



Polio News

Post Polio Support Society NZ (Inc)

May 2008

Arthur C Clarke: a Polio achiever

Famous science fiction writer and polio survivor Sir Arthur Clarke died recently in his adopted home of Sri Lanka, aged 90. He had used a wheelchair since 1995 due to post-polio syndrome and died from respiratory complications. He was the first person to propose the idea of geostationary satellites that could transmit telecommunications around the world.

Clarke was born in Somerset, England, in 1917. He started to write science fiction in the mid 1930s, joined the RAF in 1939 and eventually became officer in charge of the first radar talk-down equipment - the ground controlled approach - during its trials.

At the age of 28 he astonished the scientific community with his precise and later validated portrayal of escape from Earth's gravity and the positioning of satellites in geostationary orbit. Today the geostationary orbit at 36,000 kilometres above Earth's equator is known as the Clarke Orbit by the International Astronomical Union. Clarke was knighted in 1998. His work and writings ranged from scientific discovery to science fiction and he wrote around 100 books to become the most eminent sci-fi author of his time.

One of his most famous collaborations was with Stanley Kubrick on the movie

script for "2001 - A Space Odyssey". He also worked along noted CBS presenters for coverage of the Apollo 12 and 15 space missions and his 13-part TV series "Arthur Clarke's Mysterious World" has been screened in many countries. His latest novel, The Last Theorem, co-written with Frederick Pohl, is to be published later this year.

Sir Arthur had lived in Sri Lanka since 1956. Although struggling with Post Polio Syndrome in recent years his writing output continued undiminished. He left instructions that his funeral be not accompanied by any religious rites.



www.filmposters.it/imgposter/grandi/spaceodyssey.jpg

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About Us

The Post Polio Support Society of NZ is an incorporated society dedicated to seeking support for people who have had poliomyelitis. It does this through information sharing and where possible, assistance to polio society members and their families, whether or not they are experiencing problems at present.

The Society's Board of Management meets regularly either physically or by telephone conference, and the annual general meeting of members is held in September.

The Society's newsletter, **Polio News**, is published four times a year (March, May, August, November) and is sent to all members.

Contributions are welcome and the deadline for copy is the 15th of the month before publication.

Disclaimer: Opinions expressed in the newsletter are those of the writers and not necessarily those of the Society.

Acknowledgement: This newsletter has been paid for by a grant from the Lottery Grants Board and the JR McKenzie Trust, to whom the Society expresses its thanks.



Editorial

greenhorn

Noun: an inexperienced person; novice [originally an animal with *green* (that is, young) horns]

I found the above definition on www.thefreedictionary.com. It's a word I feel applies as I try my hand at this editing thing.

I joined the mailing list of PPSS around fifteen years ago, and felt grateful that there was a network of support "somewhere out there". It was around the time I changed my Orthotic footwear to give me more ankle support. Some years later I re-located, and lived at five different addresses over the next nine years, ending up in Hamilton. PPSS were very patient ☺, as no doubt my newsletter bounced back stamped "Address Unknown" several times. ☹ The March08 issue was the first one I had received for a while, and in it was the "editor vacancy" notice. Fortuitous timing! ☺.

In the nicest possible way Edith Morris places me in the "younger set" – those polios in their mid fifties. So as a greenhorn 50-something I am trying my hand at a new task. Please send feedback on how Polio News can be improved. My contact details are on the last page. Cheers, David



Me with grandsons Emile and Kenan (born 8.May.08) seven hours old.

Come to Conference '08

Physiotherapy

That's the theme!

- September 12th and 13th (Fri & Sat)
- Friday at the Arena Community Centre
- Saturday at the Rehabilitation Unit, Palmerston North Hospital.

