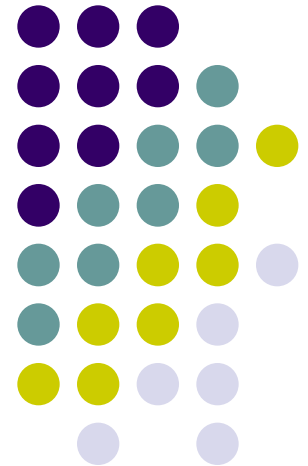


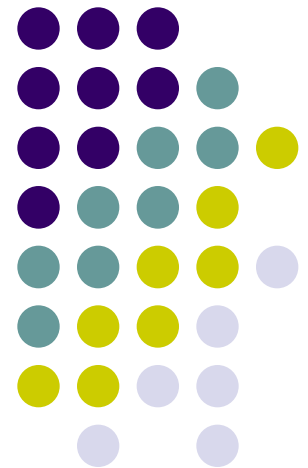
The Post-Polio Syndrome: An Orphan Disease

Peter Nolan FRACP
Continuing Medical Education

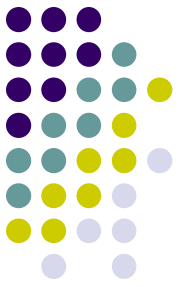


“I knew Jesus before he was a Superstar”

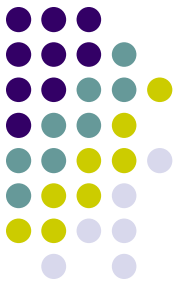
A song by Francis Henry
Beware of the Marketing
Manager!



A personal history



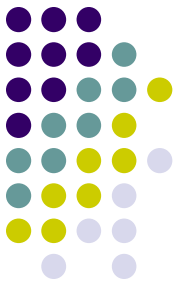
- My Grandfather was an orphan.
 - No birth certificate
 - His mother died when aged 12.
 - His Mother buried in an unmarked grave.
 - Left school age 10 to be a house boy for the landed gentry
 - Joined the AIF in 1915 with no next of kin on his enrolment papers
 - No personal possessions when he left in 1915 and arrived back in Australia in 1919.



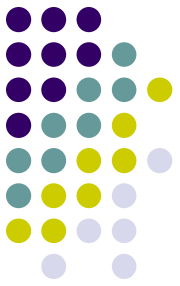
What is an Orphan?

- Form the Greek word *Orphanus* meaning bereaved.
- Bereaved; Rob, dispossess; usually of immaterial things e.g. life , hope etc.
 - Leave desolate.
- Bereaved of parent.
- Bereft of previous protection and advantages.

Why is Post-Polio an Orphan disease?



- No next-of kin. Indeed some people consider that it doesn't even exist.
- Dispossessed of any formal recognition by the modern health care system.



1985

Sleep Apnea Syndrome after Poliomyelitis

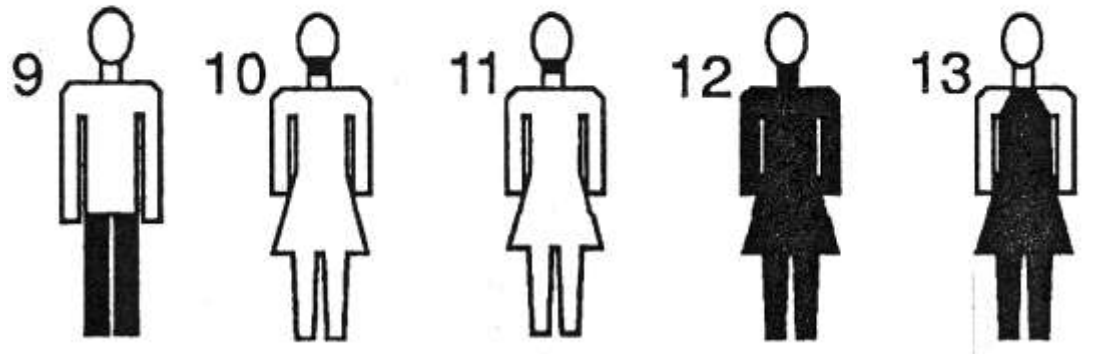
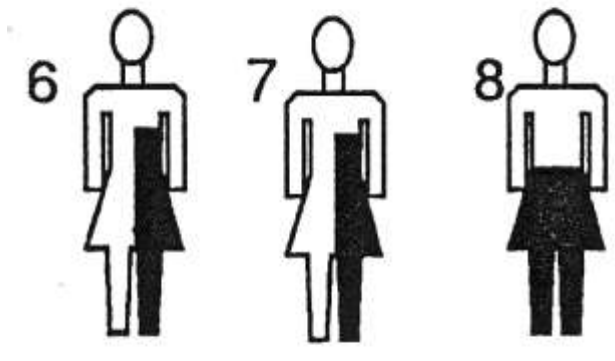
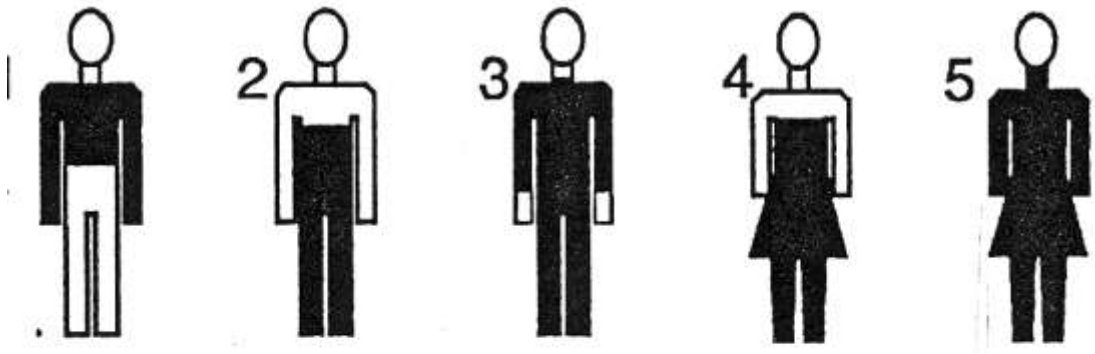
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Introduction

A variety of neurologic diseases can cause abnormal breathing during sleep, but poliomyelitis appears unique in that sleep-disordered breathing (SDB) can occur many years after apparent recovery from the acute disease. We recently studied a young man whose case illustrates several mechanisms pertaining to the pathogenesis of this delayed form of the sleep apnea syndrome.

SUMMARY We present a case of severe breathing abnormality during sleep in a young man who had had poliomyelitis 20 yr before. His sleep disorder led to respiratory failure and cor pulmonale, which were greatly improved by oxygen therapy. A study of this case and those previously described supports the notion that brainstem damage during acute poliomyelitis is important in the later appearance of sleep-disordered breathing. In addition, such patients usually have mechanical abnormalities involving the thoracic cage and respiratory muscles. These ventilatory restrictions amplify the pathophysiologic effects of abnormal central nervous system control of breathing during sleep, and we suggest that their presence has a key role in the development of sleep apnea syndrome in these patients.

