safeMinds

Sensible Action For Ending Mercury-Induced Neurological Disorders

Acrodynia, a form of mercury poisoning in childhood, and its similarities to autism and other neurological and learning disorders of children

1. **Visual comparison: autism and acrodynia**
2. **Detailed description of acrodynia symptoms**
3. **Case report of acrodynia survivor**

Features of autism; most of which can be found to some degree in other childhood neurological and learning disorders; the exact configuration of features varies by disorder: language impairment; social impairment or withdrawal; repetitive thoughts, speech, behaviors, and motor activities, obsessions; sensory abnormalities; cognitive impairments, attention and memory difficulties; higher rate of depression, anxiety, anorexia, eating difficulties; excess salivation and thirst in some cases; flat affect; excessive crying; irritability, aggression, temper tantrums; self injurious behaviors; sleep difficulties, tiredness during the day, mixed with hyperactivity; motor problems, clumsiness, fine motor impairments; numbness in hands, feet, and mouth area; hypotonia; high heart rate, high pulse, constant high or low arousal on GSR; intermittent rashes; gastrointestinal problems, constipation, diarrhea, vomiting; immune system abnormalities; gradual disease onset in most cases; onset in early childhood

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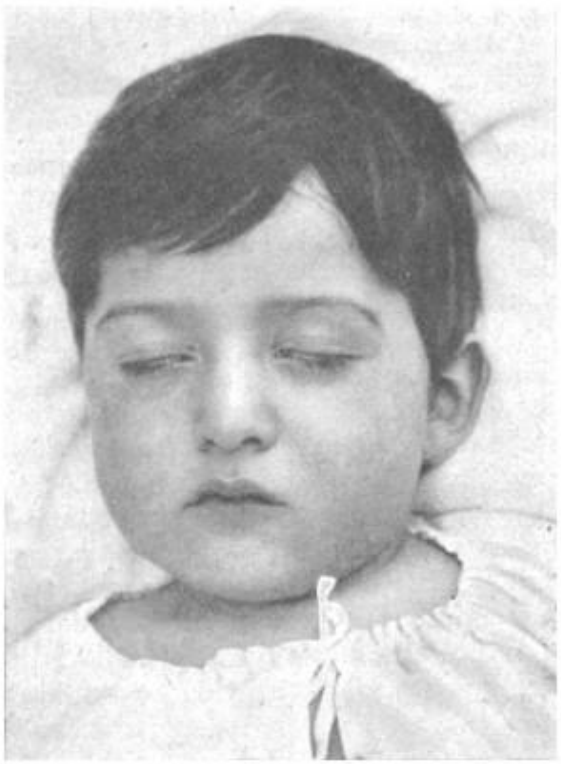
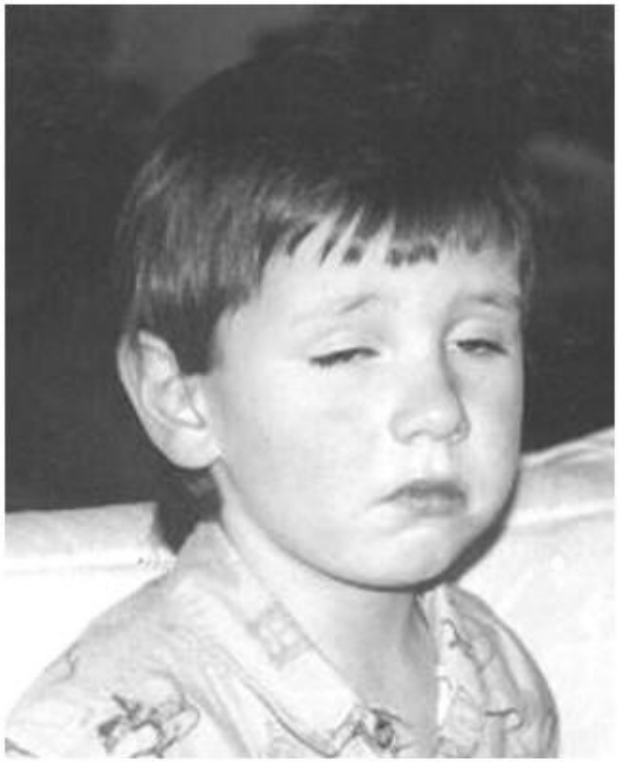


Child with Acrodynia, form of mercury poisoning
(courtesy: *L'Acrodynie* by AW Cameron, 1931)



Child diagnosed with autism
(courtesy: Lyn Redwood, Safe Minds, 2001)

Excerpts from *L'Acrodynie* by AW Cameron, 1931
A description of acrodynia before it was known to be caused by mercury exposure
Translated for Safe Minds, June 2001 (emphasis Safe Minds)

Overview

Acrodynia Infantile is the name of a disease of the CNS, probably of infectious origin, that affects particularly the vegetative system. It is characterized by the association of psychiatric, sensory, motor, vasomotor, and secretory disorders. The secretory disorders result in cutaneous lesions of specific appearance.