Keynote Speakers

- **Ms G. Jegasothy (Jega)**
Senior Physiotherapist
Late Effects of Disability Clinic
Neurosurgery Rehabilitation
Royal Perth Hospital
Shenton Park
Perth W.A.
- **Dr John de Groot**
Rehabilitation Centre PNDHB
- **Mr David Guest**
Manager Information and Policy
Enable NZ

Programme

Friday 12th September

| | |
|---------|--------------------------------------|
| 10:00am | Morning Session |
| 12:30pm | Break |
| 1:30pm | Afternoon Session |
| 4:30pm | Break |
| 5:00pm | AGM |
| 7:00pm | Conference Dinner with Guest Speaker |

Saturday 13th September

| | |
|--------|-------|
| 9:30am | Start |
| 3:00pm | End |

Travel

Air NZ flights depart from PN to most centres late on Saturday afternoon.

Accommodation

We have made tentative enquiries with hotels and motels - especially those with accessible rooms. There is sufficient accommodation for our needs.

The cost is approx \$140 a night per room or unit.

Those planning on attending Conference are asked to make a tentative booking by one of these methods:

Email: jbmunro@xtra.co.nz
Letter: P.O. Box 249 Oamaru
Phone: Ray on 0800 476 546

Please indicate your intention to attend by 15th July 2008. Further details will be available.

Conference Fee

The conference fee is \$100
This fee includes the Conference Dinner on Friday night.



President's Message

Greetings

Hello all, time is passing very quickly and the onset of winter is fast approaching. To those who are, or have been unwell a speedy recovery is our wish to you.

To those who have lost loved ones or friends our thoughts are also with you.

Polio News – Editorship

In the last Polio News a request was printed seeking a replacement Editor.

I was delighted and relieved to receive an email from David Whyte.

David has since met with Board Members Laura Ladkin and Edith Morris in Hamilton and who in their report supported David's offer as editor. We have formally accepted his offer with thanks and this Polio News will come from his computer.

Thank You David, and we leave the product in your care.

Polio Brochure

I begin this message by offering congratulations to all those involved in the production of and printing of our new brochure. They have really been a hit with many people, according to the reports and 0800 calls that I have received requesting additional copies. I now have a supply in my possession to be able to keep up with the initial demand.

Group Reports

Thanks to those who took the time to answer JB's call for reports to go in the last issue. I did not know that we were so busy in the far flung corners of this country. I am sure it would give heart to those who feel isolated to know there are so many others who are in somewhat similar circumstances. I recently had a 92 year old lady talk to me about Polio and its effect on her life. Remember you are just one of the estimated twenty million people worldwide who are survivors of past epidemics. Also remember that 'Wild Polio' still exists in some countries, and so there will be survivors around for many years yet.

Membership Information

If you are moving or making any other significant changes, please advise us as soon as possible. We have numbers of Polio News returned - 'Gone No Address' - and this is a cost that we should be able to avoid. Also if you are a group leader or representative and know of members who have shifted or passed away please use the 0800 476 546 and give us the details.

2008 Conference and AGM

I, accompanied by Sec/Treas. JB Munro, travelled to Palmerston North to inspect the facilities required to stage this event. We linked up with Professor Tim Brown from P.N., who became our driver whilst there. Tim is well known in the area and also knew the area well, so it was easy for us to find what we were looking for.

Many of our concerns for accommodation and meeting facilities have been resolved. You will be given the names of places to book accommodation. We have located 'Fully Accessible Wheelchair' accommodation in six Hotels and Motels. JB has maps that will be included in the information kit and made available to everyone, probably with the Subscription Renewal mail-out.

Fight for Justice

Melanie Trevethick, is challenging through the High Court, her right to Accident Compensation for her 'Disability through Illness' the same as they would pay for 'Disability through Accident.'

Melanie has had strong backing from many quarters including our Society's letter of support. If this should be accepted it could see our members able to challenge via the same reasoning. We will keep you informed of the progress as it makes its way through the system.

Endpiece

I have had my winter Flu Jab, so should be set for the next six months at least. Remember I am here at your service should you need help or advice. Regards Ray Wilson; President.

Remembering The Bracing Man

Harold Storey was an orthotist for 38 years and the Head Orthotist at Waikato Hospital for 22 of those years. He was a giant of a man in both stature and spirit and would bend over backwards to make the most supportive and comfortable braces, callipers, shoes, padded crutches, and anything else required. He somehow found solutions to tricky problems with whatever was on hand in the workshop. He loved people and was always available even without an appointment.

