall the hot, wet wool towels they laid on my limp legs every day. Remember when one nurse scalded me? I still flinch at the smell of steamy wet wool. Remember the day I took my first steps as I re-learned how to walk in stiff metal braces, propped up with little wooden crutches? We were all so proud as I posed for a snapshot with my physical therapist. What were those first nine months like for you back in 1952? Thirty miles from the hospital, you were only allowed to see me on Sunday and you hadn't yet bought your first car. What did you say to yourselves to endure the emotional pain of knowing your eldest daughter who now hobbled about the best she could would often be stared at, falsely perceived, and would need special help throughout the course of her life? Did you ever take time to grieve the loss of your healthy able-bodied little girl? Did you ask "why, God, why?" "Could we have done anything differently to prevent this tragedy? Is it our

fault? Maybe we kept the house too clean so we weren't immune enough to the virus. Should we have stayed home from the beach that day that we think I got polio?"

How could you afford all the medical bills? Nine months of rehabilitation, ten years of monthly trips to the orthopedic clinic, five major surgeries, new braces and crutches? How did Dad feel having to take off work one day every month to drive me to see the doctors in downtown Detroit? Did his bosses really understand? Weren't there times when you hated me because I was so much extra work?

Mom, remember how people raised their eyebrows and thought you were mean to me because you used to make me do things for myself? You'd say "go get it yourself!" or laugh when I'd fall down and flip me a chair and tell me to "get up!" Remember how I slipped and fell on a wet cigar butt in front of the drug store? We still laugh about that and one of your standard farewells to me after a visit is "well, watch out for old wet cigar butts!" We laughed through a lot of ups and downs. I recall working so hard to come back from polio. You taught me that if you can't do things the way everybody else does, a different way will work just as well too.

And so the years have passed. You continued raising your three younger children and I became pretty independent. Completed college, taught school, lived on my own, supported myself and got on with life.

But then all hell broke loose again. At the age of 35, I got the late effects of polio. While working on my Masters degree and working my way through grad school, I began to experience debilitating new pain, weakness and fatigue. One devastation led to another and I ended up back living with you and Dad -- in more pain, no job, no money, with no knowledge of what was happening to my body. A serious life crisis. Five different doctors all told me something different. None of us expected this harsh turn of events. Polio, the monster we had beaten, had returned, nastier than ever.

We were alarmed, baffled, frustrated, angry and damned scared. I got quite depressed at first. I remember you said, "Sunny, all we have to give you is a place to stay. You have to figure the rest out yourself. We are only just able to take care of ourselves now that we're older and your Dad has retired".

That comeback took almost 8 years. New rehabilitation, a post-polio support group, creating a customized job for myself that would allow me to get back in the mainstream and also help others who were experiencing the late effects of polio. It was a lot of work just like the original polio rehabilitation was. New serious instructions about pacing myself, new braces and crutches, a wheelchair for the first time and a bunch of new coping tactics.

As a result of those late effects, we've started to have reflective discussions about our life-long polio experience together -- how each of us saw it. I remember you teaching me to be as independent as possible, to be persistent, to treat my disability as an inconvenience rather than a major blockade. I remember Mom saying "do you control the situation or does it control you?" You told me that I was "just like the other kids except that I walked a little slower." Dad told me it was important for me to have several brothers and sisters, so I'd have a life-long support network. But what's the rest of our truth? Will you tell me what it was like for you? I'd appreciate your insight.

Love, Sunny





February 1, 1995

Dear Sunny,

Thank you for your most interesting letter and the questions it presented to me. As you well know, I'm not very good at "looking back" because I'm more interested in "looking ahead". I have never been disappointed for very long because any negative can become a positive. It's all in the way that you perceive the situation.

You were born beautiful and intelligent, cuddly and cute, and loving and loved. Nothing has changed in all these years. You are still "Sunny" and that's who you'll always be. We've always been "best friends".

As a child, you commanded respect from the whole family. Not only by your birth position, the first born, but by your constant accomplishments and your willingness to help us all. You were a constant source of pride for your father and me.

We never felt sorry for ourselves because we were too thankful that we still had you (with just a few strings attached). We needed you. Had you been taken away, we would have never felt whole again.

When polio struck you and your brother we were horrified, but we knew what we had to do. We had some insurance and the "March of Dimes" helped us through most of the financial problems we faced.