History

A German physician reported the first known cases of the disease at the Cassel Congress, in 1903. His report read: "**The disease is observed in girls aged 18 months to three and a half years. It is characterized by sadness, anxiety, and eventually a progressive loss of language, with psychiatric symptoms** (hallucinations, coprophagy, delirium during sleep, etc…). In addition, there are sweats and their consequences: viscous, humid skin; swollen, red and cold hands and feet. The patients feel cold and permanently irritated. They complain of being itchy, lose their hair primarily at the temples, but sometimes to the point of complete baldness. Almost certainly infection of the nail cuticles and abscesses follow. Internal organs are not affected. The disease evolution is favorable in a few weeks or a few months".

In 1914, an Australian physician, Swift, from Adelaïde, presented at the medical congress of Auckland his observations of children suffering from a disease he named erythroedema. **Fourteen children, 6 to 16 months of age, were affected. They had motor and psychiatric disorders as well as cutaneous symptoms**: a rash that could be all over the body but was mostly localized to the hands and feet.

Nine cases were reported in 1925 by Haushalter under the name of "Child Syndrome with Psychiatric and Neuro-Vegetative Symptoms".

From 1925 to 1927 I observed 11 cases that I reported in the Journal de Medecine de Bordeaux in 1928. In this publication, I discuss **the importance of separating the neurological syndrome from the cutaneous syndrome, the latter one being sometimes very mild or even lacking, whereas the neurological syndrome is always present**. This led me to describe the various clinical forms of acrodynia, and I was the first to describe the mild forms of the disease, which I think should be given more attention. Since this publication I have observed additional cases, and including 7 cases referred to me by colleagues, I have seen a total of 39 cases.

Etiology

The etiology of acrodynia is largely unknown. Few cases have been observed and most of them have been described only incompletely. The beginning of the disease usually goes unnoticed, so that the conditions of the onset of the disease are not observed.

The first known fact is that **the disease is observed exclusively in children**, especially young children. The disease is observed mostly in children less than 4 years old, although cases at age 8, 11, and 14 have been reported.

Several authors have suggested that infectious diseases may precede and favor the appearance of the disease. Cases have been reported after measles, mumps, or vaccination, but mostly after flu-like or gastric symptoms. However, it is possible that these nonspecific symptoms are the first signs of the disease rather than risk factors for the disease.

Symptomatology

All authors agree that **the beginning of the disease is very slow**. Most cases are described at a late stage. Sometimes, though, observant parents describe that children presented minor symptoms for several weeks before the typical symptoms settled in. Often, a feverish episode, thought to be the flu or a gastrointestinal virus, is described. If looked for, though, one can observe a rhinopharyngitis more or less pronounced. This episode is usually short, and in 2-3 days the body temperature gets back to normal, although it may last longer: in one case, it lasted 15 days. Because of their mildness and short duration, these episodes are usually not mentioned by the families.

Everything appears to go back to normal but soon after a depression sets in, and then the typical symptoms of acrodynia appear.

First, the child presents mood and temper disorders. She becomes sad, does not play with her toys, talks less and less, is cranky and sometimes aggressive. She complains of fatigue, does not want to walk but wants to be carried or pushed in a stroller. Little by little, walking becomes difficult, and in extreme cases, the child cannot stand on her legs. **She complains of pains, tingling, heat, and itching in her hands and feet.** The itching is sometimes present over the whole body. **Very quickly, muscles become hypotonic** and sometimes reflexes are weakened or even absent. The child also has photophobia. The child nestles in her mother's arms or huddles up in bed. She can stay for hours in unusual positions.

All children have some level of tachycardia and insomnia resisting medications. They lose their appetite and lose weight.

At the same time, excessive sweating of the whole body, but mostly of the hands and feet, is observed. As a result, the skin of the hands and feet becomes red and infiltrated. Fingers are big, red, have a sausage-like look. After a while, the skin peels. Sometimes the nails fall spontaneously. Also, infections may be observed. Other possible symptoms are stomatitis and spontaneous loss of teeth.

At this stage there is usually no fever.

This stage lasts for weeks or months before symptoms disappear progressively and the child recovers without sequela.

This is the most common form of acrodynia, with neurological, cutaneous and cardiovascular symptoms. But **the disease can take many forms, some symptoms may be absent and others, not described yet, be present**. I will now describe the symptoms in more details.

Neurological symptoms

Neurological symptoms are often observed first and play an important part in the disease.

The mood alteration is observed early and in all cases. It is the first sign to attract the attention of the parents, and, in my opinion, it should alert physicians of the possibility of acrodynia.

