Polio Survivors Serving Others

Information & Inspiration
For All Polio Survivors and their Families

The PA Polio Network

www.polionetwork.org

March 2024

Our Mission:

To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.

Inside this Issue:

Anesthesia: This topic can be complex for both polio survivors and our caregivers. You are NOT alone. We have many articles on our website, from all over the world. This month, we are featuring two.

- Selma Calmes, MD, retired anesthesiologist from UCLA has published a new article: "Anesthesia Specifics for PPS". Thank you Dr. Calmes for giving us permission to include this article on our Anesthesia Warning page.
- "Patients With A Polio History – What Anaesthetists Need To Know" is an outstanding article from Post-Polio Victoria (Australia).
  Please Note: our friends in Australia spell the word Anesthesia differently than we do here in the US.

Jean Macnamara, MD: She is an Unsung Hero of Polio Eradication. Her work identifying more than one strain of the poliovirus contributed to the development of a successful polio vaccine in 1955.

The Eradication Of Polio Has Not Come Without Sacrifice: Dr Abdur Rehman paid the ultimate price. He believed he had a 'sacred' duty to vaccinate children. He coordinated polio vaccination campaigns to stamp out the crippling childhood virus in the border areas of Pakistan and Afghanistan. His family tried to convince him that although this might be admirable work, it was also dangerous.

This heartbreaking story is one more reason we will never stop supporting the amazing and determined effort by the Rotary Foundation to eradicate this terrible disease. Thank you survivor Brad Fuller for bringing this article to our attention.

Anesthesia Concerns

We love this quote from anesthesiologist Dr. Calmes:

"Anesthesia and surgery is a process that involves anesthesia, surgery and hospital care. For an optimal outcome, ALL must be at high levels of performance and achievement.
You, the patient, must work to be sure you get these."

The QR code on our updated Anesthesia Warning Card allows your physician easy and immediate access not only to the articles, but to the authors of the articles as well. Regardless of your Anesthesia experiences (or lack thereof), we are discovering that when survivors show this card (available in both English and Spanish) to their physicians, the conversation that results can often lead to the "optimal outcome" Dr. Calmes refers to.

Are you having trouble downloading the card from our website? We're happy to send you one. Whether you are inside or outside the US - Please Send a Stamped, Self Addressed Envelope to:

PPSN – Anesthesia Card, PO Box 557, Doylestown, PA 18901 *

Our thanks goes to John Bach, MD, Norma M Braun, MD, Richard L. Bruno,PhD, Selma Calmes, MD, Polio Denmark, Polio Services Victoria, Australia, Anesthesiology Magazine with the physicians from the University of Manitoba, Canada, William M. DeMayo, MD and Richard Rosenstein, DO, for their participation in and support of this project.

* Note: Please let us know if you would like it in Spanish

ANESTHESIA WARNING!

I am a **Polio Survivor**

- **Easily Sedated**, and can be difficult to wake
- Can have difficulty **breathing** and **swallowing** with anesthsia
- **Hypersensitive** to **pain** and **cold**

May need heated blanket and increased pain medication post-op

www.polionetwork.org/anesthesia-card

Anesthesia Specifics for PPS

Selma H. Calmes, MD

1. Post-polio patients are nearly always very sensitive to sedative meds, and emergence can be prolonged. This is probably due to central neuronal changes, especially in the Reticular Activating System, from the original disease.

2. Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the poliovirus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater sensitivity to relaxants. Also, many patients have a significant decrease in total muscle mass. Neuromuscular monitoring intraop helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.

3. Succinylcholine often causes severe, generalized muscle pain postop. It's useful if this can be avoided, if possible.

4. Postop pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to "spill-over" of the inflammatory response. Spinal cord "wind-up" of pain signals seems to occur. Proactive, multi-modal post-op pain control (local anesthesia at the incision plus PCA, etc.) helps.

5. The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarring in the anterior horn "spills over" to the intermediolateral column, where sympathetic nerves travel). This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anesthetics are given.