I felt Harold understood polios and our peculiarities and fussiness, and made braces just to suit us. Although a stubborn and sometimes blunt man, I knew he cared for me and did his utmost for the many many polios all over the Waikato and surrounding areas. He mellowed with age and appreciated my visits to his home and in hospital before he died.



Original 1960's Orthotic Brace

From 1966 to 1988 he worked in the "splint and boot department" at the back edge of the Waikato Hospital complex. In those days I could wander into his workshop at any time with a broken strap or tight calliper cuff, and he would tweak a bit here or a bit there immediately. Nowadays it takes weeks to get the tweaking done.

Harold was a second generation orthotist. In 1942 he began helping his father who worked with war-injured soldiers and civilians. Now Colin follows his father as a third generation orthotist, taking up this role in 1972 working with his father until Harold retired in 1988. (Colin spoke at our last Post Polio Conference here in Hamilton last year.) What a legacy these three generations of Storey men have had into our polio lives.

Harold H Storey 1927 - 2008

by Edith Morris



Modern knee brace

Government Carers' Strategy

The New Zealand Carers Alliance, a coalition of 47 national non-profits supporting families with health and disability needs, has cheered the Government's launch of a Strategy for the country's 420,000+ family carers.

The Carers' Strategy was launched by the Hon Ruth Dyson on behalf of the Government at Parliament yesterday.



John Forman, chair of the Alliance, says we can all expect to receive or provide family support during our lives. "Caring is a fact of life for every New Zealander, but often we are ill equipped to provide this support for loved ones. Carers need quality, consistent learning so they can care safely. They need to be recognised by society for their valuable economic role as the country's biggest health workforce. And they need supports just for them, because caring can be a demanding role."

The Strategy will deliver practical help, and celebrate the role of caring, which is easy to take for granted because it's something families have always done for those who are ill, disabled, vulnerable, or frail, he says.

The Alliance especially welcomes the Government's commitment to review financial and respite supports for families during the Carers' Strategy's five year Action Plan.

"Having regular breaks is important for carers, otherwise they burn out and can't continue. Access to quality, age appropriate services was one of the major concerns expressed by carers during the Strategy consultation."

From Media Release 29 Apr 08

The complete Action Plan document can be found at:

www.msd.govt.nz/documents/work-areas/cross-sectoral-work/carers-strategy/carers-strategy.pdf

Regional Events

Waikato

Over the years our members in Matamata have been faithful attendees at our gatherings in Hamilton, a journey of an hour each way; so it seemed only right that when infirmities started to interfere with this record, the membership decided to meet for the first time at a Matamata venue.



Lesley Wills booked a cosy meeting room at their local church and organised a "Soup 'N' Buns" catered lunch, with a few extras besides, for a modest sum. Ian and Lesley and the 3 ladies we saw behind the scenes are part of the local theatre musical group and have been fundraising in this manner. Their latest production opens late May, Off Broadway Matamata, (not On Broadway NY). This is the Musical production of Footrot Flats, very rural we understand, with Lesley on the piano.

There was time for a good chat before the lunch was served to us seated at tables. Tentative dates were discussed for the remainder of the year: late August for a physiotherapist as guest speaker and latish November for the usual Pre-Christmas meeting (early goodies). We would expect to have the usual New Year garden lunch in February.

Our time at Matamata was very enjoyable and relaxing, a warm comfortable room, not having to arrange "bringing a plate",

the local people not having to travel. For the other eleven members it was a lovely country drive on a sunny day, and some even arrived early for a quick look downtown.

At the end of the event the suggestion was mooted that a Matamata lunch could become an annual event in May. We hope that the weather would be as favourable another time.

Taranaki

On the 12th of April we had 10 polio members attend our meeting.

We had a pot luck lunch and we had a speaker from the Community Law Office. He was excellent. He spoke on preparing a will and on the Power of Attorney and everyone thoroughly enjoyed it.

