

A History
of
The Multiple Sclerosis Societies
of
New South Wales and Victoria



50 Years of Service
to
Australians with MS

December 2006

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Introduction

This history of the Multiple Sclerosis (MS) Societies of NSW and Victoria was written to commemorate the Golden Anniversary of the Australian MS Society movement in 2006. I researched and wrote it over a six week period in early 2006 after receiving an urgent request from the Governor-General for a briefing for his speech at the Anniversary dinner. There was no existing history.

In 1956 the Australian Multiple Sclerosis Society, the first MS Society in Australia (and the predecessor of the MS Society of NSW) was established in Sydney. The following year the MS Society of Victoria was established. Half a century later, the MS Society of New South Wales merged with the MS Society of Victoria to form Multiple Sclerosis Limited.

Multiple sclerosis is the most common degenerative neurological disease affecting young Australians. It is chronic, progressive, debilitating, lifelong and with no known cure. The disease damages the myelin protective covering surrounding nerve fibres in the central nervous system and disrupts/destroys body functions.

People with MS (PwMS) are registering with MS Societies at triple the Australian population growth rate and the disease costs Australia over \$2 billion per annum in direct and disease burden costs.

Multiple Sclerosis Limited is part of MS Australia (MSA), the peak national federation of State-based MS Societies. MSA is the only Australian support organisation for people with MS. Its national research arm, Multiple Sclerosis Research Australia (MSRA), is the largest single non-government contributor to Australian research into the disease.

This short outline is about of the struggle from modest beginnings of the Societies in New South Wales and Victoria and their achievements in serving Australians with multiple sclerosis.

It also describes the founding of the Australian national MS Society, today called MS Australia, the slow beginnings of funding medical research, the historic establishment of MSRA, the until now forgotten role of the Society's founder, John Godfrey, and includes a brief history of the disease in Australia.

Paul A. Murnane

December 2006

John Godfrey – Founder of the Australian MS Society

In February 1956, James (known as John) Charles Godfrey, an Englishman resident in the Sydney harbour-side suburb of Mosman, and whose wife Edith had MS, approached the National MS Society in the USA requesting assistance and information that would help establish a Society to assist Australians with MS. The US response was immediate and generous. By coincidence, a (volunteer?) Regional Director of the US Society, Anne LeDuc, was touring Australia as coach to a visiting hockey team and was able to provide him with personal direct advice.

The Sydney Morning Herald published an interview with Godfrey on June 16, 1956, possibly the first public acknowledgement of MS in Australia. Some readers offered to help and the Herald published another article ("*MS is Australia's most mysterious disease*") on December 12, 1956, describing Godfrey "*...working like a beaver and almost entirely through his own efforts,...(creating) the framework for an Australian Multiple Sclerosis Society.*" Together with other newspapers, the Herald publicised the date of an open public meeting on December 18, 1956 and called for persons interested to join the Board.

***"Help Unlock the Mystery of M.S.
To Australian M.S. sufferers, we give you this message.
You are no longer alone.
You are part of a team, pledged to fight M.S. until it is
defeated, until M.S. stands, not for Multiple Sclerosis, but for
mystery solved! Join the team. We need you."***

(Brochure inviting interested MS supporters, 1956)

The meeting of nearly 100 people was held in the rooms of the League of Women's Health at 117 George Street where the Founder and President, Ms Thea Hughes, had volunteered to house the Society. Executive officers and a committee were elected to form a provisional Society, draft a constitution and register for charitable status. Blake & Ring provided the legal services to the Committee.

Godfrey's purpose for the Society was to "*aid research on the causes and cure of multiple sclerosis and to provide aid and guidance to sufferers*". After four committee meetings, the Society's first general meeting was held on February 20, 1957 at the Sydney City Mission (now Mission Australia) headquarters in Goulburn Street.

The Reverend S.A. McDonald OBE, a Baptist minister and Superintendent of the Mission since 1928, was appointed the first

President of the Society. Commander T.M. ("Ferg" or "Gertie") Gower RAN, and John Godfrey were elected Vice Presidents. Mr. Neville Harding (an accountant and ex Lord Mayor of Sydney) was elected the Honorary Treasurer and Commander Ron Phillips (RAN (Ret)) the Honorary Secretary (and effectively the Chief Executive Officer) of the Australian Multiple Sclerosis Society Inc. (*Note: on early Society letterhead Godfrey is separately shown as "Founder" and as "Vice President"*). A Medical Advisory Board of four leading unnamed "nerve specialists" was also appointed.

On March 25, 1957 the Sydney Lord Mayor, Harry Jensen, held a meeting in the Lower Town Hall to widen public support of the Society. A neurologist addressed the meeting pointing out the need for specialised research and the virtual absence of treatment for Australians with MS.

The Australian MS Society was the fourth MS Society to be established in the world, just nine years after the first Society, eventually named the National Multiple Sclerosis Society, was started by Sylvia Lawry in New York, USA in 1946. (Lawry also co-founded the World Federation of Multiple Sclerosis Societies in 1965).

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Ron Phillips – Pioneer of the MS Society in Australia

Ronald Alfred Phillips had two overriding interests during his life: the Australian Navy, which he joined at the age of thirteen, and the Australian MS Society, which he helped form in Sydney in 1956 and which he led until his death ten years later.

A quiet, unassuming man, Ron Phillips was born in Grafton on the north coast of New South Wales, in 1908. The eldest son in a family of six children, he entered the Royal Australian Navy as a cadet in 1922 and studied at the Jervis Bay Royal Australian Naval College. Graduating with colours in swimming and athletics and the class prize for engineering theory, he joined HMAS Adelaide as a Midshipman in 1926.

From there he trained as an engineer at the Royal Naval Engineering College in Devonport, England until 1930, before being appointed as a Sub-Lieutenant to HMS Shropshire. While in England he married Florence Beatrice Lyle, known always as "Paddy", and afterwards returned to Australia to join HMAS Canberra. This was followed by three years at the Flinders Naval Depot (HMAS Cerberus, Westernport, Victoria) and a tour of duty on the cruiser HMAS Sydney.

Phillips first exhibited the symptoms of MS at a time when very little was known about the illness. At the outbreak of war in 1939 he was engaged in Sydney dockyard duties (HMAS Penguin) as a Lieutenant and Third Assistant to the Engineer Manager. The activity was hectic and he found himself working day and night, converting merchant ships to fighting ships and doing repairs to warships. It was while under this terrific pressure that he first experienced double vision.

Assuming that this and other passing conditions were due to overwork, he ignored them and applied himself to his duties in the engine rooms of many Australian warships. In July 1940 Phillips was appointed to HMAS Australia, joining her in England as a Lieutenant-Commander, in which ship he served until 1944. He was then appointed to HMAS Adelaide with the rank of Acting Commander, and was promoted to Commander a few months later. At the cessation of hostilities in 1945 he was Base Engineer Officer, Darwin.

During the war Phillips served in the North Atlantic, the South African area, the Indian Ocean, sub-Antarctica, the South West Pacific and saw action at Dakar in 1940, Guadalcanal, the Solomon Islands, the battle of the Coral Sea, and at Rabaul (Papua New Guinea).

While the episodes of double vision increased, other alarming symptoms appeared, causing distress and misunderstanding. With the loss of balance and spasmodic muscle failure in his legs, rumours circulated in the Navy about Phillips' lack of sobriety. However, the officers serving closely with him showed enormous respect and solicitude, as his eldest sister, Muriel Hays, recalled:

"He hated being a nuisance and never wanted anyone to help him. Nevertheless, the younger officers were wonderful and always sensed the exact spot to position themselves to catch him if he suddenly lost balance."

Struggling with the debilitating disease, Phillips continued to serve in the Navy, including appointments in the Navy Office, Melbourne, Balmoral Naval Depot (Sydney) and HMAS Platypus (Depot Ship), and setting up and managing the post-war Reserve ("Moth Ball") Fleet (ships that were no longer operational or needed).



**Commander Ron Phillips RAN (centre) c. early 1950s
(photo: Beverley Cockburn)**

Eventually, in late 1956, the disease was correctly diagnosed and in January 1957 he was invalided out of the Navy. His track to promotion to Captain was abruptly and disappointingly ended.

Years later, reflecting on Phillips' MS, his wife Paddy wrote (1971):

"It now seems certain that the earlier attack of double vision was followed by a remission that lasted until the war was over. He may have been worried about other early MS symptoms but if he was he kept his concern to himself and continued to go about his duties quietly and efficiently."

Society President MacDonald knew Gertie Gower, a friend of Phillips and who was aware of his (Phillips') pending retirement because of MS. Together they visited Phillips at his home and persuaded him to become the Secretary of the new Society.

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The First Decade – Struggle & Success

For much of the first decade of the Australian MS Society's existence, it operated from a room at the back of Phillips' home at 9 Clarendon Street, Vaucluse, an eastern suburb of Sydney.



The MS Society's first office - Ron Phillips' Vaucluse house
(Photo: Beverley Cockburn)

Beverley Cockburn, his daughter, remembers how grateful people with MS wrote to or rang the new Society, and how Phillips spent hundreds of hours writing and talking to these people as much as he could about new theories,

treatments and helpful ideas to manage the disease and make life easier. But *"best of all, he gave the comfort that comes from knowing that there are others with the same problems and needs as themselves"*. Phillips' always cheerful disposition (*"there is nothing wrong with me"*) lifted the spirits of the people with MS he came into contact with.

Trying to establish standalone premises for the Society, Phillips was anxious to increase public awareness of the disease and saw this as a key to future funding. He regularly highlighted the fact that there were more people with MS in the USA than with polio, then a major global community health concern, and suggested the same applied to Australia. He published the first Society newsletter, "MS News", two months after the Society was established. Printed pro-bono by the Waterside Workers Federation, presumably due his Navy connections, this newsletter continues to this day (renamed "In Touch" in 2006).

Fundraising by the Society in its early years was slow. It had started with just £300 (\$600) in donated funds. Phillips worked long hours, single-handedly writing letters to the press and radio, sending out appeal letters and always working out new strategies for fund raising and publicity. His daughter Beverly recalled fond memories of the Radio 2UE Awards contest when their house literally overflowed with rancid butter papers and Kinkara Tea box tops (over a million, by one

account) – tokens mailed in by Society supporters to be sorted out by an army of volunteers and which resulted in the sponsoring companies donating money to the Society.