AM REV RESPIR DIS 1983; 127:129-131



Respiratory function during wakefulness and sleep among survivors of respiratory and non-respiratory poliomyelitis



T.E. Dolmage, M.A. Avendano, R.S. Goldstein

Respiratory function during wakefulness and sleep among survivors of respiratory and non-respiratory poliomyelitis. T.E. Dolmage, M.A. Avendano, R.S. Goldstein.

ABSTRACT: The purpose of this study was to determine whether there is a difference in respiratory mechanics and gas exchange between polio survivors and healthy, age-matched controls during wakefulness and sleep.

Polio survivors were divided into four groups. The first group included those who had evidence of respiratory muscle involvement originally (P_{RM}) and the second group included those who had bulbar muscle involvement originally (P_{BM}). The third and fourth groups had only limb involvement originally but were separated by absence (P_{SL}) or presence of a scoliosis (P_{SS}) at the time of their evaluation.

Each subject completed baseline and one year follow-up measurements of lung volumes, diffusion, flow rates, respiratory muscle strength, central and peripheral chemoreflexes and arterial blood gases. Sleep measurements included a full respiratory polysomnographic study.

Fifty polio survivors and 13 controls completed the study. The P_{RM} and P_{SS} groups had an elevated arterial carbon dioxide tension (P_{aCO_2}) (mean \pm SE 6.0 \pm 0.4 and 6.0 \pm 0.3 kPa, respectively), reduced vital capacity (2.8 \pm 0.3 and 2.9 \pm 0.3l, respectively), reduced maximal inspiratory pressure (-5.9 \pm 0.7 and -5.4 \pm 0.8 kPa, respectively) and reduced maximal expiratory pressure (9.8 \pm 1.1 and 9.1 \pm 1.2 kPa, respectively), when compared with non-polio controls. During sleep P_{RM} and P_{SS} groups experienced a higher P_{aCO_2} (6.5 \pm 0.5 and 6.7 \pm 0.4 kPa, respectively) and a lower arterial oxygen saturation (S_{aO_2}) (89 \pm 4 and 86 \pm 3%, respectively). There were no differences among groups for diffusion, flow rates and chemoreflexes. All other polio survivors showed essentially normal respiratory function.

A respiratory evaluation is important in polio survivors if there is a clear history of initial respiratory muscle involvement or the finding of a kyphoscoliosis many years later. This study does not support previous reports suggesting respiratory dysfunction may occur among those who had only limb involvement at the time of their acute polio.

Eur Respir J., 1992, 5, 864-870

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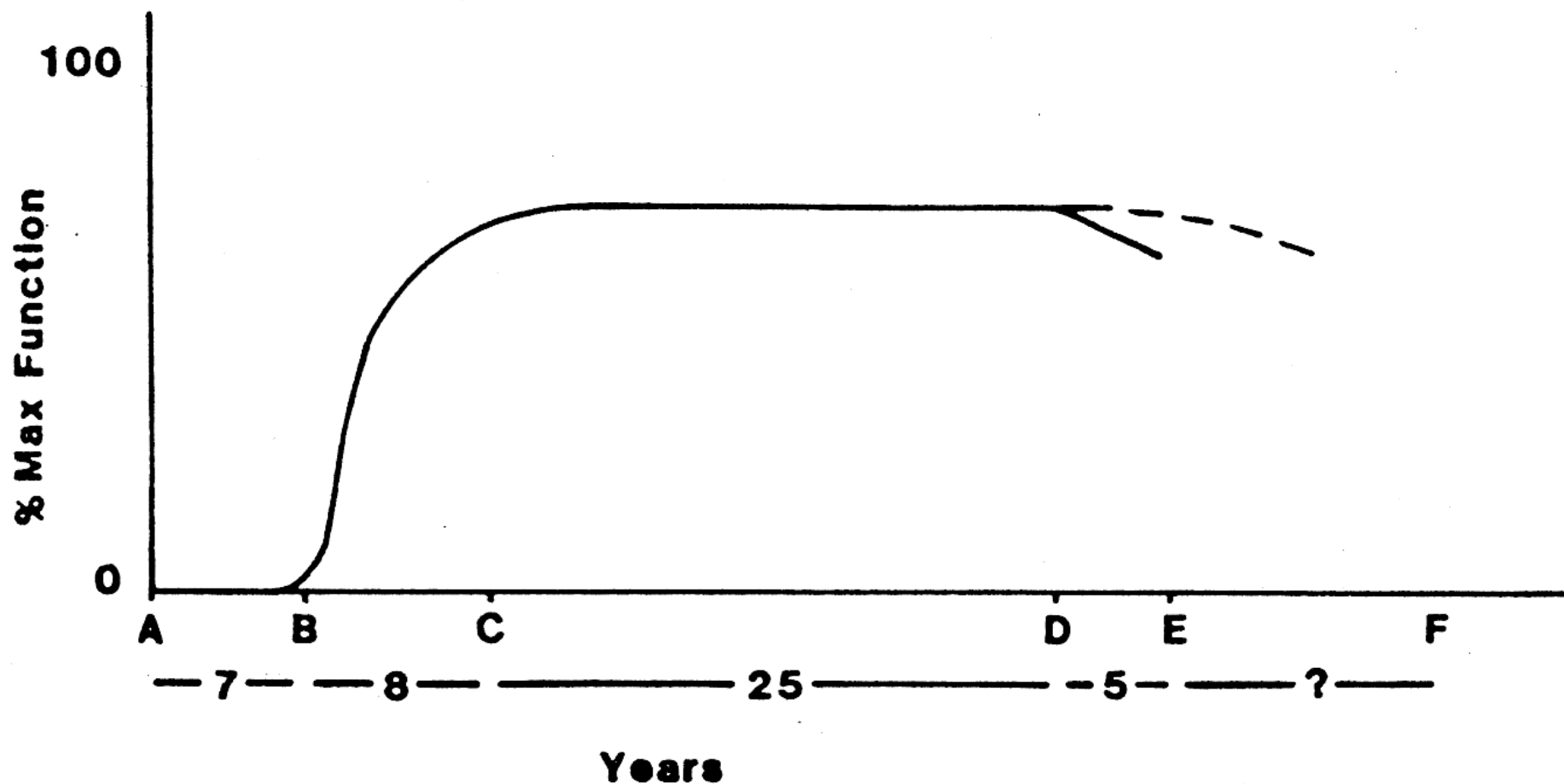
This study was supported in part by the Ontario Ministry of Health (Grant 02189), the Ontario March of Dimes, the West Park Hospital Foundation and the Respiratory Health Network of Centres of Excellence.



peutic interventions. A typical evaluation consisted of seven components:

- 1) A detailed medical history with special attention to current health problems as well as the extent of initial involvement from polio, the period of recovery, the duration of neurologic and functional stability, and the time of onset of new health problems;
- 2) A physical exam with special emphasis on assessing the musculoskeletal and nervous systems;
- 3) An electromyogram (EMG) and nerve conduction study of selected muscles and nerves;
- 4) A biomechanical and functional evaluation with special attention to orthotic and adaptive equipment needs;
- 5) A basic panel of screening laboratory tests that were supplemented with additional x rays and laboratory studies as indicated by the history and physical examination;
- 6) A psychosocial assessment; and
- 7) Referral to other members of the rehabilitation team or other medical specialists as needed.