Shirley has been busy visiting the sick in hospital and going to fund-raising meetings. She was invited to an ageing forum in Stratford where Ruth Dyson spoke on disabilities.

On April 24th a new Disability shop was opened in Hawera where there is going to have a mobility scooter available for people to use.



Continued ...

And last of all, just to let you know our books have been closed for the financial year and are going for audit.

Best wishes to everyone, keep well and with all the illnesses going round everyone needs to take care and look after your selves.

Nelson - Top of the South

Hi everybody, I hope all is going well for you at your place in this lovely mellow autumn, may winter be kind to us!



Nothing to really report on but I did wonder if anyone out there has been having hassles obtaining help from ENABLE? My request for shower railings and a retractable wall seat have been met with the statement that I didn't meet the criteria! Is this agency "Enable" or "Dis-Enable" ?? I would be interested to hear if anyone else has had difficulties!

Rex and Anne have kindly found a new venue for our mid-winter luncheon. This will be at:

- ❖ Crusoes
- ❖ Saturday June 28th
- ❖ 12.30pm

Crusoes is at Robinsons Complex, Main Road Stoke. (Next door to Kensington Court Rest Home).

Please confirm with Rex 03 547 7043
Or Jenny 03 545 1030 by 23rd June. Do hope you can all come.

Regards to all,
Jenny.

PS I have shifted House but my phone number remains the same.



Stoke as seen by Google Earth

The First Step In Management ...

Polio survivors should undergo a complete, general **medical evaluation** by a primary care physician and a specialized neuromuscular evaluation by a knowledgeable and experienced polio specialist to establish a baseline from which to judge future changes and to develop an appropriate treatment plan.

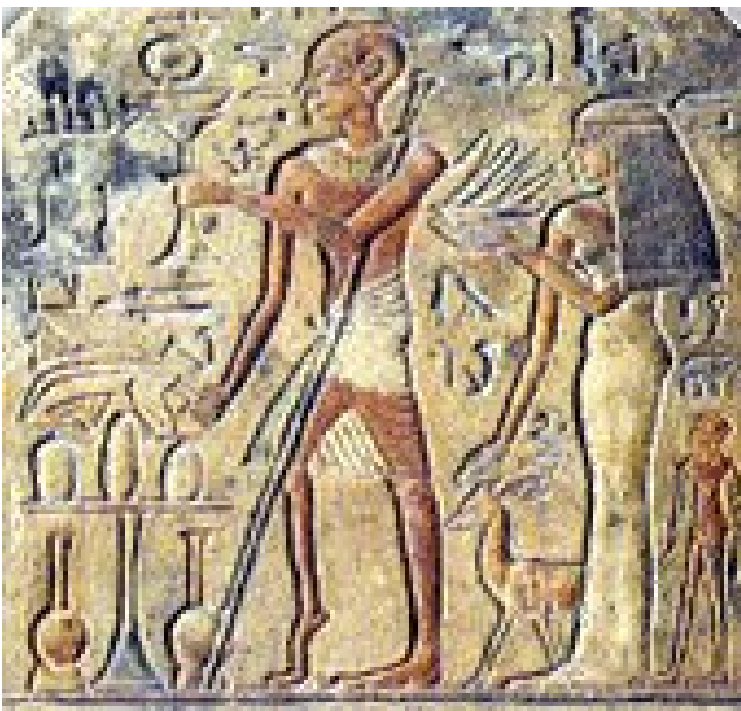
Polio survivors should first and foremost **take care of their health** by seeking periodic, basic medical attention. Be nutrition-wise, avoid or reverse excessive weight gain, and stop smoking or over-indulging in alcohol.

Polio survivors should **listen to their bodies**. Avoid activities that cause pain – pain is a warning signal. Avoid unrestrained use of pain killers, especially narcotics. Do not overuse muscles but do continue activity that does not worsen the symptoms. In particular, do not over-

exercise or continue to exercise through pain. Avoid activity that causes fatigue lasting more than ten minutes.

Polio survivors experiencing symptoms should **pace themselves** in their daily activities, resting when tired. Stop for a 15- to 30-minute rest when needed, perhaps several times a day. Management may include the increased use of assistive devices. A change of equipment or new bracing may be recommended.