Olympic swimming gold medallist Murray Rose draws an MS Society art union winner (Ron Phillips at right) c. 1960s

After this contest he started collecting and sorting stamps to raise money. Fifty years later, the Strathfield Rotary Club in inner western Sydney still collects stamps, including recycling stamps from MS Readathon, and on-sells them by the kilogram to dealers for the Society's benefit. Fashion shows, MS film nights at service clubs, fetes, bowling club fundraisers and other events too numerous to list were promoted by Phillips.

His wife Paddy remembered him on many days feeling "*off colour*" from his MS but never giving up his fundraising struggles.



Paddy Phillips, Life Governor of the Australian MS Society c. 2000

Paddy established the Society's Women's Auxiliary (or Branch) in 1959, initially mostly comprising her friends, to raise money through stalls and other fundraising social activities, and this operated for nearly a quarter of a century until 1983. In 1973 she was made a Life Governor of the Australian MS Society in recognition of her many fundraising and other contributions to

the Society "*on behalf of all those who have multiple sclerosis or other neurological disorders*", including helping establish and coordinate a network of twenty Auxiliaries around NSW.

The Society received no Government funding in its early years. Its first funding submission to the Hospitals Commission of NSW, (forerunner of today's Health Department) in 1958 was rejected. It was another seven years before it again started lobbying for government support of its Cammeray treatment centre and hostel, and a further three years before its first grant.

The first years were tough as the young Society struggled to pay its way. At one point in 1958, Zanna Barron, then a director of the Society (she was to be a director on a number of occasions until the late 1990s), recalls the desperate board approached The Smith Family to ask it to take over the Lytton Street property, assume the mortgage obligations and operate the treatment centre, over the objections of "*sell-out*" by Society President McDonald. Alternatively, the Society proposed that The Smith Family manage the Society's fundraising program. The Smith Family declined the proposals but made a small donation.

Through Phillips' untiring efforts, the Society attracted increasing numbers of senior business and other people as directors, although there was steady turnover of directors over the first decade. By 1966 none of the original directors were serving and Phillips was the surviving person from that original meeting in 1956.

Little is known about the Society's Founder John Godfrey. Believed to have run an engineering business after he arrived in Australia in 1946, he is rarely mentioned in the Society's archives and appears to have retired from the Board about 1960 after his wife died. The Society had no subsequent contact with him and his historic and single-handed role in establishing the Australian MS Society movement was forgotten until this history was written. Godfrey died in a Sydney nursing home in 1986.

In its early years, the Society had a number of leading business, political and medical persons on its board. Phillips' personal neurologist at Sydney Hospital, Sir Kenneth Noad, and James Lance (Medical Superintendent of the Northcott Neurological Diagnostic Centre and subsequently University of New South Wales neurology Professor) were closely involved in advising Phillips and the Society over this period and served at times as directors, as well as members of its Medical Advisory Board.

In 1957 the Society opened a treatment centre at 11 Lytton Street, Cammeray, a north shore Sydney suburb, in a small, rent-free building in the grounds of the Northcott Neurological Diagnostic Centre run by the RSL. Both Northcott and various Sydney hospitals referred PwMS to the centre for treatment. Phillips struggled to raise the £300 (\$600) needed for the Centre's equipment. Somehow he prevailed and Lt. General Sir Eric Woodward, Governor of NSW, officially opened the Centre.

A physiotherapy treatment unit and hostel was set up at the adjacent 7 Lytton Street a few months later, funded by £3000 of fundraising and a bank loan of £2000 to acquire and renovate the building. Treatment was first given by a physiotherapist, Ms Patricia Biershank, using Proprioceptive Neuromuscular Facilitation (PNF) techniques which were successfully adapted for the rehabilitation of MS patients at the Kaiser Foundation at Vallejo, California. Phillips himself regularly attended Lytton Street for treatment.



Miss Knott (left), physiotherapist at the Lytton Street MS Centre (Ron Phillips third from left) c. early 1960s

People with MS travelled to Cammeray from as far as the USA and New Zealand, as well as from all other Australian states, to have special multi-week physiotherapy sessions using PNF, designed to encourage people with MS to respond with their own muscles.

Ironically the Cammeray physiotherapists trained at the only other centre in the world using this therapy, the Kaiser Vallejo centre in the USA, but since that facility was only open to ex-American employees of Kaiser, Americans with MS travelled to Sydney for treatment. The

German MS Society's Summer Journal of 1962 devoted 40 pages to the Australian Society's PNF approach – "... we admire how fast you proceed with your M.S. work. We cannot build up a physio-therapeutical centre as you have so admirably done"

Part of the PNF techniques used by the Society involved what today would be called meditation techniques ("*thinking kind, positive thoughts*") and the Society's President, the Rev. McDonald, apparently played a role in this.

Phillips managed the Society's business and office administration, assisted by his daughter Beverley and son-in-law Arthur Cockburn and was to continue as Society Secretary until his MS made it impossible. He was in constant communication with many overseas MS Societies and research organisations, maintaining steady correspondence with Sylvia Lawrie, the founder of the US (and worldwide) MS Society movement. Zanna Barron recalls his "*Dickensian-looking, paper-strewn office*" and his unique ability, without being pushy or demanding, to persuade people to do what he wanted. The Society's offices were always a hive of activity and at one stage included a donated piano.

In 1958 Mr Gray Senior, the Society's Honorary Architect, was employed to manage the Treatment Centre refurbishments and a second physiotherapist, Ms Gai Stevens from California, was employed. Twelve months later a third physiotherapist was at the Centre. That year 21 patients were treated for varying extended periods, usually for ten weeks at a time but sometimes up to 3-6 months at a time. The young Society had 250 subscribing members.

The following year the Society's President, the Reverend McDonald, travelled extensively across Canada and the USA, meeting many medical authorities and MS Clinics in an itinerary arranged by Sylvia Lawry and the US MS Society. The "... *outstanding feature* (of the trip) *was the realisation of the vast amount of research being ceaselessly conducted, and the careful compilation and assessment of results achieved.*" (McDonald, 1959).

Finding Society staff trained in PNF was very difficult. To ensure it had properly trained staff, from 1958 onwards the Society sponsored US physiotherapists to travel to Sydney to provide post-graduate training courses in PNF techniques under the auspices of the Australian Physiotherapy Association. It also interviewed potential staff in England with a view to encouraging them to migrate and over subsequent years the Society was to recruit physiotherapists from a number of countries, including the USA, Germany and Denmark.



An Annual Scholarship Fund, funded by the Women's Auxiliary, was established in 1960 to send selected Society physiotherapists to Vallejo to train on post-graduate scholarships for up to six months at a time. That year the Society was able to send four staff to the USA and the first scholarship graduate started with the Society in May 1961.

Ron Phillips with an always welcome cheque c. 1959

Phillips also introduced training visits by the Royal North Shore and Royal Prince Alfred Hospitals' students who were being trained by the MS Centre's own physiotherapists in evening classes. On occasion Superintendent Edna Giovanelli, an English graduate in charge of treatment at Cammeray, had up to 60 students a fortnight passing through Lytton Street in 1960, and the Society's PNF graduates were in turn training many others. The numbers of patients treated rapidly increased every year: 48 in 1959, 75 in 1960 and by 1961 the Society was encountering the first of its subsequent perennial waiting list problems.

Phillips started to feel confident about the Society's performance. In March 1961 he reported to the board:

"There is no doubt at all as a result of the clinical records that the form of treatment which we use is worthwhile and has been highly effective in many cases ...(and) the results justify us now in expanding our activities to the utmost extent and as quickly as possible...We have been somewhat reticent in the past about making much public acclaim for our work until we could feel that we would not be misleading people in any way, because one has to be very responsible in dealing with matters of health individually and in a national extent, and to be sure false claims are not made."

Right from the first years of the Society, Phillips focussed on medical research into the cause and cure of MS.

"Proper organisation of research ... here will require co-ordination and skilled direction to prevent duplication and waste. This will be the function of a medical panel soon to be appointed which will apportion the funds approved for this

purpose and fit activities and results into a world wide pattern..." (Phillips, May 1957).

He set up controlled clinical tests in cooperation with the medical profession, surveyed GPs to discover Australian MS statistics and actively promoted the raising of funds for research into MS.

The Society's first fundraising appeal specifically targeted at MS research was "Target Turn Key" in 1961. It used the Society's "key" logo and advertising tags such as "*The key to MS is in your pocket*" and "*Help unlock the mystery of MS*". The first research funding grant in Australia was to Professor Lance's Prince Henry Hospital neurological science unit in 1963.

Phillips was successful in persuading many leading sportspeople, especially 1956 Melbourne Olympic medallists, to support the Society's fundraising efforts. The Society, recalls Zanna Barron, was the first to enlist the support of Sydney resident Betty Cuthbert, the triple Olympic gold medal track athlete, into the MS fundraising program.

Ironically Cuthbert was subsequently diagnosed with MS in 1969. She travelled to New York to meet Sylvia Laury and learn new physio techniques, and the New York MS Society in turn enlisted Cuthbert in its US fundraising activities for a time. Cuthbert has been a committed supporter of the Australian MS societies and especially research ever since.

Society President Neville Harding was clear that Society-funded research must not duplicate other research overseas – "*... it would not be fair to sufferers nor to those who might contribute to the cause*" (Chairman's Report, 1960). Phillips approached the US MS Society to argue for coordinated global MS research. In September 1961 at a World Conference on MS in Rome, the five-year old Australian MS Society, represented by Dr Basser, a member of its Medical Advisory Board, was given responsibility for coordination of world-wide, MS Society-sponsored neurological research.

The Australian Society's task was to guide the establishment of an International Society for Multiple Sclerosis "*...for the purposes of facilitation of communication and exchange of information*". As Phillips wrote at the time:

"It is to Australia's credit that we have introduced into medical research this basic principle of world co-ordination with a view to saving both money and time. The famous French physician, Jean-Martin Charcot, first recognised the disease in 1875 but

not until now – more than eighty years later – is something positive being done about it.”