Natural History of Poliomyelitis of Clinic Group



A Birth

B Onset of Polio

**C Maximum Neurologic
and Functional Recovery**

D Onset of New Health Problems

E Time of Evaluation

F Death

Archives of
 MED
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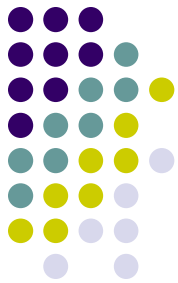
PHYSICAL MEDICINE *and* REHABILITATION

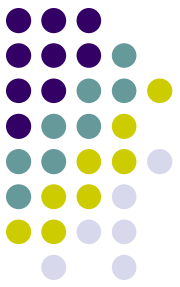
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Editor of the Month

FREDERIC J. KOTTKE, M.D.



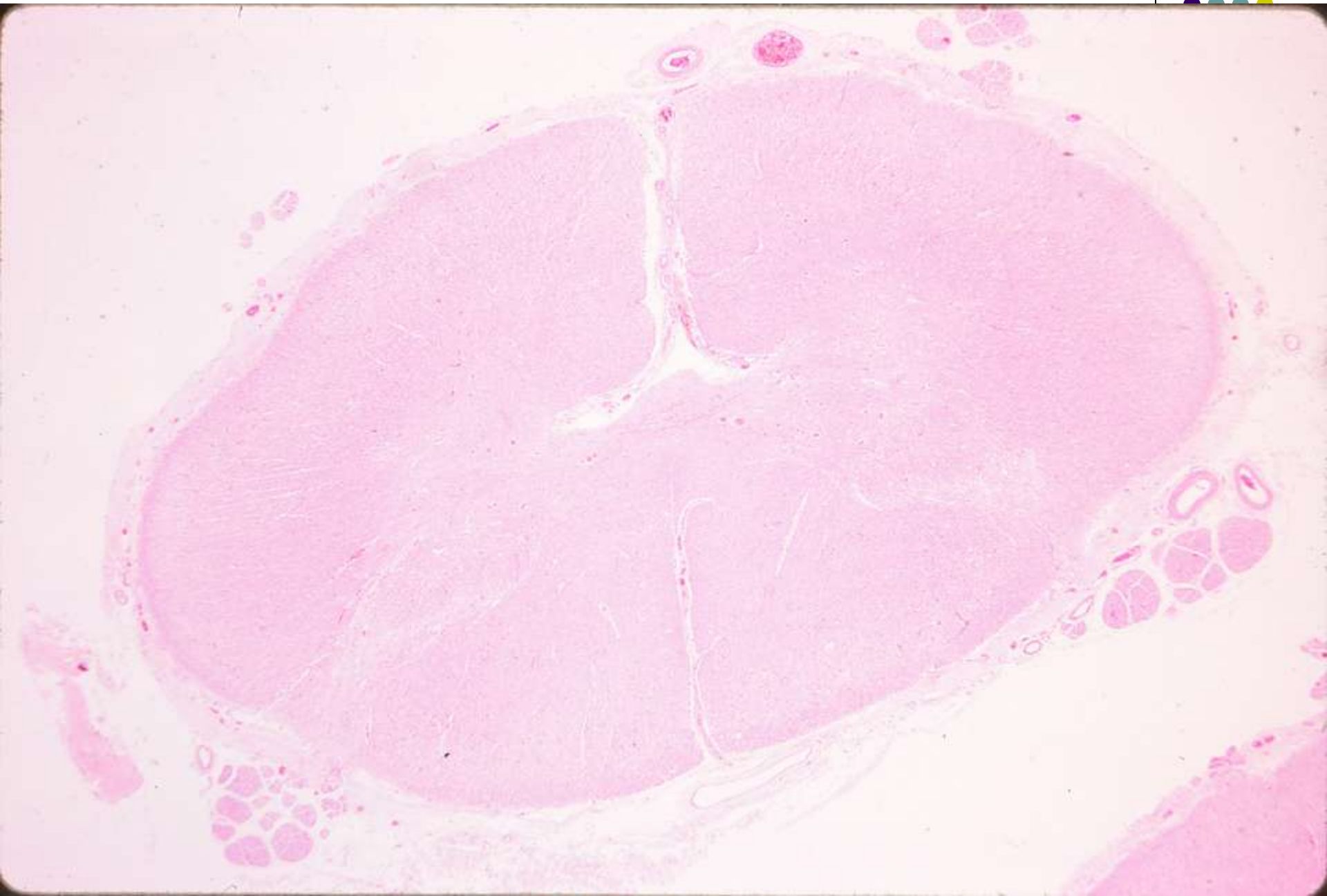


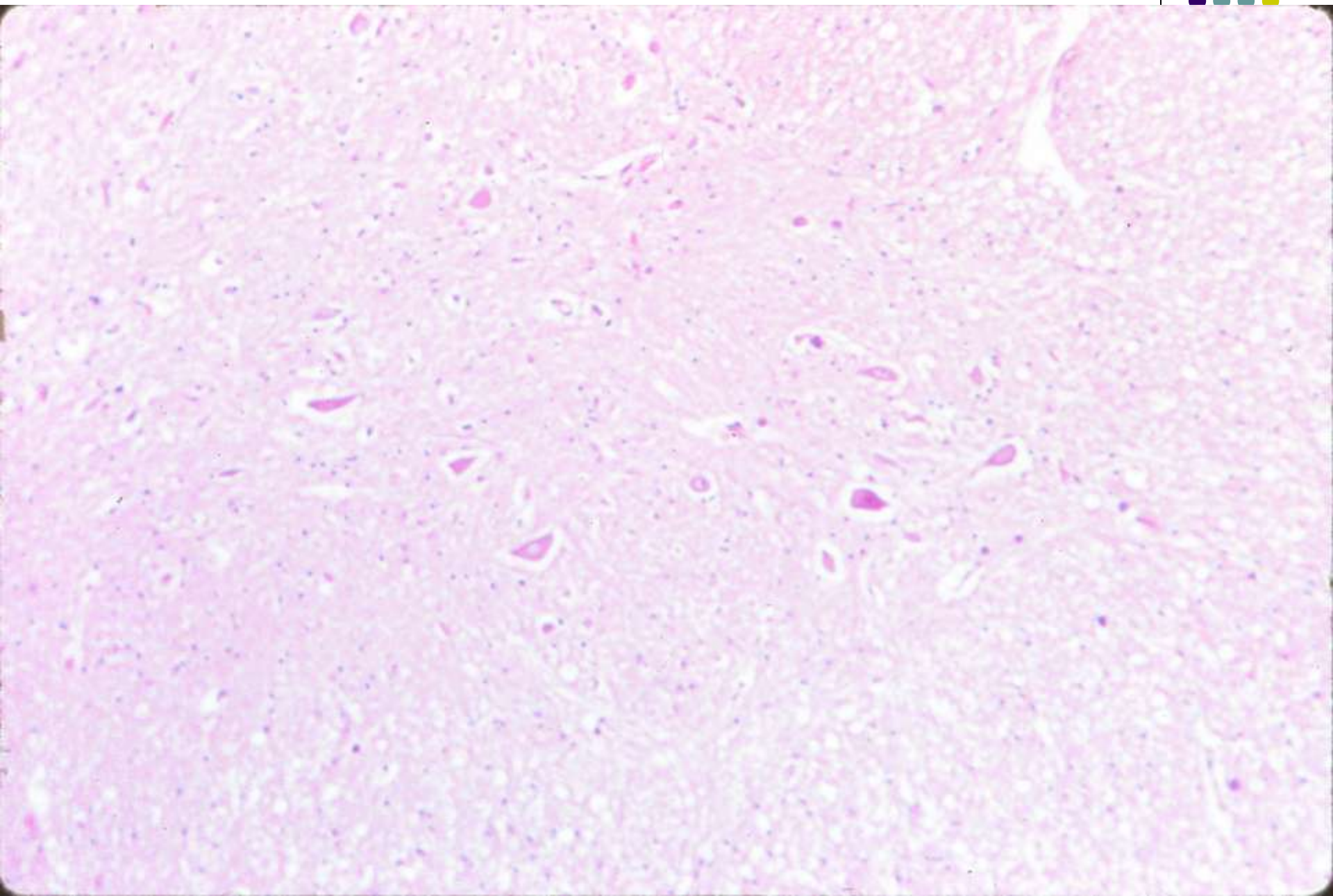
Sleep Apnea Syndrome as a Long-Term Sequela of Poliomyelitis