6. Patients who use ventilators often have worsening of ventilatory function postop, and some patients who did not need ventilation have had to go onto a ventilator (including long-term use) postop. It's useful to get at least a VC preop, and full pulmonary function studies may be helpful. One group that should all have preop PFTs is those who were in iron lungs. The marker for real difficulty is thought to be a VC <1.0 liter. Such a patient needs good pulmonary preparation preop and a plan for postop ventilatory support. Another ventilation risk is obstructive sleep apnea in the postop period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.

- COMMENT: Postop respiratory failure in these patients can be difficult to manage. The patient's pulmonary physician could help by doing a preop evaluation and being involved in postop ventilatory management. This situation might call for the resources of an ICU in a major medical center.

7. Laryngeal and swallowing problems due to muscle weakness are being recognized more often. Many patients have at least one paralyzed cord, and several cases of bilateral cord paralysis have occurred postop, after intubation or upper extremity blocks. ENT evaluation of the upper airway in suspicious patients would be useful.

8. Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fractured during positioning for surgery. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass or tendons.

9. NEW IDEAS/THOUGHTS:

- Spinals: Recent studies demonstrating the presence of cytokines in the CNS of PPS patients lead me to be less enthusiastic about using spinal/epidural anesthesia. There is no data on this situation, and there are so many benefits to this regional anesthesia, and they might be suitable in some situations. Lidocaine would not be a suitable drug choice for PPS patients.
- Regional anesthesia: Should the peripheral nerves of PPS patients be exposed to local anesthetics, especially for long periods postop? There is no data, but many PPS patients have

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atrophied peripheral nerves. Perhaps smaller doses of local anesthetics and avoiding continuous postop infusions would be safer.

- Above-the-clavicle blocks(supraclavicular and interscalene): These have a high risk for diaphragmatic paralysis and should probably not be used in PPS patients, unless the patient can tolerate a 30% decrease in pulmonary function.

SUMMARY: PPS patients can have anesthesia and surgery safely, with careful preparation. Anesthesia and surgery is a process that involves anesthesia, surgery and hospital care.

- For an optimal outcome, ALL must be at high levels of performance and achievement!
- You, the patient, must work to be sure you get these. Remember, few surgeries are truly urgent and you usually have time to get data from the web, the state's hospital licensing department, the state's medical board and other resources.
- You should also research the operation and its consequences, to be sure you can deal with them. Don't rush into anything until you're satisfied you'll get the best.

You deserve it.

Selma H. Calmes, MD

Patients With A Polio History – What Anaesthetists Need To Know

By Liz Telford OAM, Post Polio Victoria (Australia) for ANCZ Bulletin

"When presenting for surgery, people with a history of polio are often told that they are a rarity. It is estimated, however, that up to 40,000 people contracted paralytic polio in Australia between 1930 and 1988. It is also reported that migrants and refugees are increasingly attending polio-related services, so although there are no official figures, we know that there are thousands of people with polio-related issues across Australia from as young as 30 years old. Hospitals will be seeing polio survivors for at least the next six decades, with needs as broad ranging as childbirth to heart repairs.

Members of advocacy group, Post Polio Victoria. Photo Source

We are generally not keen on having surgery due to the unique risks, however the misconception that we are a rarity indicates a lack of awareness by those who should be informed. Often with a background of negative childhood medical treatment, we have the responsibility of educating the medical staff looking after us in hospital, which creates a stress beyond the normal preoperative concerns.

Not only is the onus on us, the patients, to remember to inform the hospital of our polio history, we must also provide information on its surgery and postoperative implications, not knowing how this potentially lifesaving information will be received or if it will be heeded. Polio does not "end" with the attack on the anterior horn cells of the spinal cord.

To manage anaesthesia risks anaesthetists must understand the post-polio sequelae (PPS), the neurological and muscular skeletal condition that develops 20 to 40 years later. The resulting cold intolerance, skeletal deformity, muscle weakness and denervation, osteoporosis and respiratory issues pose a number of risks. There is often increased sensitivity to sedating drugs, opiates, muscle relaxants and anaesthetic drugs (4)(5).