(Jean-Martin Charcot was a Professor of Neurology at the University of Paris and has been called “*the father of neurology*”).

The far-sighted Phillips thus played an important role in the evolution of the global MS Society movement. By the mid-60s, Dr June Brierley, the Society’s first Medical Director, was regularly attending international MS conferences, sometimes representing other state MS Societies (which contributed to the costs of her travels).

The Australian Society became a foundation member of the World Federation of Multiple Sclerosis Societies in 1965, later (1967) to be known as the International Federation of Multiple Sclerosis Societies. Subsequently this organisation was renamed the Multiple Sclerosis International Federation (MSIF), today’s major global MS network of 41 national MS Societies. There are 75 national MS societies in the world today (2006).

Through fundraising and donations, the mortgage on No. 7 was repaid by 1964 and the property was further double-mortgaged to buy a two storied brick duplex property at No 13 Lytton Street, adjoining Northcott and adjacent to No.7. This was converted to a central office and a physiotherapy and occupational therapy unit. No. 7 was converted, with voluntary labour, into a 12 bed self-care hostel accommodation unit for country and interstate/overseas people with MS (\$4 per week accommodation only).

Dr June Brierley had started as the Society’s part-time employed Medical Director in April 1965, the same year the Society’s first Public Relations Manager was hired. Arthur Cockburn, the Society’s Chairman, was able to report that year that the Cammeray Centre’s team of three physiotherapists was treating at least 13 PwMS a day and accommodating an average of eight per week in the hostel throughout the year, on an annual Society income of \$30,000.

The purchase of No.13Lytton Street resulted in a heavy financial burden on the still small Society and by late 1965 there was fear of losing this building, causing Phillips considerable distress. Default on the mortgage was averted by loans by Ron and Paddy Phillips and others and he urged helpers, members and friends to strive harder to assist the Society.

Part of the crisis was apparently caused by the alleged failure of Society President Neville Harding to remit £6,000 from Art Unions he had been personally promoting on behalf of the Society since 1963.



Neville Harding, second President of the Australian MS Society c. 1960s

The Chief Secretary of the NSW Government carried out an audit of Harding's activities, found major deficiencies and threatened to deregister the Society as a charitable organisation if Harding remained as Chairman and director. Phillips and his son-in-law Arthur Cockburn moved a vote of no confidence in Harding and he was removed

from the board and replaced by Cockburn in February 1965.

Eventually fundraising Auxiliaries (today's Branches) of the Society were established in 20 country towns and cities throughout the State. The Society's activities steadily expanded and full time administration staff were employed. Finally, in 1967 the NSW State Government recognised the Society's services to the community by granting \$5,000 to assist with maintaining and extending patient services. The Society membership lists at the time recorded members from across Australia, including WA, Victoria, SA and Queensland as well as NSW.

Ron Phillips died in 1966. He was remembered with great affection by those he helped in the early days when MS was an even greater mystery than it is now. In his honour, in 1967 the Society's Lytton Street Centre was named the R.A. Phillips Memorial Centre. Two Australian Navy Admirals and a Navy Chaplain led the dedication ceremony.

The plaque on the building read:

*"His unwearied labours during ten years
as Honorary Secretary of this Society,
his unaffected kindness, his serene resignation
under no ordinary trials
were a source of inspiration to all."*

When the Lytton Street Centre was moved to the present Mowbray Road, Chatswood site in 1974, the new building, formerly a nursing home, was rededicated in his name. The Centre was renamed "The R.A. Phillips Rehabilitation Unit" in 1973 to conform to NSW Government requirements and today is known as the Phillips MS Centre.

Speaking 25 years after Phillips' death, the then NSW Governor, Rear Admiral Peter Sinclair AO, perhaps best summed up Phillips' achievements. Recollecting that he had known Phillips when he (Sinclair) was a lowly midshipman and sub-lieutenant:



Paddy Phillips and His Excellency Rear Admiral Peter Sinclair AO, Governor of NSW, at the MS Society's 30th anniversary 1986

"... he was a special sort of senior officer who always treated even midshipmen kindly. He was ...a doer, an achiever who reacted to his affliction in a positive and constructive way. The world, or at least our small part of it, is a little better off because of his efforts. There can be no more fitting tribute than that." (Address at 35th Anniversary of MS Society, Sydney June 18, 1991).



His Excellency Major General Michael Jeffrey addresses the MS Society's 50th Anniversary Dinner - March 2006

At the Society's 50th anniversary 15 years later, the Australian Governor General, His Excellency Major General Michael Jeffrey, said:

"Congratulations to MS NSW/Victoria, on its 50th anniversary. What a wonderful achievement – the first in Australia, and the fourth to be established in the world.

"Why did the Society get off to such a determined start and so early? I believe we owe much to the vision, dedication, compassion and grit of Commander Ron Phillips. Despite himself suffering from MS, he helped forge a magnificent organisation.

"And what a familiar, typically Australian story. The early years were hand-to-mouth existence; the 'national office' was a spare room in Ron Phillips' home for much of the first decade; there were long hours of letter writing to press and radio, preparing appeal letters and directing fund raising programs..."

"This is grassroots action at its finest. But as we know, kindness and good intentions aren't the sole elements of a successful organisation; it also requires nous and hard, often unglamorous work behind the scenes. From its modest origins the organisation has survived and grown – a little like the bumblebee; aerodynamically it shouldn't be able to fly, but the bumblebee doesn't know that, so it goes on flying anyway."
(March 6, 2006)

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1970-2000

New South Wales

Phillip's son-in law, Arthur Cockburn, had worked closely with him on Society activities through the 1960s, becoming Vice President and eventually President.



Arthur Cockburn
Third President of the
Australian MS Society

Cockburn worked to establish links with the emerging Victorian and other state MS Societies, modernised the Australian Society's governance and management structures and practises and was instrumental in recruiting its first full time Executive Director, Ken Donahue, in December 1969, on a salary of \$6000 plus a car.

Treatment centres expanded with the opening of a Society PNF centre at the William Lynne Hospital in Newcastle. Home visit physiotherapy programs were introduced and psychiatric and neuro-ophthalmology services were started. By the mid 1970s, the Society could report treating 400 patients, giving 2,600 treatments and training over 350 physiotherapy students annually.

Around 1975-6 the Canadian High Commissioner, whose wife had MS, invited the MSNSW Chairman, John Studdy, to Canberra to discuss improving support for PwMS in the ACT. Until this time there had been an informal group of MS supporters who met privately but with no resources or organisation, as the ACT was covered by MSNSW. They were very keen to be independent and worried about being run from Sydney.

With the urging and support of Studdy, a series of meetings over the next two years eventually resulted in the establishment of the MS Association of the ACT in 1978. Discussions about the MSACT and MSNSW relationship continued. In 1979 Graham Tribe, a director of MSNSW, visited Canberra in an unsuccessful attempt to establish closer relations or a merger with MSNSW. The ACT name was changed to the Multiple Sclerosis Society of the ACT in 1983 and the ACT Society became an incorporated body in October 1984.

By the early 1970s it was apparent that the Cammeray premises were too small to accommodate the increasing demand for services. In

1974 a larger property, the "the R.A. Phillips Rehabilitation Unit" in Mowbray Rd, Chatswood, was purchased for \$87,000. The Board at that time, led by Cockburn, realising that more had to be done, established the "Project 500 Appeal" under the Patronage of the NSW Premier, Sir Robert Askin. The aim was to raise \$500,000 for the acquisition of land and erection of a building for the Society's services and expansion and to eventually house all the Society's activities under the one roof.



The Phillips MS Centre, Chatswood - 2006

As more effort was put into fundraising to help meet this demand new premises were leased for fundraising and administration in Crows Nest and then in Bryson Street, Chatswood.

The Society's dream came a step closer to fruition when in 1982, under the Chairmanship of John Maddison (an ex Attorney General of New South Wales), the NSW Government approved the Society as trustees of 6.25 hectares of Crown land at Lidcombe, adjacent to the Lidcombe Hospital, for the construction of a 50-bed Nursing Home, Activity Therapy Centre and Hostel. This decision made it possible for the Society to qualify for Federal funding under the Nursing Homes Assistance Act, although there was initially some Federal Government opposition to the project. At this time the expansion and refurbishing of the Mowbray Rd Centre was also completed.

Led by Society Chairman John Studdy, the Western Region Project at Lidcombe, in Sydney's fast growing western suburbs, was completed three years later at a total cost of \$6 million and officially opened on

19 October, 1985. When the first stage of the Lidcombe Centre was officially opened (a planned hostel wing was never constructed), the Society housed 50 PwMS, as well as physiotherapy, assessment and administrative facilities.



The MS Society's new Lidcombe MS Centre in 1985

The NSW Government contributed \$750,000 towards the cost of the Lidcombe project, the balance being met by the generosity of many of the Society's supporters, including corporations, through a special capital campaign and the Project 500 Appeal.

The same year another property was bequeathed to the Society in Kogarah, allowing the Society to provide treatment services in the southern suburbs of Sydney.

1986 saw the formation of regional Councils of People with Multiple Sclerosis. Zanna Barron and Garry Anderson helped form the NSW State Council of People with MS the following year and gave a valuable voice to Australians with MS. This continues today through the Society's Multiple Sclerosis Advisory Councils (MSAC) in NSW and Victoria.

The Society also opened a small day care Centre in Wollongong in the same year. Subsequently it was relocated to Dapto and renamed the Illawarra MS Service.

In the pursuit of funds to meet the ever increasing costs and demand for services, the Society in 1987 established its first commercial venture in the form of a telemarketing bureau – MS Telemarketing. New offices were leased in Willoughby to accommodate this business which was eventually sold in 1990. (This activity was resumed, for

the Society's own internal use, in the mid-1990s and continues today in MSL).

A hydrotherapy pool was opened as Stage 2 of the Western Region Centre at Lidcombe and two years later a Baulkam Hills five bedroom respite cottage, today called "Leafy Lodge", was leased from the NSW Department of Housing.