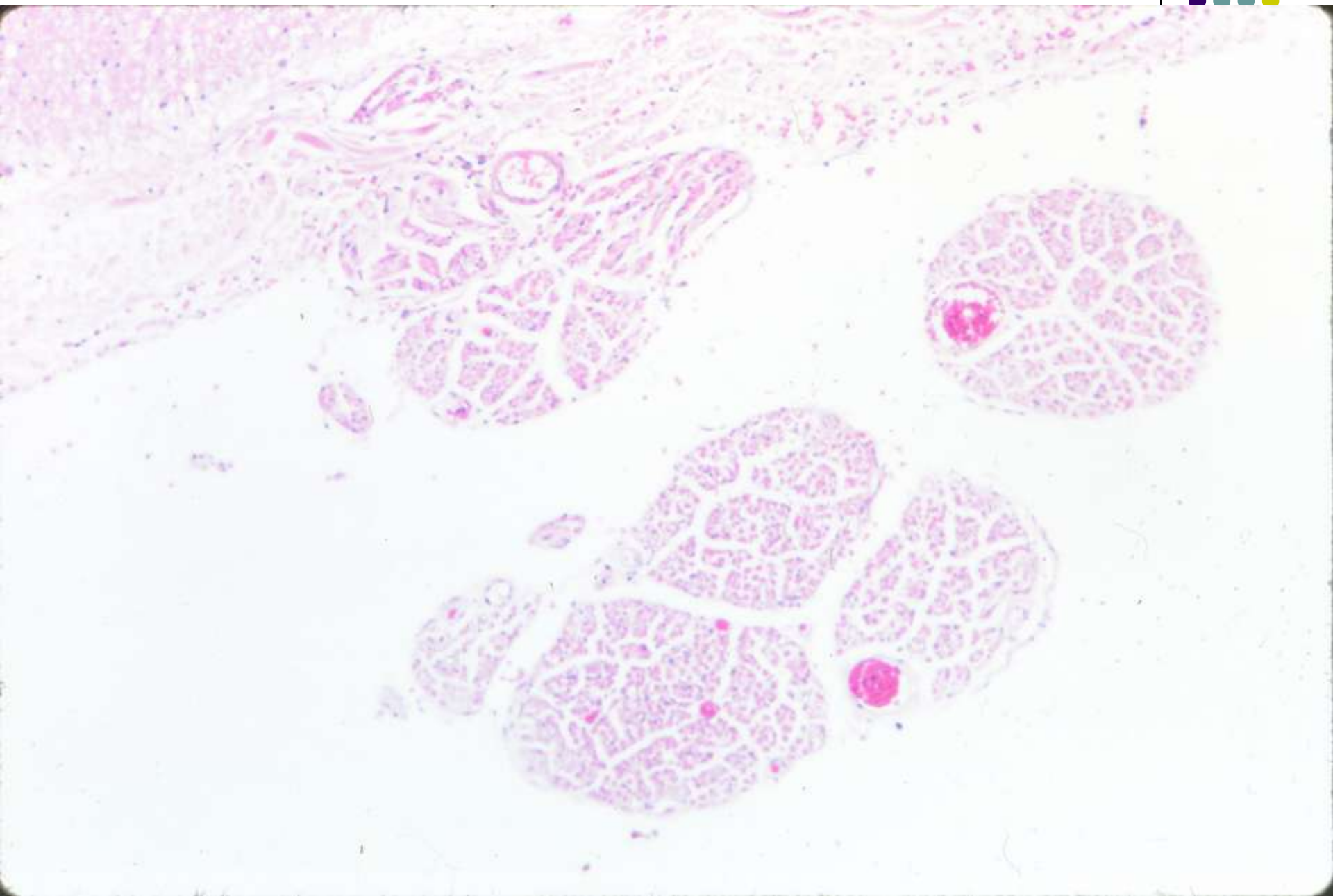
Christian Guilleminault and Jorge Motta

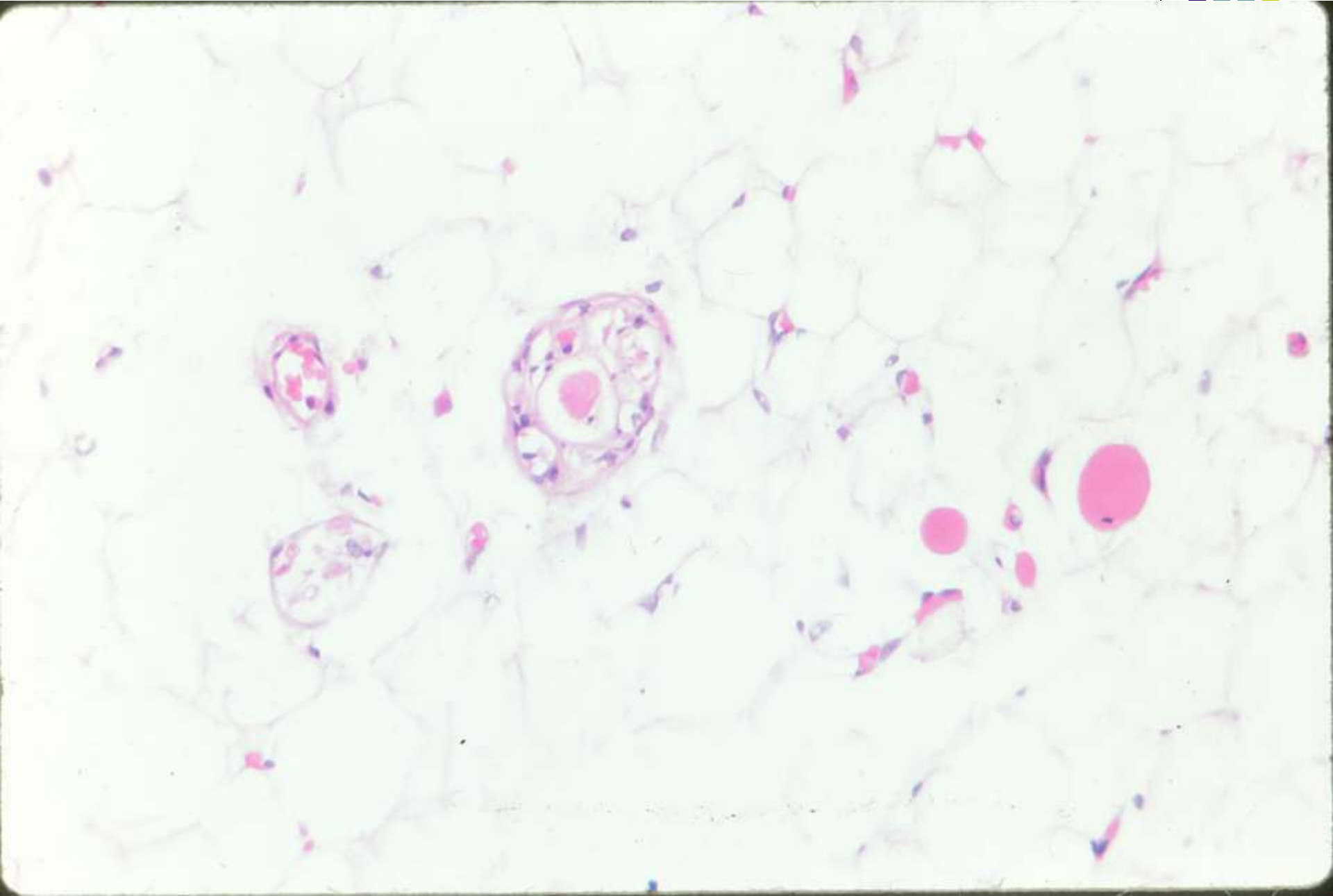