The first sign is a **loss of joyfulness. The children stop playing and laughing, and may go weeks or months without smiling. Their faces reflect sadness**: the forehead is wrinkled, the look melancholy or even desperate. The children appear to suffer physically and morally.

At the same time, **the children stop talking. Some cry constantly. Most are cranky, complain, and moan.** One of my patients, aged 3, repeated constantly: "I am so unhappy!"

Affectivity is modified. Most often it is diminished or disappears completely. Some children appear unaware of their parents, don't respond to their kisses, do not seem to notice them when they come close or leave.

In most children, there is **some irritability, sometimes hostility. If someone comes close, they move away and cry. Some children bite or hit their mothers and siblings. Some have strange behaviors:** a girl, who was very well behaved before her illness, would get up secretly and relieve herself on a rug.

Some children turn their anger against themselves. They hit themselves, bang their heads against furniture, throw themselves on the floor, pull their hair. They behave in strange ways. One little boy refused to walk and then started running away. Very often, depression follows these outbursts. The child remains completely quiet and silent and has a hostile look.

Excitation and depression are often alternating. However, in most patients, there seems to be three periods: initially, in the first stage, sadness dominates, then in the second stage, excitation and aggressiveness, followed by a period of anxious depression.

Intelligence may remain intact. But in serious cases, it appears diminished. Some children repeat the same words for hours. One child repeated constantly "I want some coffee" with a monotonous voice. Some patients appear to be obsessed with scary images. One child, four-years old, saw a wolf jumping on him all the time.

These symptoms may be so pronounced that the disease resembles an acute psychosis. A five-year old girl, well behaved before her disease, had attacks where she would throw things at her parents, curse, tear off her clothes, bite, pull her hair out. These attacks were followed by prostration. Institutionalization was recommended.

I reported a similar case in a two and a half year old girl in a publication. She first presented with agitated sleep, reduced appetite, attacks of crying. She then stopped playing and started moaning almost all night. She would complain of being tired during the day but could hardly sleep. Her face became hard, and she would not move for a whole day or, on the contrary, she would be very agitated and scream. Her speech became incoherent. Such extreme symptoms are exceptional.

Another symptom is **the particular subjective sensitivity of the hands and feet**. Four signs can be observed. The first one is **tingling of the palms and soles**. One girl complained that she had "pebbles in her shoes". Another one complained of "sand in her hands and feet" or at other times "needles". A boy said "he had like mosquitoes biting his legs and arms". A four-year old girl would say "it stings, it stings!"

The second sign is a sensation of burning heat. A seven-year old complained that "his arms were on fire". Some children want to keep their hands in cold water (figure 4). Most children, when in bed, keep their hands from outside the blankets, and keep moving them to cooler spots. One girl would take her shoes off and put her feet on cold tiles. Some children ask their parents to blow on their hands.

A sensation of itching is also present, often very early on. Almost all children ask to have their palms and soles scratched. Because of these sensations, some children keep rubbing their hands or keep them pressed against each other. Some children keep looking at their hands and feet. Also, they pull on the fingers of one hand with the other hand.

In most cases, real pains accompany these signs. Some children complain of twinges in their fingers and wrists painful to the point of provoking screaming. These children keep their hands flexed and resist stretching them. A twenty-three month old girl, who had mostly cutaneous symptoms, had such pains in her knees that an experienced doctor initially diagnosed her with rheumatism.

These pains can extend beyond the limbs. A frequent location is the abdomen. One child kept saying "Don't touch my belly!" If one examines the abdomen, there is no muscular contraction. A final painful symptom is headache. In all cases I have observed, at least in the initial stage, patients suffered from headache.

All these symptoms are highly variable. They are sometimes so mild that they go unnoticed, or they are so intense that the child suffers intensely, sometimes for weeks or months. In any case, these signs are always present, and because of their specific nature should evoke acrodynia.

Because of the pain and psychological condition of the patients, modifications of the objective sensibility are hard to study. Spots of anesthesia, hyperesthesia, or paresthesia have been reported. However, it is not easy to sort out hypoesthesia from muscular hypotonia.

Hypersensitivity appears more common than hyposensitivity. Muscles are often aching. Further studies are necessary to assess symptoms of objective sensitivity.

Another symptom is **insomnia.** At the beginning, sleep is agitated. The child wakes up often at night; then, as the disease progresses, she stays up long hours, sometimes all night, unable to sleep. It is an important symptom because insomnia is very rare in children. **Some children spend weeks sleeping only one or two hours a night**. This insomnia is obviously related to the pains. However, it seems to also be present in children suffering little. In some cases, this nocturnal insomnia is accompanied by somnolence during the day. One child was diagnosed with encephalitis because of this marked somnolence.