Leafy Lodge Respite House - 2006

In 1988 the "Sydney to Gong Ride", established in 1981 and now an iconic event within the Australian cycling community, was gifted to the Society by its founder Warren Salomon and held for the first time. This event has since raised over a million dollars for the Society and celebrated its 25th anniversary in 2006 by grossing over \$1.1 million on the anniversary ride.



**25th Anniversary Sydney to the Gong MS Ride - 2006
(Photo: Ken Robertson, Mercury News)**

During the 1970s and 1980s the NSW Society's profile grew enormously, helped by increasing awareness of the disease and the Society's very active fundraising programs. However, it was not always financially solid and in some years it barely survived. In 1977 poor Society finances resulted in major staff redundancies.



Actress Gina Lollobrigida visits the Phillips MS Centre c. late 1960s

Alan Fudge was recruited to re-energise fundraising activities. Debutants balls, sporting and film stars publicity visits, capital appeals, the reintroduction of the "Unlock the Mystery" key program and the highly successful MS Readathon program, introduced and adapted from the US, were established to get the organisation's finances back onto a sustainable basis.

In 1977 Zona Tripp started the Dr Jeffrey Tripp Committee to acknowledge the MS Society's support to her and her late husband from the time of his MS diagnosis in 1957. Over the following 30 years the Committee raised over \$1 million for the Society. Zona was made a Life Governor of the Society and the Western Region Centre hydrotherapy pool named "The Jeffrey Tripp Hydrotherapy Pool" in recognition of her commitment and dedication to PwMS. She was awarded an OAM in 2000.

In 1993 the Society purchased CBD office space in Kent St, Sydney which remained its State headquarters for the next ten years until head office operations were relocated to the Studdy MS Centre (the Western Region Centre at Lidcombe renamed in honour of John Studdy in 2001).

This coincided with the sale of the premises at Kogarah and the relocation of the Southern Region office to Miranda, all designed to further consolidate the Society's financial resources.

The proceeds of these property sales, together with a significant bequest from the Stanley and Millicent Fox Foundation, allowed \$2



MS NSW Society state headquarters 1993 - 2003

million of overdue refurbishment and modernisation at both the Phillips Chatswood and Studdy Centres whilst establishing a substantial investment portfolio of some \$3 million.

The Australian Navy connections and support of the NSW Society continued through the decades after Phillips died. During the first few decades, whenever the Society launched a public fundraising event, a Navy bus with a band would usually appear as support. Various ships' crews organised fundraisers and this support has continued to this day. Several retired Navy admirals were to serve as Society directors until quite recently (the last being Rear Admiral Tony Horton) and one CEO, Russell Vasey, was a Navy ex-serviceman. A number of NSW Governors who were ex-Navy took a close interest in supporting the Society's activities as Patron.



Beverley Cockburn and her mother Paddy Phillips with the NSW governor, Sir James Rowland, after he launched the commemorative book "Unsung Heroes and Heroines of Australia" – in which Beverley's story about her father is included – at Government House.

Victoria

About the same time as Godfrey was starting the Sydney-based Australian MS Society, the Victorian MS Society was in its early stages of being established. On October 28, 1956 a preliminary Working Committee was formed at a Melbourne general meeting of 31 people with an interest in MS. The Multiple Sclerosis Society of Victoria (MSVIC) was registered as a charitable non profit organisation on March 5, 1957.

The inaugural President was Mr C. Nicholls and the Honorary Secretary (or CEO) Mrs Kathy Fitzgerald. Ron Phillips' worsening MS prevented him from travelling to Melbourne for the first public meeting of the Victorian MS Society on April 28, 1957. This was in the Royal Australian Artillery Hall in Batman Avenue and the occasion was marked by showing a US National MS Society film on MS narrated by movie star Danny Thomas.

The Navy connection with MS continued in Victoria – the following year Nicholls was succeeded as the Victorian President by Commander F. D. Shaw who was a friend of Phillips and Gower.

This Victorian MS Society was associated from its formation with the Victorian Society for Crippled Children and Adults (VISCCA). For reasons unclear (lack of funds is suspected), in 1962 it became the MS Auxiliary (or Branch) of VISCCA. In 1977 VISCCA merged with the Yooralla Hospital School to become the Yooralla Society of Victoria. (Today Yooralla is coincidentally a tenant of The Nerve Centre, the principal Victorian MS centre in Blackburn, Melbourne).

In 1966 The Association Leading to Aid and Relief of Multiple Sclerotics (ALARMS) was formed in Brighton and in 1967 changed its name to the MS Society of Victoria. These two organisations appear to have operated independently, with VISCCA being the one to fund MS research at the University of Melbourne. Little is known of their respective histories but at some point, the ALARMS-originated Society prevailed and became the sole MS Society of Victoria (MSVIC).

During subsequent years a number of financial “crises” appear to have occurred, resolved by the efforts of people such as Simon Resch (President), Brian Goldsmith (President and a well-known Melbourne restaurateur and night club owner), Lord James Zouche (President) and Ranald Macdonald (Managing Director of The Age).

Goldsmith, who was also was Chairman of the Society’s “Key Committee”, raised a considerable amount of money for the Society, clearing some critical debts, through a number of very successful events.

MSVIC was eventually incorporated as a company in 1972, the same year that 616 Riversdale Road, Camberwell was purchased following a less than successful public appeal to establish MSVIC’s administrative headquarters. Two part-time nurses (Beau Sloan and Margaret Browne) organised volunteers and provided welfare services from an old house on the site.



**John Foley - First Executive
Director of MSVIC**

John Foley, a school teacher, was appointed MSVIC's initial Executive Director under President Hans Spitz OBE. Funds were subsequently raised to pay for the capital and operating costs of the Centre which opened in 1974. It was conceived as a rehabilitation and day care facility concentrating on specialised physiotherapy along Cammeray, Chatswood and Vallejo lines.

The principal Victorian volunteer leader in the 1970s was Louis Pyke, subsequently knighted for services to people with MS, and then Chairman of the substantial and publicly listed building company, Costain (Aust) Ltd. Pyke was a renowned lobbyist on the Society's behalf. On one occasion he came away from a "casual breakfast

call" on Minister Lindsay Thompson, just prior to a Victorian State election, with a large area of land at a peppercorn rent for the Society's St Albans treatment centre.



**Sir Louis Pyke
President MSVIC**

The Sir Louis Pyke Award was subsequently established as an annual award given by MSVIC, and today by the MSL Board, as continuing recognition of the many leadership contributions and benefactions of Pyke in the Society's early Victorian years. It is the highest honour bestowed upon an individual who significantly contributes to the organisation or someone with MS for outstanding service that has contributed to enhancing the lives of all PwMS.

The inaugural recipient was Yvonne Smith who, together with her husband Allan, had been involved with MSVIC since its inception. Yvonne, who herself had MS, served on the MSVIC Board and was an active fundraiser through the Blackburn Auxiliary.

The Foley/Pyke duo usually led by example, pioneering and funding programs before advocating government financial support or wider community access to any new service. Together they changed MSVIC from a small self-help group to one of the State's leading and respected non-profit service agencies.



The MS Bus - Melbourne's first wheelchair taxi

Foley recruited Dr. Peter Colville, a well-known rehabilitation medicine specialist who had had past major involvement with the Victorian State Health Department polio division, the Children's, Royal Melbourne and Fairfield hospitals, the Victorian Society for Crippled

Children, Yooralla and the Spastic Children's Societies. Initially Colville was an honorary medical advisor but subsequently became MSVIC's part-time medical director and joint chief executive in 1972. A condition of his acceptance of appointment was that people with other than MS would be accepted by the Society if there was no alternative available and their needs could be met by the Society.

Colville's leadership was crucial in the development of MSVIC's practical, evidence-based services, in promoting services and basic research and recruiting qualified health professional staff. His major interest had always been the management of significant permanent disability.

He saw a depressing contrast in the availability of assistance between those who could not receive compensation support and those who could, although the needs of a disabled person are unrelated to the manner in which it was caused. Colville's approach was a belief that when disability is severe, the motivation for those attempting to help must be to provide a service that will be a useful improvement in quality of life looking from the bottom up, not the top down. This philosophy has prevailed ever since.

Colville programmed and pioneered the use of a computerised disability profile (adapted from work presented by Grainger at an international meeting), initially using a phone link to Melbourne University computers. This approach showed that the perceived primary focus by the founders of MSVIC for more and better physiotherapy neglected many greater needs for PwMS.

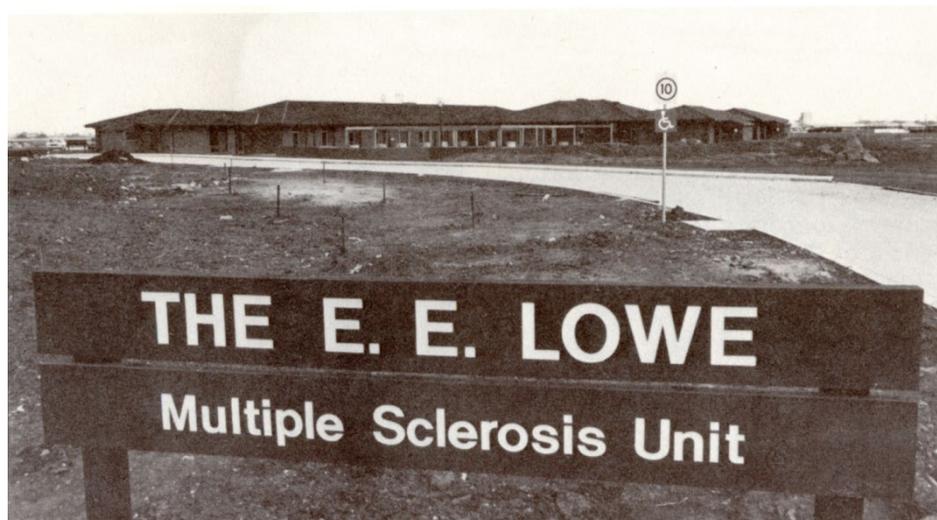
As a result, initiatives such as a full time handyman for home modifications, a consultant urologist and a neuropsychologist (Lindsay Vowels) were implemented. The first of these was

discontinued when this service became generally available after a few years. The second improved awareness of best management of the disease and was soon less required.