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The usual question about drug allergies is not enough, as while the patient with PPS may not have any allergies they may not be aware of the sensitivity of their central nervous system.

"The power imbalance between doctor and patient is often exacerbated when there is a history of childhood disability."

Anaesthetists need to know that not all people with a history of polio will raise these issues. Some will not realise that their polio history is relevant to their impending surgery, or have the knowledge, confidence or the command of the English language to provide this information. The power imbalance between doctor and patient is often exacerbated when there is a history of childhood disability. It is important for the anaesthetist to take the time to understand the patient's polio history. We have many and varying hospital experiences. One anaesthetist initially refused to read the online resource regarding anaesthesia and polio provided by a patient about to have emergency surgery at a Melbourne hospital. With only a tense and brief preoperative discussion of her polio history, postoperatively the patient experienced hypotension, extreme cold and suffered a lower back injury from poor positioning.

Positive examples occur such as when the anaesthetist took the polio history of a patient, read the information offered and discussed the PPS implications. The risk for the patient was reduced, and she had her surgery with the confidence that the anaesthetist understood her specific situation. Polio already affects all aspects of our lives. It should not also be our responsibility to ensure that hospitals are safe for us. The COVID-19 pandemic, and those affected, will be considered and studied for years to come. Those of us living with the impacts of the global polio epidemic or lack of vaccination programs would like to have the confidence that when in hospital we are in the hands of people who have taken the time to educate themselves about our condition."

Article Source: ANCZ Bulletin, Spring, 2020

This Polio Doctor Believed he had a 'Sacred' Duty to Vaccinate Children – He Paid the Ultimate Price

Story by Ben Farmer, Ashfaq Yusufzai

"The family of Dr Abdur Rehman had pleaded with him to give up his work. Coordinating polio vaccination campaigns to stamp out the crippling childhood virus in the border areas of Pakistan might be admirable work, but it was also dangerous."

"Scores of Pakistan's polio workers and their police guards have been shot dead by militants who are opposed to vaccination and also see the medics as soft targets in a wider war against the state."

"On January 19, the worst fears of Dr Rehman's family were realised. The senior health official was ambushed by gunmen and shot dead as he returned from work in Bajaur district along the Afghan border. One of his police guards was injured in the attack. His death brought the number of polio staff and their police guards killed in the country to 108. Most have been community workers and policemen, going door-to-door administering drops to children when they were shot dead by motorcycle-riding assassins.

Dr Abdur Rehman was ambushed by gunmen as he returned from work along the Afghan border - Ashfaq Yusufzai© Provided by The Telegraph

Officials at the United Nations children's body, Unicef, said Dr Rehman was the first doctor to be killed on duty. His daughter, Zakira, told the Telegraph: 'He regarded his duty as very sacred and always tried to reach the accessible population and convince them of vaccination.' "

"There was no immediate claim of responsibility for the shooting. The area is infested with militants and the

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Tehrik-e-Taliban Pakistan (TTP), an umbrella group of armed factions, has been waging a long-running insurgency targeting security forces and government officials.”

Dr Rehman with one of the nine children he leaves behind - Ashfaq Yusufzai© Provided by The Telegraph

“Pakistan and neighbouring Afghanistan are the only two remaining countries where polio is endemic, after a 35-year global eradication campaign has cut cases to just a handful each year. Six cases were detected in Afghanistan in 2023 and six in Pakistan. Neither country has reported a case so far in 2024.”

“The virus has proven frustratingly difficult to finish off in this part of the world, despite huge sums of money being spent and the regular mobilisation of armies of anti-polio workers. Ranged against the campaign is a stubborn mix of suspicion, poverty and insecurity. TTP militants have in the past ordered halts to vaccinations, but opposition has also been a rallying cry for many firebrand clerics and extremist groups in the region.