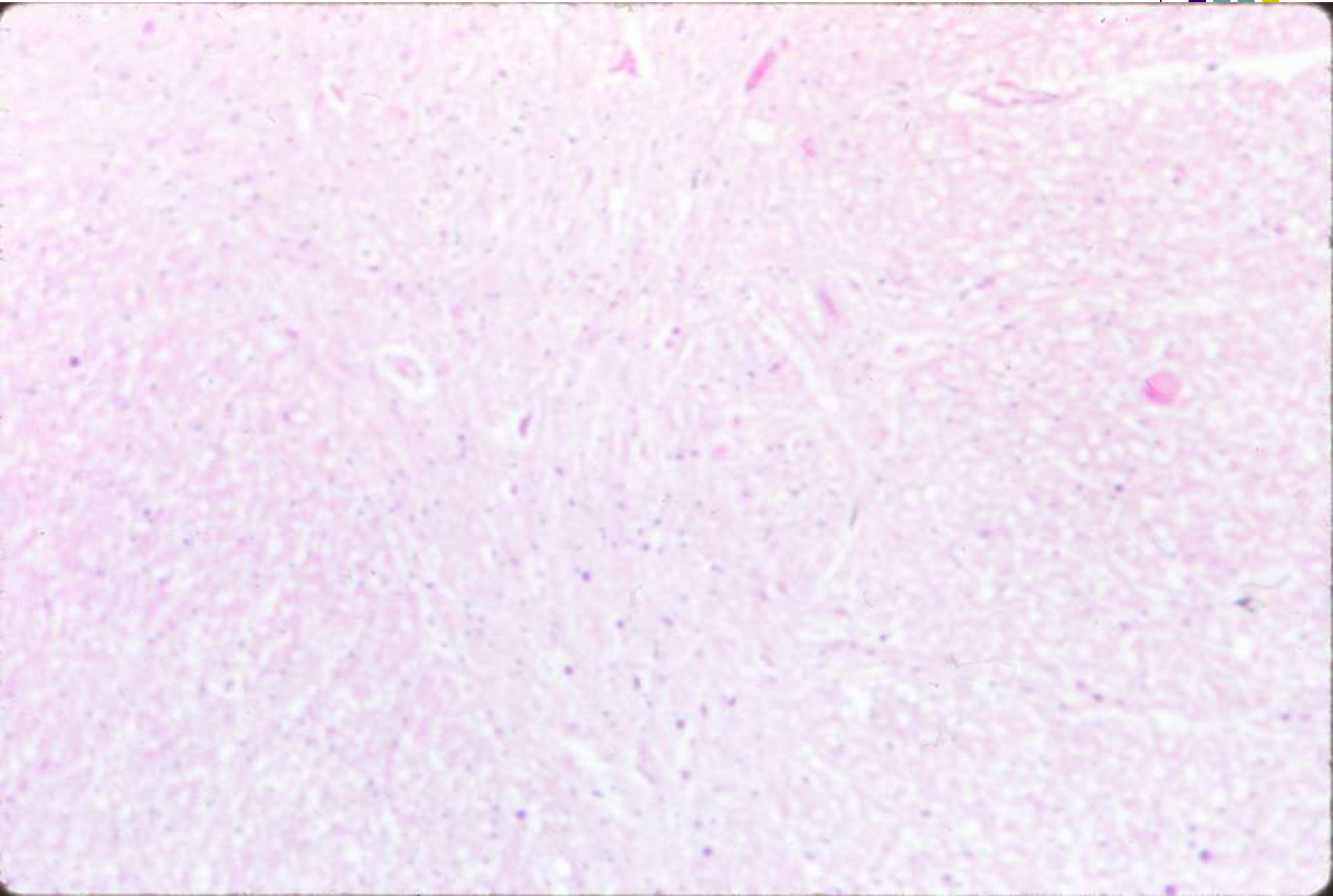




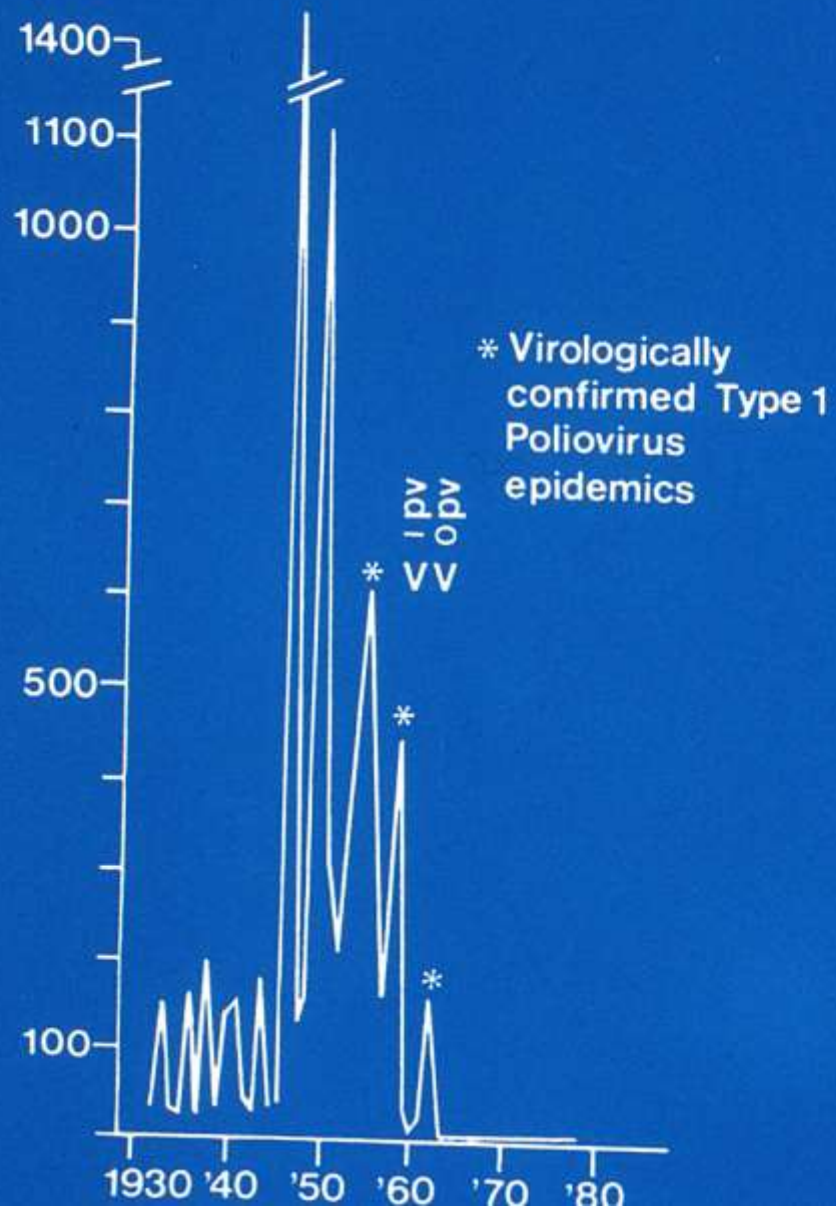




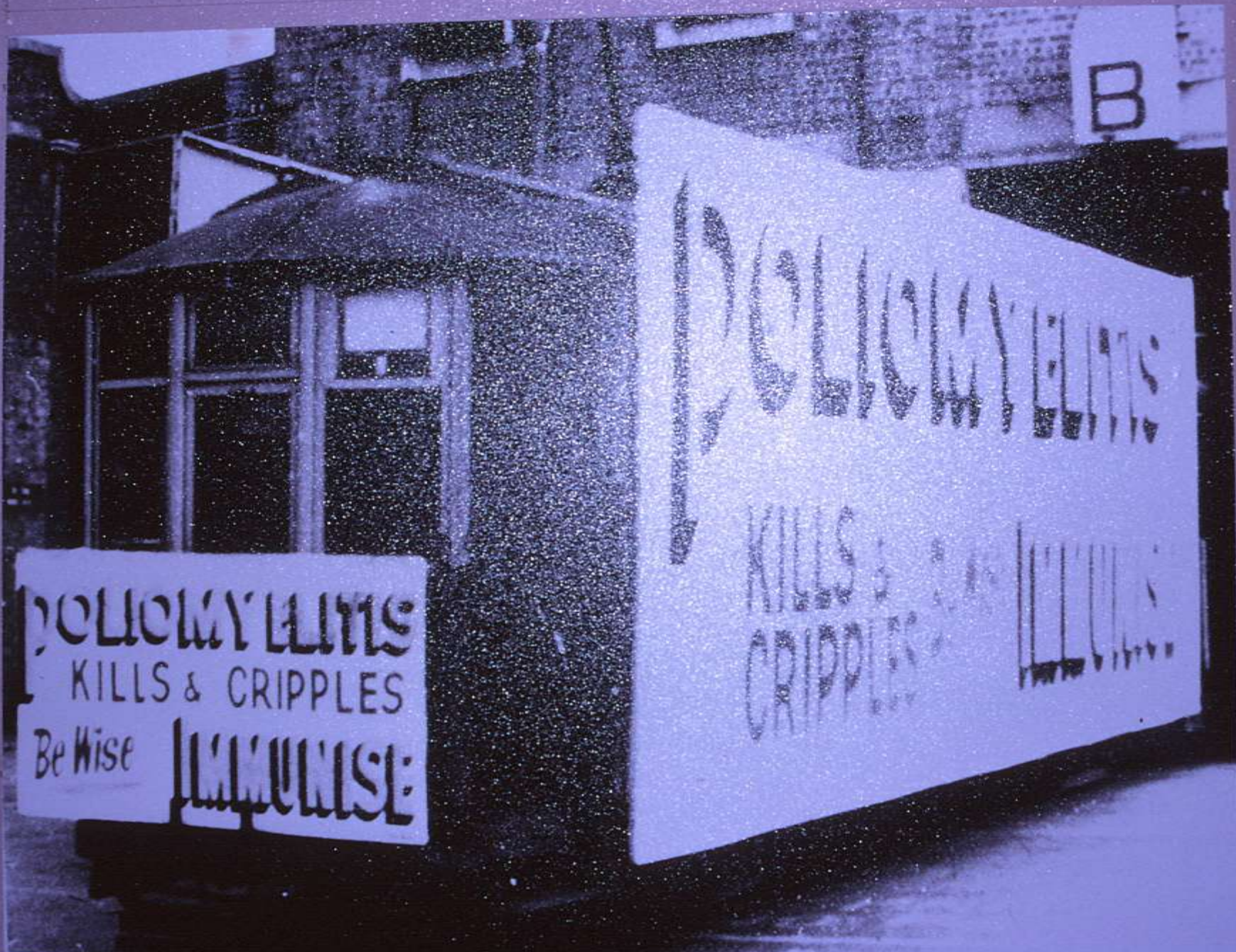