The last of these initiatives generated a PhD and international recognition of Dr Vowels' work on that aspect of the disease and its impact on disease management. Her research showed that what had commonly been seen as a normal psycho-social response to disability could be a much more complex problem due to central neurological damage when disability in MS was compared to the disability from other causes.

Success in obtaining both private and government funds led to MSVIC becoming practically involved in the plight of younger severely disabled PwMS who, then as now, often found themselves residents in what were geriatric nursing homes. The Society purchased and operated the 20 bed Westbury Nursing Home in Deepdene in 1976 and the 30 bed Riversdale Nursing Home in Hawthorn in 1983. This in turn led to more informed advocacy and action, including, for example, employing builders, plumbers and carpenters in a Home Alteration program for PwMS otherwise at risk of nursing home admission.

With the appointment of community health professionals such as Tony Pelosi (later Deputy Chief Executive and Development Manager), MSVIC expanded its services. Small MS centres were established at Ivanhoe and Braybrook, the latter becoming a large Western Suburbs project – the E.E. Lowe Centre, a 50 bed Nursing Home and specialised rehabilitation centre at Furlong Road, St Albans.



The E.E.Lowe MS Centre St Albans

This was an innovative model of accommodation and managed by Joan Rowlands. Subsequently an accommodation project aimed at less disabled people with MS was built in the north-eastern suburbs at Greensborough. These units were planned after community-based surveys were undertaken to evaluate the needs of PwMS and their families and were funded largely by a capital appeal and a donation by the Hicks family.

Apart from his skills as a public and government fund raiser Foley had an innovative approach to service delivery. At one staff meeting there was a request for an additional staff aid by the physiotherapists. Foley asked whether this was the best way to spend another \$10,000 in the next year. What about giving a cheque for \$500 to 20 families known by staff to have such a need? Foley asked for a list of families by the end of the week. An initial review of those receiving these grants showed that two were wasted but a follow up of the original recipients seven years later showed their situation had much improved.

Subsequently the MSVIC accountant, Doug Fraser, would visit some families reported to have financial problems to help with fiscal management. He would carry a pair of scissors, if needed, to cut up the credit card! This direct un-tied and unsolicited financial aid program to PwMS continued thereafter.

Resources were substantially developed through fundraising, government funding and profits from Society businesses. The main fundraising programs were direct marketing from 1973, intermittent capital fundraising (for Camberwell, St Albans and Greensborough in particular), deferred giving, special events, MS READ-a-thon from 1976 with assistance from the National MS Society of the US, large donors, and trusts or foundations. MSVIC helped other state MS Societies establish many of these fundraising programs.

In contrast to the NSW Government's historically poor support of PwMS, Victorian Government funding eventually became a very significant source of MSVIC services resourcing, starting with capital and operating grants for the Camberwell MS Centre under the then Handicapped Persons Assistance Act and continuing under other State and Federal programs.

Lyn Moran, a Senior Social Worker with MSVIC, undertook a pioneering study of the economic needs of families using the Henderson Poverty Line as a basis. Her findings led to direct financial grants being given to families and further lobbying of government for assistance to families of PwMS. This study was the forerunner of MS

Societies' understanding of the economic cost of MS, most recently updated with the publication of findings from the MS Life Study (previously called the Australian MS Longitudinal Study) and the Access Economics Report for MSA in 2006.

The MSVIC story would not be complete without mentioning the businesses established by the Society over the years, as in NSW and other states, to help provide profits and cash for services for PwMS. MSVIC commenced the MS Mail House (a direct mail business subsequently sold), the home and attendant personal home care business initially called Multicare (today Australian Home Care Services), MS Telemarketing and several other ancillary initiatives.

In 1991 John Foley left Victoria to continue his MS career by becoming the CEO of MSNSW until his retirement in 2000.

MSVIC sold the Camberwell property in 2001 and purchased a property in Blackburn, combining administrative and services staff from the Toorak and Camberwell offices. The following year the Society's Lifestyle Planning Service began operations.



The Nerve Centre, headquarters of MS Victoria - 2006

Australian Home Care Services Pty Limited (AHCS) has been a wholly owned subsidiary of MSVIC since 1986. AHCS subsequently made a friendly acquisition of the similar smaller operations of the MSNSW subsidiary, HANDS Pty Ltd, in 2004. Over the past twenty years the Company has established itself as the largest provider of in-home personal and home care services to people with disabilities and the

frail aged in Victoria, with operations in New South Wales and the ACT.

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The (Re) Establishment of the Australian MS Society

Right from 1956 there was regular correspondence and visits between the Australian (NSW) and MSVIC directors, including detailed discussions and exchanges of information, treatment procedures, and constitutional and organisational matters involved in establishing an MS Society. Both Societies ended up with almost identical purposes, compatible constitutions and very similar newsletters, at least in the early years. By April 1957, one month after MSVIC's establishment, Phillips and Fitzgerald were discussing the formation of a "Federal Association" and adopting similar policies and procedures:

Phillips to Fitzgerald:

"...the Society formed in Sydney was constituted with an Australia-wide objective and it is felt that so far as possible there should be conformity between the divisions operating in all states of the Commonwealth in order that we might present a national front and that the activities be nation-wide from the medical, financial, social, publicity, bulletin and other incidental points of view.

"In this respect I do not mean to suggest that the Society founded in Sydney wishes to limit activities elsewhere but on the contrary, to encourage and support such, purely with the objective of effective research...

"None of us are interested personally in the holding of office or in personal prominence which I am sure applies equally to you and your associates and we welcome in every respect the movement that has been initiated in Victoria. If...it is not too late I suggest our constitutions should conform one with the other so that we are established as divisions of the one Society on an Australian national basis..." (Letter, April 18, 1957).

Phillips later went on to suggest that *"...research could be better organised by a Federal Association of Societies, and we feel that at some future date such a body should be formed of representatives of each Society."* He pointed to the Australian MS Society in Sydney having members resident in a number of other states and hoped *"...that with our help or perhaps help (from) ...Victoria (they might) form their own Societies"*. (April 26, 1957).

By May that year, however, the Victorian Society, while agreeing to the future aim of a Federal Council of State Bodies, was arguing to Phillips that:

"The styling of the Sydney Society as Australian Multiple Sclerosis Society could cause confusion in our relations with Overseas MS Societies as well as the Australian public. We respectfully suggest that your organisation should change its title to Multiple Sclerosis Society of New South Wales and it be mutually agreed that eventual applications for admission directed to one Society from residents of the other state always be referred to the respective state Society."

The Sydney board declined to change its name but agreed to inform its Victorian-resident members, as well as Victorian applicants for NSW membership, of the Victorian Society's existence. It proposed the two organisations exchange board minutes, provide reciprocal assistance to visiting people with MS in each state, etc. These proposals were declined by MSVIC.

Interstate cooperation between the various state societies continued on an erratic basis through the late 1950s and early 1960s. The Queensland MS Society was established in 1958 and the Sydney President attended its inaugural meeting. Phillips, unable to travel because of his MS, provided much assistance on constitutions, policies and procedures, as well as medical information and PNF training for MSQ staff.

The same year the Sydney President flew to Tasmania to assist in establishing the MS Society there. Again, legal and other operating advice and systems were provided.

In mid-1959 the Queensland MS Society raised again the idea of a national MS body, suggesting to NSW and Victoria that the three societies form a Federal Multiple Sclerosis Society. The Victorian Society declined on the basis that its constitution had been changed to restrict the use of its funds to Victoria only.

However, the obvious need for national collaboration continued and by the mid-1960s the NSW Society directors were again discussing establishing a national Australian MS Society.

" We feel it is essential that a National MS Society be formed in Australia: the New Zealand societies are already in the process of forming their own National New Zealand body, however it has been very difficult for us to try and bring such a body into

being, due unfortunately in the main to interstate jealousies..."
(Phillips, Board paper, 1965).

The following year NSW Chairman Arthur Cockburn tried again and convened a March meeting of the Victorian, Tasmanian and South Australian MS Societies at the Cammeray Centre to form a committee to draft a constitution for the Australian National M.S. Society. *"However, in view of the irreconcilable attitudes of some of the...state bodies, it appears little can be done...at this stage"* (MSNSW Board Minutes, March 1966). Ad hoc discussions between the state societies continued for a further five years.

Eventually, 16 years after Godfrey and Phillips started the inaugural Australian MS Society, all the state MS societies formed the National Multiple Sclerosis Society of Australia, officially the National Multiple Sclerosis Society of Australia (NMSSA) but often referred to from its commencement as the Australian Multiple Sclerosis Society, in February 1972. The NMSSA appears to have operated as an unregistered association until 1975 when ASIC records indicate its formal registration as a company.

The Secretary General of the International Federation of Multiple Sclerosis Societies visited Sydney for the event and Sir Kenneth Noad KBE, Ron Phillips' medical advisor, announced the formation of the Society's first National Medical Advisory Panel. The first National President of the National Multiple Sclerosis Society of Australia was Melbourne lawyer Simon Resch who drafted the initial Memorandum and Articles of Association. The Secretary was Ken Donahue, the Executive Director (CEO) of the NSW Society and the Assistant Secretary was Carol Newman, also of NSW.

That same year (1975) the original Australian MS Society changed its name to the MS Society of New South Wales, bringing it into line with other state societies.

In 1979 John Studdy, a prominent Sydney accounting firm partner and company director, was appointed Chairman of NMSSA and began a long period of growth for the Society. Studdy, who had no connections to MS, was requested to stand for the presidency by the then President of MS International, Jim Wolfensohn, and Sir Louis Pyke. Wolfensohn was a US-based Australian investment banker who subsequently went on to be President of the World Bank. Studdy finally retired as Chairman of NMSSA in November, 1997. He was succeeded by Graham Tribe and Rob Hubbard.



John Studdy AM
2006

During the mid-late 1970s period, NMSSA started a real focus on research with the formation of the National Multiple Sclerosis Research Foundation, and a Medical Research Advisory Board (MRAB) which recommended the funding of MS research projects using a peer review process for each project.