“Accusations are rife that the drops are harmful, tainted with pork, or even a Western plot to sterilise Muslims, leading to boycotts and hostility. Opposition intensified when it emerged the CIA ran a fake hepatitis B vaccination programme trying to pinpoint Osama bin Laden by taking DNA samples from children to identify his relatives.”

“Dr Rehman, who leaves nine children and two wives behind, had spent his career overseeing campaigns in South Waziristan and Bajaur, two districts notorious for their militancy and violence. He often told his family it was his dream to see a polio-free Pakistan, his daughter said. ‘I am speaking to highlight the bravery of my father and dozens others who have laid down their lives for the sake of children,” she said.’ ”

“They now fear that their own lives may be at risk. Ms Rehman, a second-year student, said: ‘We are in extreme fear because we are afraid that Taliban militants will harm us. Taliban are against polio and they have already killed my father.’ ”

Scores of Pakistan’s polio workers and their police guards have been shot dead by militants opposed to vaccination - SOHAIL SHAHZAD/EPA-EFE/Shutterstock© Provided by The Telegraph

“The family are asking the government to give them accommodation in nearby Peshawar, away from Bajaur. Dr Rehman’s death comes at a time of growing optimism in the polio eradication campaign that the final few cases may be on the verge of being stamped out.”

“Campaign officials say access for the campaign in Afghanistan has improved sharply with the end of the war. The Afghan Taliban had previously banned door-to-door campaigns during their long insurgency against the internationally-backed government, accusing teams of spying on them and gathering intelligence.”

“Now the Afghan Taliban have taken power, they have removed their prohibition and the end of hostilities means polio teams have better access to the country than they have seen for several years. In Pakistan too, epidemiologists say stubborn reservoirs of the virus, in Karachi, Quetta and around Peshawar, have now been clear for some time.”

“Meanwhile, Dr Rehman’s family are left with his memory. ‘We never saw him angry,’ said Gul Meena, one of Dr Rehman’s wives. ‘He was very loving and kind towards all family members and wanted to provide education to all children, especially his daughters.’ ”

Article Source: The Telegraph, Article by: Ben Farmer, Ashfaq Yusufzai 2/21/2024

Dame Annie Jean Macnamara, MD

Polio Physician Jean Macnamara's Work Proves Viruses Can Be Vanquished

"Living through a global pandemic will have a wealth of unintended consequences positive and negative, but one will certainly have a greater appreciation for those in the medical professions - from those on the front lines treating patients to those researchers laboring behind the scenes, seeking to isolate viruses and to discover vaccines both now and in the past.

Dame Jean Macnamara worked tirelessly for the disabled, but it was her research that helped lead to the polio vaccine that she is most remembered for. ©HOWSTUFFWORKS

Dame Jean Macnamara was one such heroine. She witnessed and made remarkable contributions in her chosen profession - medicine - principally in the area of polio research, and her work with patients with partial or complete paralysis." (1)

She was born in Victoria, Australia, April 1,1899, into a family that prized hard work and education, and she excelled at both. A teenager during the First World War, was to be determined to become "of some use in the world." (2) While attending the Presbyterian Ladies College, she became the editor of the school's magazine, winning the prize for general excellence. A high-achiever from the age of 15, she graduated from the University of Melbourne in 1922 with degrees in both surgery and anatomy. She went on to become a resident medical officer at the Royal Melbourne Hospital. After completing her residency at the then Children's Hospital, she was consultant to the Poliomyelitis Committee of Victoria led by Dr. John Dale and was poised to be an honorary advisor on polio to authorities in three states. After leaving the hospital, Macnamara worked as a clinical assistant and as a children's outpatients' physician before entering private practice to focus on poliomyelitis patients. (1) (3)

By the time of the epidemic in the late 1920s, Dr. Macnamara was well positioned to respond in the laboratory. She'd had a brilliant year that included working with Sir Frank Macfarlane Burnet (who later won a Nobel Prize for medicine) and fellow Walter and Eliza Hall Institute researcher, Dr. Lucy Bryce.