Polio survivors should **educate** themselves, their families, and if need be, their health professionals. Post-Polio Health International, through its conferences and publications, provides accurate and updated information. Polio survivors may benefit from the support and knowledge of other polio survivors.



An Egyptian drawing from the 15th century BC showing an *equinus* polio leg. The original is in the Carlsberg Glyptotek. We thank them for permission to publish. And yes, the glyptotek is related to the beer of the same name!

Questions from family and friends regarding POST POLIO SYNDROME

Dr Richard L. Bruno, Director of the International Post-Polio Task Force at the Eaglewood (NJ) Hospital and Medical Centre in the USA provides some of the basic facts.

What is Post Polio Syndrome?: It is the unexpected and often disabling symptoms of overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anaesthesia, cold and pain, as well as difficulty swallowing and breathing that can occur 35 – 40 years after the polio virus attack in 75% of paralytic and 40% of “non-paralytic” polio survivors.

What causes PPS? PPS is caused by decades of “overuse abuse.” Virtually every muscle in the body could have been affected by polio including the brain activating neurons that keep the brain awake and focus attention. Although damaged, the remaining neurons compensated by sending out “sprouts”, like extra telephone lines, to activate muscles that were orphaned when their neurons were killed. These over sprouted, poliovirus-damaged neurons are now failing and dying from overuse, causing muscle weakness and fatigue. Overuse of weakened muscles causes muscle and joint pain, as well as difficulty with breathing and swallowing.

Is PPS a progressive disease? PPS is neither progressive nor a disease. PPS is caused by the body tiring of doing too much work with too few poliovirus-damaged, over sprouted neurons. However, polio survivors with untreated muscle weakness were found to lose about 7% of their remaining, overworked motor neurons every year.

Continued ...

Is there treatment for PPS? Yes. Polio survivors need to “conserve to preserve”

energy and stop overusing and abusing their bodies to preserve their abilities. Polio survivors must walk less, use needed assistive devices – braces, crutches, canes, wheelchairs – plan rest periods throughout the day and stop activities before symptoms start. Also, since many polio survivors are hypoglycaemic, fatigue and muscle weakness decrease when they eat protein at breakfast and small, more frequent, low fat/higher protein meals during the day.

Isn't Exercise the only way to strengthen weak muscles? No. Muscle strengthening exercise adds to overuse. Pumping iron and “feeling the burn” means the polio-damaged neurons are burning out. Polio survivors typically can't do strenuous exercise to condition their hearts. Stretching can be helpful, but whatever the therapy, it must not trigger or increase PPS symptoms.

Is treatment for PPS effective? Yes. The worst case is that PPS symptoms plateau when polio survivors stop overuse abuse. Most polio survivors have significant decreases in fatigue, weakness and pain once they start taking care of themselves and any sleep disorders are treated. However, because of emotionally painful experiences related to having a disability, many polio survivors have great difficulty caring for themselves, slowing down and especially “looking disabled” by asking for help or using assisted devices that they had discarded years before.

What can doctors; family and friends do to help? Polio survivors have spent their lives trying to act and look “normal”. Using a brace they discarded in childhood and reducing overly-full daily schedules is frightening and difficult. So, friends and family need to be supportive of life-style

changes, accept survivors' physical limitations and any new assistive devices. Most importantly, friends and family need to be willing to take on taxing physical tasks that polio survivors may be able to do but should not do. Doctors, friends and family need to know about the cause and treatment of PPS and listen when polio survivors need to talk about how they feel about PPS and lifestyle changes. But friends and family shouldn't take control of polio survivors' lives, neither gentle reminders nor well-meant nagging will force polio survivors to eat breakfast use a stick or take rest between activities. Polio survivors need to be responsible for caring for their own bodies and ask for help when they need it.

Although many of today's doctors were not around when Polio struck, because of the introduction of the Polio vaccines, we need every doctor to know about the cause and treatment of PPS and give to Polio survivors the care needed.