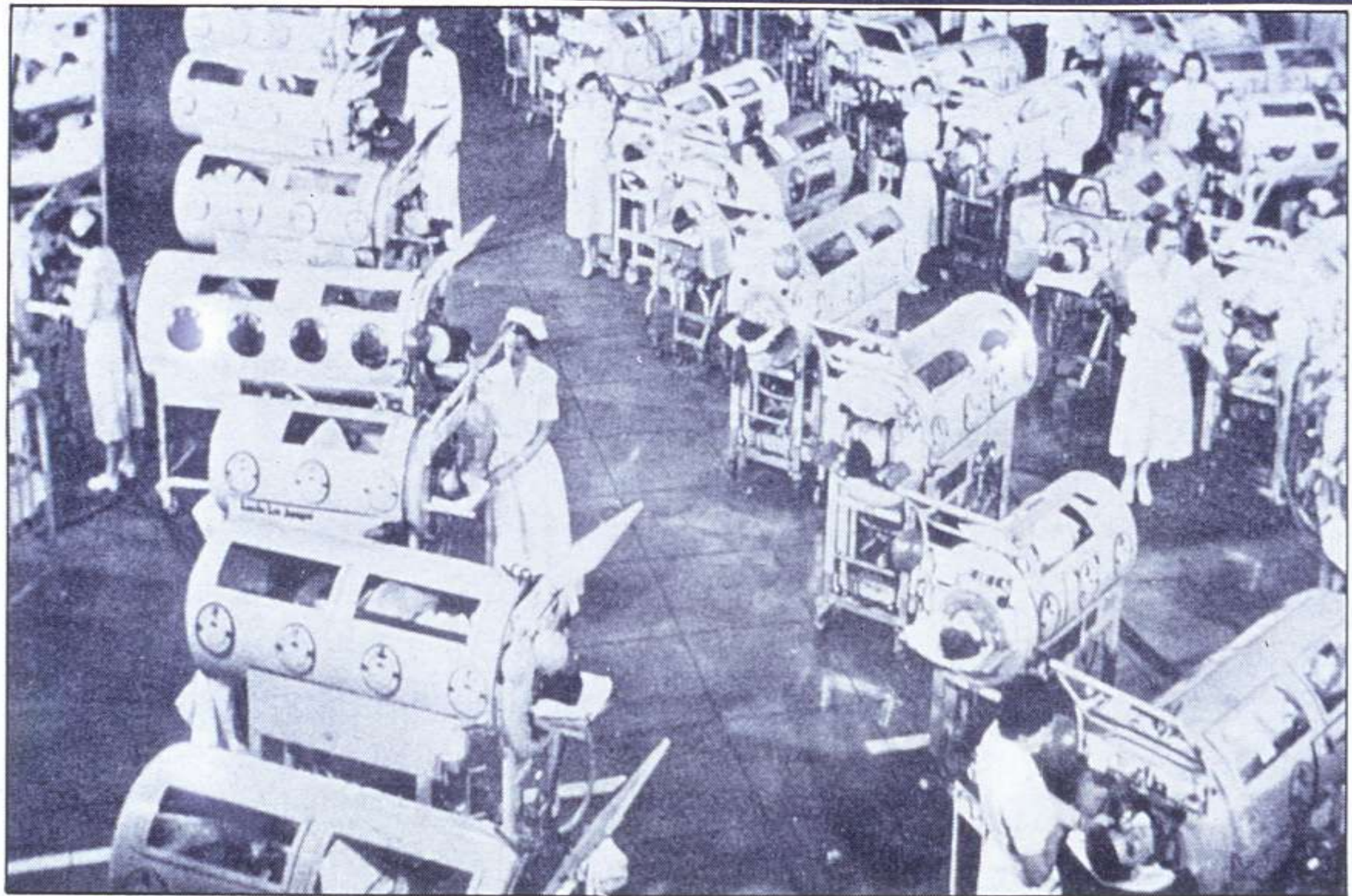
sufferers remain paralyzed



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