In 1977, NMSSA established a Research Fund under the control of the national Society and a panel of researchers. Six years later, this became the National MS Research Foundation (NMSRF) and in 2004, MS Research Australia (MSRA).

One of NMSRF's early major projects was a nationwide MS epidemiological study conducted by Professor James (Jim) McLeod. A five year project completed in 1984, this was the first study to show the increase in frequency of MS with increasing latitude in Australia, usually referred to as the MS latitude gradient effect. It confirmed the gradient pattern found in the northern hemisphere also existed in the southern hemisphere.

After a year of discussion, in April 1999 NMSSA changed its name to Multiple Sclerosis Australia (MSA) as part of the modernising of the organisation's image. A national magazine, MS Life, was launched in October the same year, bringing a consistent voice for people with MS across the country.

That year the John Studdy Award was established to acknowledge Studdy's many contributions to the MS cause in Australia. This annual award, MSA's highest honour, is given to individuals who have made a significant contribution to the MS movement in Australia.

Over the years various attempts were made by the national Society to establish national fundraising programs. These attempts mostly failed to get off the ground because of the difficulty of agreement and coordination within the MSA federal structure of the MS state-based societies in Australia.

As the demands for adequate funding and a desire for a stronger national organisation grew, the MSA Board decided to hire a national CEO and reconstitute itself as a more independent board. In February 2001 David Brettell, who had just completed several years with the 2000 Sydney Olympics organisation, was appointed CEO of MSA. Subsequently the MSA Board changed from one where State Presidents automatically held a position as directors to one which had independent directors answerable to the Members (the seven State Societies).

As a result of this decision, the MS Society of WA withdrew from MSA although it continued to attend MSA Board meetings as an observer. It subsequently re-joined MSA in 2006.

David Brettell resigned in March 2003 and subsequently the State Society CEOs proposed acting jointly as the national CEO. This became known as the National Executive Management Team (NEMT). A series of regular NEMT meetings, usually in Melbourne or Sydney, followed over the next two years.

Due to the differing state views on how MSA should proceed, the initial priority was agreement on a national strategy which resulted in various State CEOs taking responsibility for national functions. From this came a national advocacy function led by MSVIC CEO Lindsay McMillan and based in Melbourne. A national MS Readathon program was proposed and South Australian MS Society CEO Peter Whitehouse led the first attempt to establish MS Readathon as a national fundraising program. This was successful with Readathon using central production of materials and State Society-based local management.

However, MS Readathon, while financially successful, did not grow as rapidly as expected. A truly national program, with central management and communications committed to investing in growth, was developed for 2004. While this change grew the program significantly, financial results were disappointing and in 2005 further changes were made, including appointing a national General Manager. This resulted in both very strong growth and financial returns.

While this was happening, a national MS Direct Mail program was developed with centralised management and local input which increased funding for services. This program was modelled on the successful MS Canada direct mail program and was led by Queensland MS Society CEO Trevor Farrell, with executive involvement from MSNSW's fundraising team.

Another result from the NEMT strategy development work was agreement on how services to PwMS would be delivered. The number of people registering for support with MS Societies had been growing significantly at 7-8% per annum over the prior decade, whereas government funding was flat and with the societies' own fundraising total revenue was growing at about 3% per annum. This demand pressure, together with the Societies' desire to reach out to all PwMS, resulted in the CEOs developing a service delivery model focussing on the Societies' core skills and using partnerships and education to

spread their services geographically. This was called the MSA National Service Model.

However, the real result of the NEMT process was a continuing growing together of all the MS Societies into an increasingly cohesive national organisation while recognising differing points of view.

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Multiple Sclerosis Research Australia

The first known Australian MS Society medical research grant was in Sydney in 1963. For much of the first 30 years of the state MS societies' existence, they individually contributed small amounts to medical researchers in their respective states in an uncoordinated way.

During the 1990s the State MS Societies began contributing a small portion of their turnover to an MS Australia research fund that was administered by the Medical Research Advisory Board (MRAB). In 1995, for instance, \$817,000 was provided for a broad range of grant applications. In 2000 the Australian MS Longitudinal Study, a pioneering 20 years duration research study, now rebranded as the Australian MS Life Study, was one of the more significant projects initiated and has been funded by the Societies, and subsequently MSRA, since that time.

Over the 1980s-90s, however, the combined Societies' contributions to MS research had steadily declined each year. By 2002, the MS Societies' annual research funding had nearly halved from the 1995 level due to the conflicting pressures of funding client services, funding research and reluctance to fund outside state boundaries.

The historical Australian research funding model was simply not delivering the focus on research or the funding needed, since there was no single person or organisation solely dedicated to this challenge. The few research funds available were being too thinly spread over an increasing number of projects to have a major impact on MS research in Australia. The fact that research was becoming more national, rather than state-focussed, in nature, further reduced the societies' impact on MS research.

Moreover, donors were concerned that there was not enough transparency about funds intended for research actually being deployed for research. Both MSNSW and MSVIC, for example, had on occasion reduced or substituted their annual commitments to research via MSA with bequeathed funds directed to research. One result was that fundraising organisations independent of the Societies began to be established, for example, the Trish Foundation in NSW and Charity Works for MS in Victoria, to specifically focus on MS research fundraising outside the MS societies' control.

Most significantly, the US MS Society, then and now a very large sponsor of Australian MS researchers, had also started openly pressuring MSA to increase its research funding.

Research funding by the various Societies had in effect become the “poor cousin” of their twin objectives of serving PwMS, namely “*providing the care, finding the cure*”.

In 2001 a small group of state Societies’ directors and CEOs started discussing the overdue need to “recommit” to research funding via a new business model. In May 2002 Paul Murnane circulated an email proposing the establishment of an independent “Multiple Sclerosis Research Institute of Australia”.

Eventually, at an historic MS Australia Board meeting in Bondi, Sydney on Oct 12, 2002 (the day of the Bali bombing) it was decided to establish an national Australian MS research arm with appropriate research governance and resources, independent of MSA to transparently manage any possible conflicts of interest.

Considerable work by the Societies over the next eighteen months led to Multiple Sclerosis Research Australia Limited (MSRA) being incorporated in early 2004 as an independent national MS research initiative. Dr Bill Carroll and Prof. Graeme Stewart played critical roles in establishing MSRA’s world-class research governance framework. The actual MSRA legal entity was created by renaming MSA’s National Research Foundation. A board separate from MSA but with a minimum number of two MSA directors was seen as necessary to give MSRA the focus and drive necessary to recover from the long period of the societies’ historical research neglect. MSRA’s aim was no less than finding a cure for MS.

With investment banker Simon McKeon (then an MSVIC director) as inaugural chairman, and Jeremy Wright as its first Executive Director, MSRA became operational in late October 2004. The initial plan was to raise a fund of \$30 million via a capital campaign to be led by a prominent group of Australians. Research grants would essentially be self-funding via annual disbursements of investment income from this fund.



Prime Minister John Howard and Betty Cuthbert - MSRA launch Canberra 2005

However, the MSRA board soon realised this ambitious strategy was very difficult to implement, given the lack of track record in research funding and the likely insufficient investment returns needed to

finance MSRA's research ambitions. The board changed to a more opportunistic but very successful strategy of fundraising from high net worth individuals, trusts and foundations, governments, etc.

Since then, and assisted by an annual Commonwealth Government \$250,000 infrastructure funding grant, MSRA has consolidated a small organisation based at the Phillips MS Centre, Chatswood. In a short time, it has developed national research partnerships with over twenty Australian universities and research institutes and built a major fundraising program. It is planning to launch its Betty Cuthbert Fellowships in partnership with the National Health and Medical Research Council (NHMRC).

Importantly, MSRA has made good progress in building directed research, that is, research in broad directions initiated by MSRA, as opposed to the traditional investigator (or researcher) driven research. It continues its scientific research governance focus and hopes to gain Category One status with the NHMRC.

The early result has been a substantial increase in new MS research funding, with over \$1.2 million being spent in 2005/2006, *more than the societies donated to research in the previous decade* – together with a public commitment to increase this funding to a minimum of \$3 million per annum for the next ten years.

MSRA has also recently provided administrative support for an independent MS community-based initiative devised and led by Ian Ballard, a Sydney-based businessman and a PwMS, involving Australians with MS for the first time directly fundraising for research facilitated by MSRA. Called "Foundation 5 million" (or F5M), its name reflects its aim.

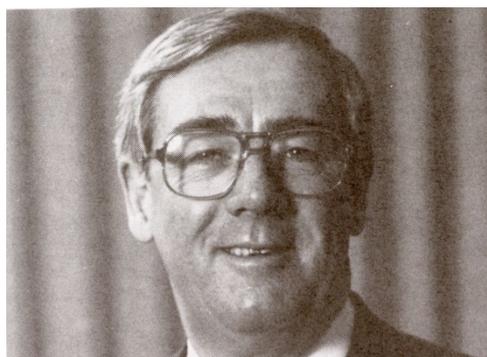
MSRA's 21st century research funding strategy still reflects Ron Phillips' pioneering 1961 objective – "*to avoid duplication of overseas research*" - now expressed as "*funding Australian MS research where it will make a significant contribution to the world wide effort*".

Most importantly, Australians with MS are now at last actively and directly influencing the country's research agenda through MSRA – to accelerate knowledge toward the cause, treatment and cure of MS.

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Merger of MS NSW & MS VICTORIA

In the late 1980s there were discussions between John Studdy, Chairman of MSNSW, and his Victorian counterpart, Mark Rayner, (CEO of Rio Tinto, that reached informal agreement on a merger of the two Societies. However, before this agreement could be formalised, a change of Victorian Chairman and opposition from Victorian Society management derailed the idea for another twelve years.



Mark Rayner, President MSVIC

By 2003 MSNSW and MSVIC, the two largest MS Societies in Australia, were delivering a large range of services to over 8,000 people with MS in NSW and Victoria, whilst also contributing to national research fundraising programs and providing the administration of the national organisations MSA and MSRA.