Having you in hospitals for so long was rough because we had to rearrange our lives somewhat. We had to have sitters for the other kids, so we could come to visit you. Once we brought your little brother out to Sigma Gamma Hospital with us so you could see him from your window and he could see you. We wanted to make sure your bonds stayed strong. They did, because Scott always felt needed and he became very protective in a good many ways.

I will never forget one of your childhood observations and how it could relate to your present job -- that of diversity awareness. At Sigma Gamma there was a delightful black lady who cared for you and seemed to be very interested in you. She made everyone around her feel good. Once day you said to me "Mama, I think God loved her a lot because he took the time to color her with his crayons". You were 5.

When you finally came home to stay, we had moved into a house that was easier for you to get around in. Dad made you a little chair on a platform with casters on the bottom so you could get around when you didn't have your braces on. I never would have a wheelchair in the house because I didn't want you to become dependent upon it, even though it would have come in handy a lot of the time.

The new house had a bedroom and bath on the main floor. The master bedroom was upstairs so we had an intercom we called the "squawk box" installed so we could hear you at night. Sometimes, we would have to come downstairs and help you turn over because your abdomen and back were still weak. Dad and I would take turns answering the calls. We were always busy making things "better" for everyone.

I always wanted you to be happy and to have little goals to achieve, so we would go to Ona Craft Shop every week and get crafts we could all do together. It was good for your hands

and it helped to instil creativity and a sense of independence in you. "Busy hands make happy hearts".

Life has been good and even though we've had problems, we've managed to see the light at the end of the tunnel most of the time.

We wanted you to go to public school and be with the real world since that's the one you'll always live in. It taught you that you could control the way you were perceived by others. You were special, but not too special.

Now, that Dad and I are in the twilight of our lives, our plans are coming to pass and you are as independent as we planned for you to be. We plan to help you as long as we can and as long as we are able, but there will come a time when we will be gone, just as our parents have left us. We mourned for awhile, but life goes on for you. Keep the best of us in your heart and always see the best in those around you. Remember what your grandma, Nana, said -- "Life is like a game of cards. It's not the hand you're dealt that counts. It's how you play the cards that's most important".

Love, Mom

*If there is someone in your life you'd like to talk with about the history of your polio experience? If there is, why not do it while there's still time?*

## Bits 'n' Pieces

- **PPN is on the Internet!** Our Librarian, Tony Marturano, has set up a home page for us on the Internet. The Website address is

<http://www.ozemail.com.au/~tonymski>

Tony will now be placing copies of the Newsletters and other PPN material on the Internet for the information of post-polios around the world.

- Member Lil Vickers has written to tell me of a service available to country people which will be of great benefit to post-polios. Called **Country Care**, it is a volunteer driver project, meeting country people coming into Sydney for medical treatment. Co-ordinated by Sister Enid of *The Sisters of Charity*, a simple phone call will find a friend to meet you at the railway station or bus stop and take you to your destination. Sister Enid may be contacted on (02) 332 6430 or 1800 806 160 (it's usually better to contact her in the mornings), or by writing to her at 438 Victoria Street, Darlinghurst.

- The **Physical Disability Council of NSW** will be holding a Public Forum to discuss:

- Issues relating to personal care
- Provision of aids and equipment for people with physical disabilities
- Amendments to the PDC Constitution

Date: Saturday, 22 June 1996

Time: 2:00 to 5:00 pm

Venue: Parramatta Town Hall No. 2  
Church Street Mall  
PARRAMATTA

For further enquiries or to obtain maps of the venue and parking facilities, please ring Bernice Daher on (02) 287 2929.

- **Dr Robert Adler**, Rehabilitation Specialist who has rooms at the Specialist Medical Centre, Westmead, has advised us that his new telephone number is (02) 689 3712.



## Post-Polio Post

 Thank you for publishing the two reviews of Tony Gould's "A Summer Plague". Tom Shakespeare's review raises two interesting issues.

First, because it's the cardinal sin of reviewing. He criticises the author for not writing the book the reviewer thinks he should have written. The author wrote the book he wanted to write and it should be judged accordingly.


Secondly, and more importantly, he accuses Gould of "showing no understanding of recent developments in the disability world not least language: "Here we read of the "disabled", the "wheelchair bound", and "polios". Gould may possess impairment, but lacks insight into disablement".