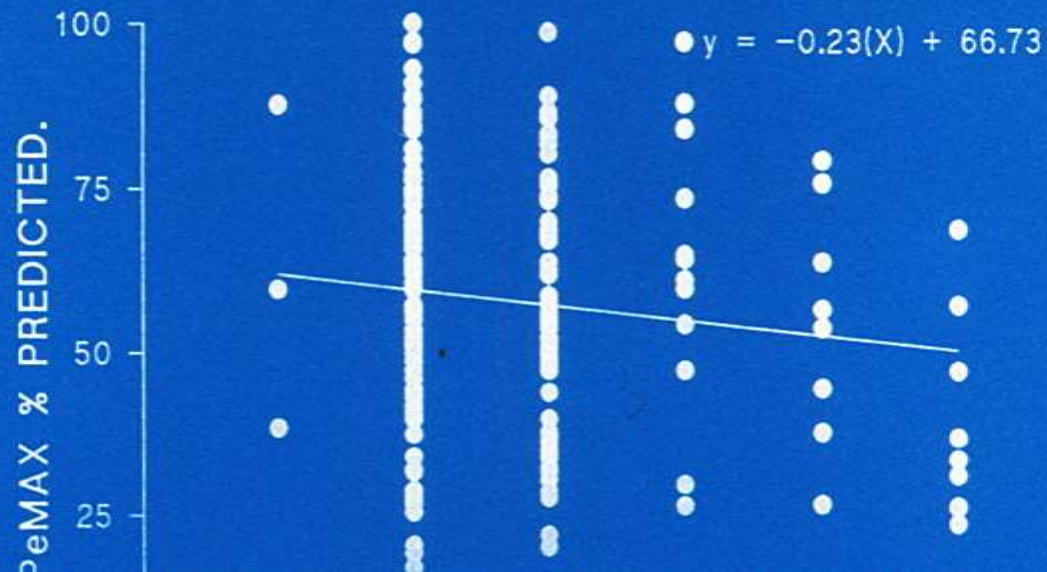
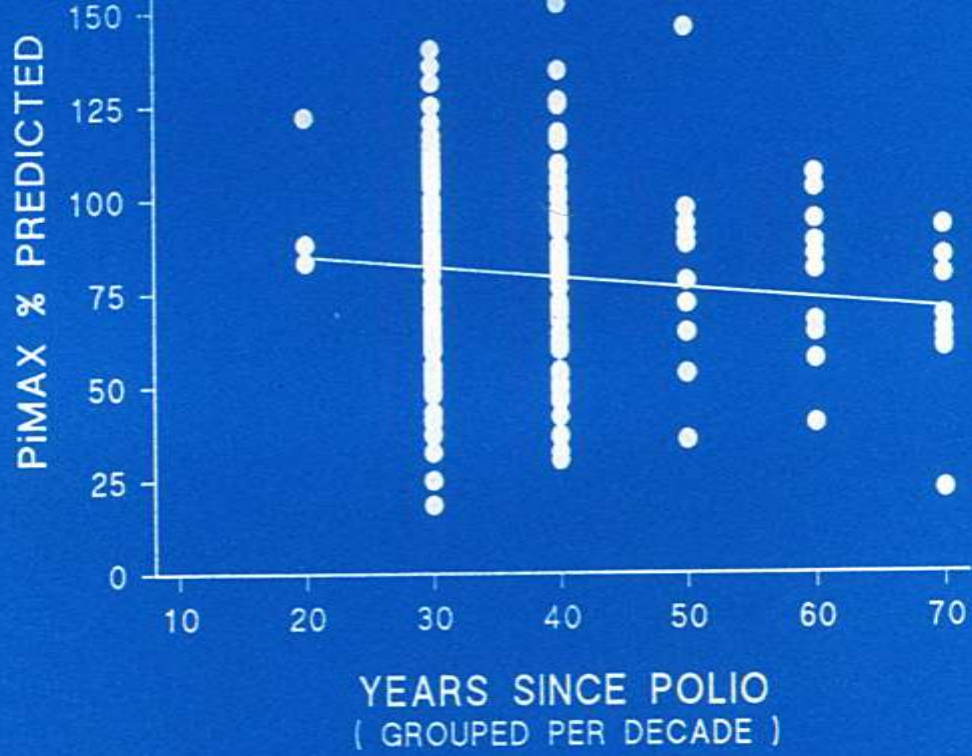
POLIO MY ENEMY
KILLS & CRIPPLES
Be Wise IMMUNISE