Both Societies were faced with steadily increasing numbers of people being diagnosed with MS, averaging between 7-10% per annum, demands for expanded services, declining government funding and highly competitive fundraising environments. In 2003 the two Societies started informally discussing ways to collaborate and operate more efficiently through integrating various back office functions. This coincided with changes to the boards of both Societies and a less state-focussed parochial view of MS.

In a move to push the talks forward and develop a more constructive framework, in late 2003, the directors of both Societies invited their counterparts to nominate an independent director to each other's board. The two states started to exchange board papers, research papers, and other information.

After a lengthy due diligence process in 2004-05, both State boards, chaired by newly appointed directors Paul Murnane (MSNSW) and Terry Winters (MSVIC), recommended a full merger to their respective members who unanimously approved it in November, 2005.

Multiple Sclerosis Limited (MSL) is the successor organisation to MSNSW and MSVIC. The mechanism to implement the merger involved MSVIC's name being changed to MSL and MSNSW staff and assets transferring to it (MSNSW will be voluntarily liquidated in early

2007). Murnane was the first chairman of MSL and Winters the Deputy Chair. Bill Younger, an engineer and seasoned businessman, was appointed the inaugural CEO of MSL in June 2006. Later the same year Christina Gillies, an experienced company director, businesswoman and a PwMS, was elected Chairman of MSL, the first woman chair of an MS Society in 50 years.

The merger aims to meet the growth in demand for services from PwMS, and to increase revenues to more effectively support and promote the best quality of life for PwMS and fund medical research via MSRA until a cure is found. MSL is now the NSW-Victoria member of MSA.

There are around 15,000 individuals (in 2006) who have registered nationally with MS Societies as PwMS. On a combined basis, MSL services some 9,000 of these individuals, or nearly 60% of the Australian total, spread almost equally across the two States. Of them, 42% of registered clients in NSW and 28% of registered clients in Victoria reside outside the metropolitan areas of Sydney and Melbourne respectively.

To deliver these services, MSL employs (in 2006) 107 full-time staff and 287 part-time and casual staff and utilises the services of over 2,500 volunteers as well as health care professionals who work in the mainstream health care system.



**Christina Gillies - MSL
Chairman 2006**

A network of 14 staff offices and 19 volunteer branches or auxiliaries (14 NSW and 5 Vic) are located across both states, together with 48 support groups and three supported accommodation facilities. A total of 4,007 short term respite and 13,643 long term accommodation bed nights are provided annually. Two MS clinics attached to major NSW hospitals or universities are operated or subsidised by MSL and a further six MS clinics attached to hospitals in Victoria work closely with MSL.

MSL's Nerve Centre at Blackburn, under the leadership of MSVIC CEO Lindsay McMillan, pioneered the sharing of operating costs by a group of non profit organizations in Australia, and the operating costs of the facilities are internally funded with partners making contributions for rent and consumables.

MSL's Nerve Centre partner organizations currently (2006) include the Brain Foundation Victoria (stroke support and carer programs), The Yooralla Society (specialist equipment and communication electronic service), Maroondah Halfway House

(emergency women's housing service), DEAC (Disability Employment Action Centre) and Tourette's Syndrome Association (family support and education).

MSL's business plans to 2010 place particular emphasis on services for PwMS, with the centrepiece being the plan to improve and expand client services programs across NSW and Victoria through the progressive implementation of a new services strategy.

The service strategy will:

- Deliver specialist assessment, consultation, education and support programs to PwMS and their families from the time of diagnosis and throughout the course of the disease, to minimise the impact of MS so that they can live as normal a life as possible
- Facilitate equitable access to MS expertise for all PwMS by sharing MSL's skills and knowledge and building partnerships with mainstream public health service providers.
- Distribute MSL resources equitably across program areas so that it can facilitate the best options for individuals' needs.
- Focus on innovative and responsive ways to meet individual needs to promote health, wellness and quality of life. This includes partnerships with Government, health and community service providers, advocacy activities that encourage State and Federal policies that support the needs of people with MS and their families, and research that leads to improved understanding, treatment and care.

To build and maintain MS expertise, MSL has a specialist multi-disciplinary lifestyle management service. This involves a core base of best practice programs in health and lifestyle management that includes hands-on service delivery, so that MSL staff can build and maintain specialist competencies in MS management and be relevant and effective consultants and educators to mainstream Australian health service providers.

The significantly increased emphasis and effort in educating and collaborating with other service providers to build specialist capability within the mainstream service system is intended to promote, over time, the delivery of best practice services to people MS close to where they live.

This will assist in providing equitable access to MS expertise for all PwMS, particularly those in regional, rural and remote areas.

While a number of client programs will be developed and delivered nationally in collaboration with other state societies, the bulk of MSL programs will continue to be delivered locally, in partnership with mainstream providers, using different strategies tailored to local situations.

Planned programs include:

- A single 1800 information line providing timely and quality information, support and referral with linkages to local services.
- Programs for newly diagnosed including information resources, web casts, on-line communities and teleconferences.
- “Living Well with MS” education and health programs
- Peer support programs – training programs and on-line communities, for both PwMS and carers.
- Education and support programs for MS families and informal carers.
- New health professionals’ education programs – written resources, web casts and satellite broadcasts.
- An active MS Ambassadors program to promote the interests of PwMS.
- Collaborative applied research with external researchers (universities, hospitals etc).



**Olympic gold medallist Betty Cuthbert and MS Ambassador Maina Gordon
Sydney 2006**

The revenue of MSL in 2006, excluding AHCS, is approximately \$24 million (\$11 million from various governments, \$13 million from fundraising). After operational costs, which are principally direct and indirect staffing costs of MSL's medical and allied medical professionals, approximately 70% of revenues or around \$16 million, will be spent on services to people with MS.

Today AHCS employs over 2,500 full and part-time staff and generates \$40 million in annual revenue. AHCS provides specialised in-home care and assistance to disabled and frail aged people living in NSW, Victoria and the ACT, and is considering expanding its operations across Australia.

Profits from AHCS contribute to providing services to Australians with MS in NSW and Victoria. Although a subsidiary of MSL, AHCS operates with its separate board and management team. AHCS is expected (in 2006) to deliver profits of over \$2 million per year, approximately \$1 million of which will be channelled back to MSL to support the infrastructure costs of services to people with MS, with the balance reinvested in AHCS' future growth.

By late 2006, the MSL merger progress was encouraging. The board had committed to continuity of its membership to ensure it met its obligations to members, supporters and staff and retained their support. Staff members in both states were adjusting well to the merger, and the organization had achieved savings in key operating areas that exceeded its minimum merger goals.

The merger plans called for a 30 percent increase in services spending over the first four years, partly funded by about 15 percent savings in back office costs (and excluding merger costs, redundancies, etc.), as well as more effective general fundraising. Even better from a financial standpoint was that the costs of the merger — about \$2.5 million — had been substantially covered in the first year of merger by a fortuitous and generous \$2 million gift from a benefactor. MSL is well on its way to delivering its original goal – expanded services to PwMS in a more cost efficient and businesslike way and increased funding for MSRA research.

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Australian History of MS the Disease

Along with the many changes in MSNSW/VIC and its model of service delivery, the past 50 years have also seen an amazing number of changes in the understanding of MS the disease and its symptoms. Advances in technology have aided earlier diagnosis and new medications and management strategies have been developed to treat both the underlying disease as well its symptoms and wide-ranging effects. (For a more complete overview of the global history of MS, see "*The History of MS: The Basic Facts*" on the website of the National Multiple Sclerosis Society of the US).

Dr. Jane Frith reviewed the history of MS in Australia in 1989 and found that the first published description of the disease was in 1875 by Doctor Alfred K. Newman, a young physician returning from Aberdeen University. The first clinical case was reported in 1886 by Dr James Jamieson. This was only a few years after the disease was first recognised as a specific disease in England, in 1873, and in the USA, in 1878.

Australian physicians and researchers continued to publish reports in subsequent years. In 1960 Sir Kenneth Noad, Ron Phillips' doctor, reviewed the known and unknown features of MS and provided a thorough description and the then contemporary theories of the disease. (For a more detailed history of MS as a disease in Australia, see "*History of Multiple Sclerosis. An Australian Perspective*", J.A.Frith, *Clinical and Experimental Neurology*, 1989, the journal of the Australian Association of Neurologists).

It was, however, Dr John MacKay Sutherland, an eminent neurologist from Queensland, who was the first neurologist in Australia to focus clinical research on MS. Having already established a reputation through his epidemiological studies of MS in Scotland in the 1950s, he emigrated to Australia and carried out further studies with John Tyrer and Mervyn Eadie and their colleagues. These studies demonstrated that the prevalence of MS was considerably lower than in the UK. Other studies in Western Australian and South Australia supported these conclusions. (For a more detailed overview, refer to "*Multiple Sclerosis in Australia*", J.G. McLeod, *Journal of Clinical Neuroscience* 1997, 4 (4) 425-431).



Dr. John Mackay Sutherland (1964)

Sutherland and his collaborators undertook a very rigorous epidemiological study of MS in Perth, Newcastle and Hobart, published in 1968, which clearly demonstrated the gradient of the frequency of MS, with the disease becoming more frequent with increasing distance from the Equator.

Similar earlier studies had discovered this in New Zealand and the northern hemisphere.

As mentioned earlier, in the late 1970s Professor Jim McLeod, Simon Hammond and colleagues carried out an ambitious, first-ever epidemiological study of MS in all Australian states (excluding the ACT and NT), supported by MSA funding, to reassess any changes in frequency of the disease and the relationship between latitude and MS frequency. McLeod was a member of the University of Sydney's Medicine Faculty, and also a past member and chairman of both MSA's Medical Research Advisory Board and MSNSW's Medical Advisory Panel.

This study clearly showed that there was a 7-fold increase in the latitudinal prevalence of MS between tropical Queensland and Hobart. The study's findings demonstrated the influence of an environmental factor in the disease, possibly a viral infection, although this has never been confirmed. Subsequently there was an active research program at the Walter & Eliza Hall Institute in Melbourne to try to find the environmental factors.