Copies of our recently published brochure for Health Professionals are available and can be ordered by contacting our Secretary at

jbmunro@xtra.co.nz

**or write to
PPSS of NZ Inc
P.O. Box 249
Oamaru 9444**

or freephone 0800 476 546.

Review of Long Term Disability Supports

The review of long-term disability supports was established to advise government on how to improve disability support systems.

On 18 February 2008 Cabinet agreed to the review's recommendations in a paper "Improving Long Term Disability Supports - maintaining momentum".

Cabinet noted that there is significant work under way across government to improve the provision of disability supports, and agreed to an outcomes framework as a statement of the government's direction and a basis for monitoring progress across government, and Cabinet has asked government agencies to work towards:

- greater flexibility of supports, better tailored to the specific needs of individual service users
- simplifying or reducing the assessment processes for small and low-cost disability supports
- greater use of direct funding approaches
- accelerated workforce development and training initiatives for the disability sector
- improving how new and existing policies and programmes fit together
- making sure the social services non-government organisations (NGOs) services are inclusive of disabled people
- simplifying and standardising contracting arrangements
- investigating the feasibility of an accessible website for government information on disability supports via a single entry point
- access to mainstream services for disabled children and young people.

Ministry of Health long-term conditions framework hui

28 May to 12 June 2008

The Ministry of Health's Long-Term Conditions team is developing a strategic framework for their work.

They would like the assistance of those working daily with people with long term conditions in shaping that framework.

The purpose of the hui is to develop the relationship between the community and voluntary sector and the Ministry of Health, in the area of long-term conditions.

The hui will also provide an opportunity to up-date community and voluntary organisations working in this area on current projects in long-term conditions.

The dates and venues of the hui are:



Wellington - 28 May

Toi Poneke
Wellington Arts Centre
61 Abel Smith Street.
10.00am until midday

Pataka Museum
cnr Norrie and Parumoana St
Porirua.
1.30pm until 3.30pm.

Auckland - 5 June

Athol Syms Community Hill
11 Griffith Street
One Tree Hill
10.00 am until midday

Te Atatau South Community Hall
Edmonton Road
1.30pm until 3.30pm.

Christchurch - 6 June

Meeting Room 3
Christchurch Convention Centre.
10.00am until midday
1.30 pm until 3.30pm.

Dunedin - 10 June

Windle Room
Dunedin Centre
1 Harrop Street
10.00am until midday.

Whangarei - 12 June

Cafler Suite
Forum North
Rust Avenue
10.00am until midday.

For more information:

Contact: Carolyn Bevege
Programme Administrator
Phone: 04 816 3663.
Email: carolyn_bevege@moh.govt.nz

May 7, 2008

From Canada

Federal Court of Appeal Denies Airline Application to Overturn Historic Disability Transport Decision

The Federal Court of Appeal has denied Air Canada and Westjet's application for leave to appeal a historic decision of the Canadian Transportation Agency (CTA) that allows Canadians with disabilities to travel by air without having to pay for a second seat to accommodate their disabilities, whether for themselves or their attendant. In January 2008 the CTA ruled on a complaint launched by the Council of Canadians with Disabilities (CCD), the late Eric Norman and Joanne Neubauer seeking to ensure that persons with disabilities traveling by air would not have to pay for a second seat for their attendant or because of the nature of their disability. Train, bus and marine services do not charge for additional seats. Only the airlines made people with disabilities effectively pay double what others pay to fly. "CCD is ecstatic over the decision of the Federal Court of Appeal," said Marie White, Chair of CCD. "We knew the airlines did not have a legal argument. They were simply trying to stall implementation of the CTA decision and thus save money by continuing to discriminate against people with disabilities," said White. "Canadians with disabilities have been raising this issue for over 20 years and the decision of the Federal Court of Appeal says to the airlines they must abide by the CTA decision. Finally this issue is put to rest and once again the courts have made it clear that people with disabilities must be accommodated," said Pat Danforth, Chair of CCD Transportation Committee. CCD thanks David Baker our legal counsel for his long and determined support.