"Preventing the spread of the disease was seen as the holy grail of public health – a mission that medical scientist Dame Jean Macnamara prosecuted with zeal, the welfare of children her guiding light." (3) It was her conclusion that immune serum needed to be used in polio treatment during the pre-paralytic stage. Although it was a treatment that was never widely administered, she published and defended her results in both Australian and British journals.

However, it was her discovery in 1931 of more than one strain of the polio virus (along with Australian virologist Sir Frank Macfarlane Burnet) that made her reputation. "Burnet agreed to collaborate with Macnamara to see if the convalescent serum would be effective against the latest outbreak - and it was this work that gave rise to a major discovery. While carrying out experiments at the institute, Burnet thought it might be interesting to compare the Melbourne strain of the virus with a virulent strain obtained from the Rockefeller Institute, called MV." (3)

Two laboratory monkeys had each recovered from paralysis from one of the strains. But once tested with the other strain, both animals were again struck down with polio - this time fatally. The two strains did not cross immunize and showed there was more than one type of polio virus. Their finding is credited as one of the contributions that led to a direct impact on the development of the polio vaccine in 1955. (2) (3)

This earned her the award of Dame Commander of the Order of the British Empire.

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She traveled to England and North America on a Rockefeller Fellowship from September 1931 to October 1933, even meeting with President Franklin D. Roosevelt, himself a victim of polio. She married a fellow physician, dermatologist Joseph Connor in 1934.

Lady Jean Macnamara
Photo Source:
El País de España

In addition to her passionate interest in curing disease, Dr. Macnamara sought to alleviate the pain and suffering it left in its wake. She is credited with ordering the first artificial respirator (or ventilator) in Australia. She introduced novel approaches to rehabilitation and splinting damaged limbs, most developed in conjunction with conversation with patients and her own splint-maker. She was a tireless advocate for people with disabilities long before it was in style to do so.

She died in 1968 of heart disease. In 2018, when she was honored in Melbourne, her daughter (Merran Samuel) said: “Dame Jean was a humble and shy person, who was driven by a sense of duty and service. Educated on a scholarship, she was one of the first two women residents at the Royal Children’s Hospital.”

According to Google, Dame Jean Macnamara “applied her tireless work ethic to better understand and treat various forms of paralysis including polio.” Google honored her with their “doodle” on April 1,2020.
“The doodle with which Google is honoring her depicts Dame Jean Macnamara working directly with children to give them a hope to one day walk without needing crutches (with the two sides of the mirror depicting before and after.)” (2)

“Today's #GoogleDoodle honors Australian medical scientist Dame Jean Macnamara, whose work contributed to the development of a successful polio vaccine in 1955.” (April 1, 2020)

Article Sources:
(1) Polio Doc Jean Macnamara's Work Proves Viruses Can Be Vanquished
(2) Eight things to Know About Pioneering Polio Doctor Dame Jean Macnamara
(3) Multiple strains of the polio virus discovered, an early step towards the Salk vaccine.
(4) Jean Macnamara

Thank You

Thank you for the inspiration that comes with your kind words and generous donations.

Dental Anesthesia – Have you had any issues?

We're hearing from survivors that they are having / or have had an issue with Dental anesthesia. Medications have changed through the years. We have two professionals who are curious about the following Dental Anesthesia/Sedation concerns:

1. What was your procedure for?
2. What medication did you receive?
3. What was your issue?
4. When did this happen?
5. Did you tell your dentist/oral surgeon what occurred?

Please email us, putting "Dental Anesthesia" in the Subject line.
info@polionetwork.org

More on this topic:

Preventing Complications in Polio Survivors Undergoing Dental Procedures
By Richard L. Bruno, HD, PhD

Each and every day that goes by . . .

Ordinary People do Extraordinary Things.

Unless noted with the article, feel free to copy and share what you see. Always give credit to the original source, include a visible, working link to our website: www.polionetwork.org and email us a copy of what you "share". THANKS.

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