POLIO MY ENEMY
KILLS & CRIPPLES



An iron lung ward in the early days of treating polio.







Heroin's lonely grave her only Qld memorial

RECOGNITION was at the end of a long, hard road in Sister Elizabeth Kenny's life so she should not be greatly disappointed that 40 years after her death no suitable hometown memorial exists for this international heroine of the dark age of poliomyelitis.

If you are middle aged you will remember pain, infantile paralysis it used to be called back then, the dread disease of our school days. Everyone knew someone who was struck down in the 40s and 50s. It has been forgotten since the miracle of the vaccine conquered it.

But the memories come back as you stand by Sister Kenny's grave on a silent, sitting hill just outside her darling Downs hometown of Nobby.

It is in a tiny cemetery, as quiet a tiny town, and as you approach you expect to be sedately attracted by a formal one or monument of some significance, certainly something that might stand out on the norm of a country cemetery on a lovely hill.

Instead, the last earthly remains of Sister Kenny lie beneath a white slab marked simply by a flat but slightly raised marble plaque.

It is neat but disappointing, the more so because the simple inscription to this very noble lady gives her age inaccurately as 66 rather than her 72 years when she died in 1952. Then again, if it was anything like the ones I know, she will be thankful for that slightly fltering mistake.

But disappointing it is when you remember this is the grave of a Nobby raised woman whose unorthodox methods for treating polio were adopted in 14 countries and saved countless thousands of polio sufferers from lives as cripples, despite being constantly derided by sections of the medical establishment.

This is the woman who in many honors, mainly in the United States, where she was once named Woman of the Year and for 10 consecu-



Kavanagh's
Queensland

This is the woman whose life was portrayed in film by Hollywood star Rosalind Russell, a film which attracted more than 20,000 fans to New York's Times Square to see her at her first world premiere in 1946.

And there she lies in an unpretentious Nobby grave that would no doubt have been her modest epitaph had she never aspired to any thing more than a life on the family farm.

That life apparently was not for such a woman as Elizabeth Kenny. She developed a consuming interest in medicine when, as a youngster recovering from a severely broken wrist sustained in a riding accident, her Toowoomba doctor gave her a book on human muscle structure. It was the foundation of a nursing career unquiescent in Australia.

Her first ambition was to become a missionary in India and she studied nursing with that career in mind. But she soon became aware that there was a great need for medical services in her own district and she decided to become a bush nurse.

In 1911 she was confronted with her first case of polio, a small girl on a farm outside Nobby whose limbs were twisted and deformed by the disease. Sister Kenny telegraphed her doctor in Toowoomba describing the symptoms and asking advice.

The doctor replied it was infantile paralysis, that there was no known cure and that she should do what she thought best to relieve the pain.

The accepted medical treatment was to immobilize the affected limbs with splints and bandages. The young nurse was unaware of this treatment and experimented with hot and cold



ELIZABETH Kenny ... her unorthodox methods for treating polio were adopted in 14 countries.

tion of the treatment which best lessened the pain.

Remarkably the girl recovered, whereas others untreated by the Kenny method would spend the rest of their lives crippled.

There followed an amazing career, first as an army nurse in the 1914-18 war during which she was badly wounded by a shell blast and later as an international leader, a miracle worker to many and much less to others, particularly the establishment.

But she is remembered in her hometown of Nobby as a miracle worker and there is hope that some time in the future, if the public is generous, a suitable memorial will be dedicated to her in Nobby, thanks to a small group of district residents who have formed a memorial fund committee.

It was formed four years ago with a target of \$31,000 for a brick and glass building in Nobby's main street. But after four years of fund raising in an area which has been

hit by drought the Sister Kenny Memorial Fund is still \$19,000 short.

The state and federal governments have refused to help now and in the past.

In 1925 the Queensland government constituted a Royal Commission to inquire into the validity of the Kenny method of treating infantile paralysis, spastic paralysis and birth palsy, and to compare the results of the Kenny method and the results of orthodox methods.

After a three year study was done the Kenny Royal Commission was critical of her methods, finding her claims of success in the treatment of polio were unproved.

But the medical establishment was by no means united in its condemnation of Sister Kenny.

In 1939, six leading Queensland doctors backed her with declarations that she had made an important contribution to the fight against polio and that her methods had advanced the rehabilitation of significant numbers of cases.

They urged the then Queensland premier Forgan Smith to help Sister Kenny get to the US where she might get more general acceptance for her treatment.

The government agreed to pay her fare and so began an international career that was recognised more in the US than it was in Australia.

Her clinics, which had been established in several centres in Queensland and interstate, spread to 14 other countries following her acceptance in the US.

She did not accept payment for her work but lived on a small wage pension, relying after 1945 on a trust for the disabled and a bursary.

So you can see the battle to raise money for a Sister Kenny Memorial in Nobby is running true to form.

If you would like to help raise the \$10,000 needed to complete the memorial send a donation to the memorial fund secretary, Mrs. L. Hickett, Pine Lodge, M.S. 223, Nobby 4360.