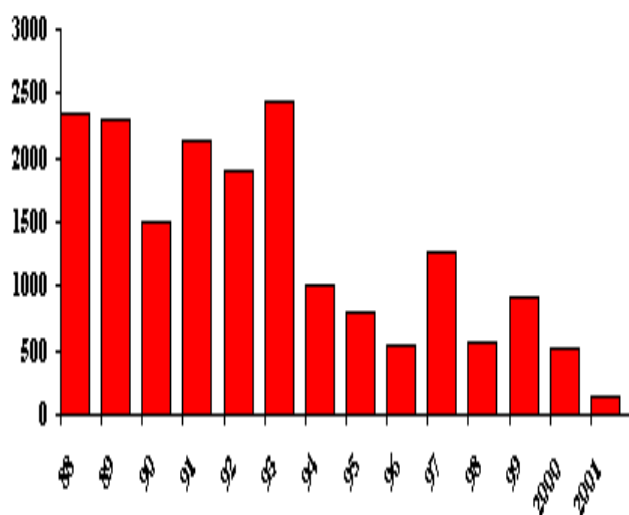
CCD also thanks the CTA for understanding the importance of this issue and the strong decision they handed down.

CCD calls upon the Minister of Transport to regulate access to federal transportation systems thus making it clear that carriers must remove barriers to the mobility of Canadians with disabilities. "It is time for the Department of Transport to show some leadership and lessen the burden disabled persons and their organizations are having to bear through long hard fought legal battles like this and VIA Rail," said Laurie Beachell, CCD National Coordinator.

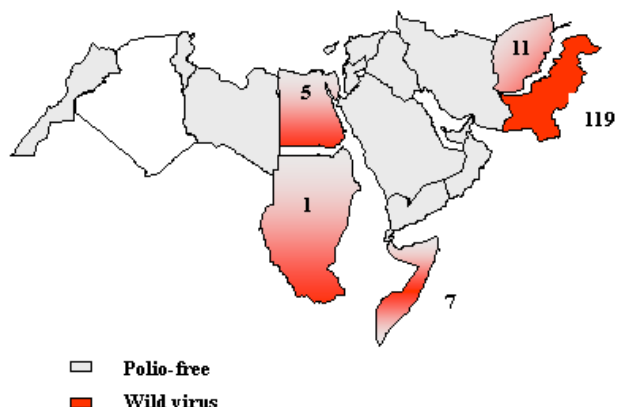


Good news from WHO's Eastern Mediterranean website report

Rapid and significant progress towards the eradication of poliomyelitis continues to be witnessed in all countries of the Eastern Mediterranean Region. In 1988, poliomyelitis cases were reported from 22 of the 23 countries of the Region, with more than 2000 cases reported by weak surveillance systems that did not reflect the true incidence of poliomyelitis. By 2001, poliovirus transmission had been interrupted in 18 of the 23 countries of the Region, and virus transmission had become more geographically localized in the remaining five countries (Afghanistan, Egypt, Pakistan, Somalia and Sudan). Sudan has not reported a poliomyelitis case for more than one year, indicating possible interruption of wild poliovirus transmission.



Reported poliomyelitis cases, Eastern Mediterranean Region 1988–2001



Reported poliomyelitis cases, Eastern Mediterranean Region, 2001

In the presence of a very well developed and efficiently performing surveillance system, the number of confirmed cases of poliomyelitis reported during 2001 in countries of the Region has decreased to only 143 (virologically confirmed cases) (Figures 1 and 2). Through the end of June 2002, 28 cases were reported from only 3 countries (Afghanistan, Pakistan and Somalia), as compared to 41 for the same period in 2001. In 2001, wild polioviruses types 1 and 3 were detected in Afghanistan and Pakistan, type 1 was detected in Egypt and Sudan, and type 3 was detected in Somalia. Wild poliovirus type 2 has not been isolated in the Region since 1997.

The full report can be read at

<http://www.emro.who.int/RC49/Documents-INFDOC3.htm>



Effective orthotic devices are not readily available to all polio survivors.

Directory: Information about membership and local support groups

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