For myself I am not bothered by words and think the fashion for political correctness in avoiding such terms as disabled is both stupid and self-defeating. I am completely comfortable with the term and very much prefer it to the prissy alternatives such as "differently abled" or "physically challenged". Similarly, I find "polios" a useful shorthand for people who have a polio related disability and frequently use it in my own life and writing.


To say that Gould "lacks insight into disablement" suggests to me that Shakespeare either did not read the author's personal story or was himself lacking insight into Gould's very sensitive and insightful analysis of coming to terms with disability. I had the pleasure of discussing these things with Tony personally in London and I know he is very aware of these things.

I have no wish to get into a slanging match with Shakespeare but I will use his review in our next newsletter to try to promote a discussion on attitudes to and the vocabulary of disability (or disablement). I would be very happy to have comment from you or any of your readers.

*Denis Hogan, Post-Polio Support Society, New Zealand*


 I am writing to say thank you for your excellent newsletter and the positive articles featured. I recently had to start using a C-pap machine for my sleep apnoea problem and for a while I suffered loss of self esteem because at 54 years of age I felt too young to be connected to a machine for perhaps the rest of my life. However after reading the testimonials of other polio network members I realized that by using the machine I am improving my health and taking charge of my life and in control of the situation.

*Graham Duncan, Cooranbong, NSW*

 I would like to thank all of you at the Network for the support I have received since I joined in 1991. It is as a result of this that I finally contacted Dr Katrak at Prince Henry Hospital and found that whilst I do not suffer from the syndrome, I needed a splint to prevent my frequent falls from the effects of a deteriorating fusion in my left foot.


Yesterday morning I was duly fitted with the splint and twenty four hours later am on cloud nine. At the age of 74 I feel I am walking like someone at least ten years younger. No longer afraid of falling down there is the added bonus of the departure of sciatic nerve pain and I can bend down to pick things off the floor without a lot of back pain. I can also leap up from my chair if the phone rings without the risk of it cutting off because it took so long to get there.

*Elizabeth Lynes, Medlow Bath, NSW*

 As a country member of the PPN I would like to tell you how much I enjoy the newsletter. Your newsletter is the only publication that comes into the house which is read and re-read -- every word, and thoroughly enjoyed.

I am amused sometimes when I go to a new doctor and he asks me if I am a health professional!!! Because I am so knowledgeable about my condition, and use the correct medical terms. How could I not when I have been exposed to them for so long ... 46 years! I have learnt a great deal from your newsletter! Your articles such as "Changing Your Life by Conserving Energy" Feb '96, really strike a chord ... Who? Me? Make lists and cross them off? Never!!!

*Lynne Ellis, Kincumber, NSW*

 *Metro Shopping Centre, Marrickville*

I recently visited this shopping centre, on the corner of Smidmore and Murray Streets, and recommend it to any member living in this area. It has lots of disabled parking, "travelators" (escalators to you and me) and instead of the usual steep ramps there was also a lift down to the one-floor shopping area. They have wheelchairs for use free of charge and a Gopher. (They suggest you book the latter by phoning 519 1066).

There is a wide range of shops, including two supermarkets, fresh food, clothes, and many others. You can get a map from the information desk and perhaps if you phone they might send you one.

*Dr Alicia Lee, Lilyfield, NSW*

 *Vitalcall Personal Alarm*

I had a bad fall recently in the middle of the night, banging my head on a hard floor. Perhaps I could have got to my phone but there was blood all over the floor and I could barely move from the severe pain in my shoulders. I therefore pressed the button on the pendant which I wear on a string round my neck all day. This connects you to an operator at any time in 24 hours, whom you speak with directly.

I told the operator I needed an ambulance. My doors were locked but Vitalcall give you a padlocked box to hold your key. You fix it to something outside and tell them where it is and they tell any authorised person the combination to open it and get your key. It takes a minute to contact the operator and the time from when I buzzed to when the ambulance people walked through my door was ten minutes, which I find pretty amazing.

I have had the unit about five years and used it three times. It is fairly expensive, but I think of it as insurance. I tell my story in case there are PPN members living alone who are worried about such calamities. At the risk of sounding like an advertisement, I must say I feel much safer being connected. The service is available all over Australia.

*Dr Alicia Lee, Lilyfield, NSW*