Over the past 50 years the diagnosis and treatment of MS in Australia has continued to improve. As the early years of the MS Society in Sydney indicate, there was little medical science could do for PwMS, apart from physiotherapy treatment. The MS Societies had relatively little to do with neurologists. The advent of magnetic resonance imaging (MRI) started to change this. In 1987 the first MRI machine was opened at the Royal Melbourne Hospital and now there are over 100 MRI scanners in Australia.

The MRI has shown that MS is a more active disease than previously believed and has become an essential tool in diagnosis, as well as an important research tool. In 2001 an international committee of experts on MS developed guidelines incorporating the use of the MRI for the diagnosis of MS, today known as the McDonald Criteria, based on the work of New Zealand-born Professor Ian McDonald in London (and subsequently updated).

When the Australian MS Society started in 1956, MS was known as one disease. Today four different types of clinical course are recognised – relapsing-remitting, primary progressive, secondary progressive and relapsing-progressive. Scientists and clinicians now have a greater understanding of the underlying pathological processes and the role of the immune system with attention focussing not just on myelin but also the oligodendrocyte (the cell that makes myelin), the nerve fibres themselves, as well as genetic and environmental factors.

The medical treatment of MS today includes the management of an acute attack, the management of complications and long term therapy for the disease. Mild relapses usually require no medical intervention, but more severe attacks are treated with corticosteroid therapies to hasten recovery, although it makes no difference to long term disease outcomes.

However, it was the arrival of MS drug therapies in the last decade that really changed the MS Societies' relationships with PwMS, neurologists and pharmaceutical companies. Prior to this the Societies were very focussed on disability and impairment. Since then the Societies, MSRA and pharmaceutical companies have worked more closely together, cooperating to get drugs approved by the Pharmaceutical Benefits Commission ("PBS") and assisting PwMS to maintain their compliance with the drug therapies through education and training.

MS clinical trials commenced in Australia with a trial of transfer factor which showed a reduction in the rate of progression of disability in MS and was published in the Lancet in 1980. (Transfer factor is a substance made of certain white blood cells that "transfers" capability to cause an immune response to a specific antigen). This was followed by a trial of alpha-interferon compared with transfer factor, published in 1989. The first international drug trial in which Australian PwMS in Melbourne and Sydney were involved was for Rebif (beta-interferon-1a) in 2001.

Research in MS in Australia and overseas has dramatically broadened and now includes laboratory, clinical and applied research into

physical symptoms and the psychosocial impact of disease (e.g. financial issues). Research networks and collaborations continue to be developed, in part through the efforts of MSRA. International Workshops on Longitudinal Data collection were held in 2000 and 2004.

The MS Societies' growing relationships with pharmaceutical companies, as new drug treatments have become available, has led to increased research and development, further clinical trials and closer Societies' working relationships with neurologists. These companies have demonstrated a commitment to education of PwMS, health professionals and neurologists and have sponsored many MSNSW/VIC PwMS education and training conferences and seminars with unrestricted grants. A number of Australian private sector biotechnology companies are currently involved in developing MS drugs.

In 1993 the pivotal trial results of the positive effect of Betaferon on reducing the relapse rate in mild relapsing remitting MS were published in "Neurology". Three years later Betaferon was listed on the Australian Pharmaceutical Benefit Scheme as a treatment for MS. This was followed by Avonex and Copaxone in 1999 and Rebif in 2000. These developments led to MSNSW and MSVIC establishing immunotherapy support programs in 1996 (followed by other state MS Societies), several in partnerships with pharmaceutical companies, which now provide information, education and support to thousands of Australians with MS.

In 2006, evidence for benefit well beyond that found with Interferon was reported for a new drug, Tysabri, which acts by blocking the entrance into the brain of cells of the immune system (T lymphocytes) circulating in the blood. Whilst use of Tysabri has slowed due to unexpected side-effects, its effectiveness has provided proof of the importance of activation of immune cells in the body which then cross the blood brain barrier to attack myelin and cause disease. MS Australia is very active in lobbying the Australian Government to include Tysabri on the PBS.

As mentioned previously, scientists now know genetic and environmental factors are involved in MS, but their precise nature remains elusive. In 1972 the first MS gene, a tissue type known as HLA, was identified and soon after confirmed in Australian patients. The HLA genes play a pivotal role in the function of the immune system and hence this finding added considerably to evidence involving the immune system in MS (HLA science has resulted in several Nobel Prizes including one to the Australian, Peter Doherty, in 1996).

Finding further MS genes has proven difficult but the pace of discovery has quickened rapidly since the description of the full human genome, the development of technologies to genetically type large numbers of patients and the formation of international consortia of which Australian researchers and PwMS are a part.

Convention and the evidence mentioned above suggest that MS is an autoimmune condition. However, recent findings from pathological studies of early MS lesions, including the internationally renowned work of Professor John Prineas and Dr. John Barnett at the University of Sydney, have challenged this thinking, at least in some patients, to the extent that scientists are starting to reshape understanding of how MS evolves.

One of the factors contributing to central nervous system injury in MS is the unexplained death of the resident oligodendrocyte population, the cells that make the protective nerve protein coating called myelin. This stimulates an influx of inflammatory cells, significantly amplifying the tissue damage resulting from oligodendrocyte death.

Following the now famous 2004 "Prineas- Barnett" paper (Annals of Neurology) outlining this alternative hypothesis for the development of MS, scientists, including those at the Garvan Institute in Sydney and the University of Sydney, are now using data obtained from the investigation of changes that occur in immune cell physiology in animal models of central nervous system inflammation and combining this with studies on human post mortem material. Their aim is to develop therapeutic strategies to reduce disability in humans. MSRA plans to launch a \$1.5 million Australian MS Brain Tissue Bank to support this research in 2007.

Perhaps the biggest change over the last half century has been the move away from focussing on the disease only and onto the individual with MS. This in turn has influenced the evolution of the MS Societies' structures and activities. A PwMS is now seen in the context of family, friends and environment. Lifestyle wellness, fitness and exercise now factor into these considerations.

The PwMS management team has broadened and team members can now include dieticians, wellness practitioners and case managers as well as the more traditional disciplines such as physiotherapy and occupational therapy. With the new immunotherapy treatments available there is an increased involvement of neurologists. Service location and type has diversified to include inpatient, outpatient,

community-based, domiciliary, work-based and MS clinics, many sponsored by MSL.



**Sarah Phillips OBE, President of MS International
addresses the MS 06 Conference - Sydney March 2006**

MSA has successfully hosted two MS International Federation (now MSIF) conferences, the first in Sydney in 1986 and the second in Melbourne in 2001. The latter, attended by 1800 people from 32 countries, was an opportunity for MSA and MSRA to showcase their PwMS services and demonstrate the legacy of its half century commitment to research, as well as learning from the experiences of international delegates.

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Australian MS Societies 50 Years On

Today (2006) the Australian MS Societies' combined efforts:

- directly serve over 16,000 Australians with MS nationwide
- generate total gross revenue (including commercial businesses) of \$90 million
- spend over \$30 million in support of, or services to, Australians with MS
- are well on the way to spending an additional \$3.0 million per year on national research into the cause and treatment of MS.

Achieving this will see the Australian societies (through MSRA) funding research at the same per capita rate as the National MS Society in the US, the largest global MS society. MSRA, with its singular focus on research, is confidently expected to become the single biggest annual contributor to direct MS research in Australia, including the NH&MRC, within five years.

Looking back over the past half century, there have been many positive changes and advances in MS understanding and treatment that point to an exciting future. MSL is committed to maintaining the momentum and continuing to seek the answers to MS. The need to identify the cause and establish the cure whilst at the same time continuing to learn about the individual impact of MS on those affected by it is just as critical today as it was in John Godfrey's day.

Speaking at the MSA 50th Anniversary Dinner in Sydney in March, 2006, MSA President Graham Tribe said:

"... I like to think John Godfrey and Ron Phillips would be proud of what they started and that the world is a little better off because of the efforts of the many thousands of people they inspired.

"... (thank you) for joining us tonight to recognize half a century of struggle and accomplishment. Most of all, to recognize the inspirational achievements of our



**MSA Graham Tribe
President 2006**

fellow Australians living with MS, and their families, and to continue the fight to find a cure.

"MS Australia's pledge is to continue the fight on behalf of Australians with MS until, to use John Godfrey's & Ron Phillips' words, the letters MS stand not for "Multiple Sclerosis" but for "Mystery Solved"."

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Acknowledgments

Many past and present directors, staff, PwMS and supporters have assisted in the preparation of this 50th anniversary history of the MS Societies in NSW and Victoria.

The early archives of both Societies have been poorly maintained and are virtually non-existent. Critical to this anniversary history was a priceless selection of early MSNSW board correspondence, memoranda, newsletters, ephemera and magazines in the personal archives of Zanna Barron. She had quietly resisted the Society's destruction of its archives over the decades by keeping a personal collection in a hidden large suitcase found by Shelagh Bott in the foundations of the Phillips Chatswood MS Centre in early 2006. Barron revealed this secret cache of information to me from her nursing home bed.

It was Barron's archives that revealed the totally unknown (until now) role of John Godfrey in founding the Australian MS Society movement, and the early history of the MS Society in Victoria, until now thought to have started nine years after its actual establishment in 1957.

Equally important was a memoir written by Paddy Phillips in the early 1970s, together with a collection of press clippings and photographs, located by her daughter Beverley Cockburn. Beverley's own memoir of her father, published in 1988 (see below), complemented her mother's papers in describing the pioneering role of Ron Phillips in the early years of MSNSW and other state Societies. Another important historical source was a brief history of the two Societies written by John Foley.

These collections are now hopefully secure in MSL's archives.

Needless to say, there will always be omissions and errors, disputed interpretations and overlooked contributions whenever a history covering 50 years is assembled in a rush.

In particular, we acknowledge the many thousands of unsung people, those unmentioned staff, PwMS, volunteers, donors, researchers and supporters without whose assistance and support over the decades the MS Society could not have carried out its essential mission.

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Any mistakes, omissions and oversights are solely the responsibility of Paul A. Murnane and any and all corrections and further contributions to this history are welcomed.

Copies of this history have been deposited with the National Library of Australia and the State Libraries of New South Wales and Victoria.

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