Disorders of mobility are part of the syndrome. At first, children complain of being tired, want to be carried or pushed in the stroller. Then, walking becomes difficult, the patients have trouble keeping their balance. They walk with small steps, their belly pushed forward, or stagger like children getting up after a long stay in bed. In some patients, walking becomes impossible. These walking disorders seem to result from several causes: first from the pains in the feet, but also from the fatigue and the muscular hypotonia.

Muscular hypotonia is one of the most common and striking symptoms of acrodynia. Muscles are flabby and movements are impaired. The muscle hypotonia is responsible for the lordose of patients when they walk. Hypotonia may be limited, or observed all over the body. It affects preferentially neck muscles: the child has trouble holding her head straight. The head bends forward or sideways (figures 6 and 7). Some patients even have to hold their head with their hands. When it affects trunk muscles, children can hardly sit in their bed.

In some patients bradykinesia is observed. One of my patients, three and a half year old, who had the typical cutaneous signs of acrodynia, had such bradykinesia. The child refused to stand up, although she could move her legs perfectly in bed. She would lie on her back, completely inert, the muscles of her thighs, calves, and arms particularly flaccid. If asked to do a particular movement she would do it but extremely slowly. If you raised her arm, rather than drop slowly, it would stay in position for a few moments, with the hand hanging. After a few seconds, the arm would start shaking and would keep shaking until the arm fell back on the bed.

Shaking is fairly common. It is observed mostly in the hands, and is started or exacerbated by voluntary moves. More commonly than shaking, **one may observe clonic movements of the muscles**. Mrs. Nobecourt and Pichon reported clonic movements of the left eyelid and of the muscles of the corner of the lip in a seven-year old patient. Mr. Pehu reported in **one of his patients jerking of the hands and fingers as if by an electric shock**.

Convulsions are rarer. I have not seen any in 32 patients.

If the lumbar punction is done early on, lymphocytes are present in excess (one patient:10 lymphocytes/mm^3; another patient: 45 lymphocytes/mm^3). A few days later the number of lymphocytes had gone down. Albumin is also elevated, whereas the glucose is usually lower than normal (see page 35 for details).

Cutaneous symptoms

The skin presents with excessive perspiration. Hands and feet when touched are wet and cold, which is surprising because the sweating is often accompanied by a burning sensation, as mentioned before. One of my patients complained that his hands were burning when his mother reported that the hands looked like they had been plunged in cold water.

The skin of the hands and feet looks irritated; the color is bright pink, light red, bright red or deep red.

What one should remember is that these typical cutaneous lesions don't appear right away. Sometimes they appear only several weeks, or even a couple of months after the start of the disease. They can also disappear before the patient has completely recovered.

The intensity of these symptoms varies: sometimes they are obvious; sometimes they need to be looked for carefully. Their duration is also variable: sometimes they last only one or two weeks, sometimes they last several months. It is noteworthy that the neurological signs may be present long before the cutaneous signs.

There may also be an erythema on other body parts. They may have different looks: sometimes large patches formed by the merging of small vesicles surrounded by a red circle; sometimes it resembles a scarlet fever; sometimes a mixture of scarlet fever and purpura; sometimes it looks like a measles rash.

The face is also affected and **often the nose and cheeks are red**. Sometimes, the color is darker, like suntan. Where the rash is present, the skin is rough. Whatever the look of these rashes, they are almost always very itchy.

Hair becomes brittle and falls out easily. In addition to this true alopecia, many children pull their hair.

Circulatory symptoms

They are almost always present. They appear at the beginning of the disease and remain present until the cure.

The first symptom is **tachycardia** (140 to 180/minute). In one of my patients, the pulse was 200/minute, for over six weeks. The child recovered completely and the pulse returned to normal. **This tachycardia is continuous, not affected by exertion, screams or sleep.** The pulse is usually regular.

Blood pressure is elevated. According to Feer, hypertension is the most common sign of acrodynia. The systolic pressure varies between 110 and 130 mm Hg. The diastolic pressure has been reported less often; among my cases it also seems to be elevated. This hypertension lasts as long as the tachycardia.

The heartbeats are normal as well as the ECG. In a few cases, though, an enlargement of the heart has been noted.

These cardiovascular signs are important for the diagnosis as well as the prognosis. Only after they completely disappear can the child be considered cured.

Blood changes: The number of red blood cells is very often elevated (5.5M to 6.5M and even more). Many authors think that it is due to the excessive sweating and resulting dehydration. Also, there is almost always a hyperleukocytosis, with the number of white blood cells varying between 10000 and 40000 (most often between 12000 and 25000). Most authors who do not believe in an infectious cause ascribe this hyperleukocytosis to the cutaneous infection, although it has also been observed in patients with non-infected skin.

Leucopenia is exceptional.

Chemical changes are limited. The glucose level may be elevated; calcium is normal; phosphorus is low; hemoglobin is almost always low.

The cutaneous itching lesions are often accompanied with swelling of the corresponding lymph nodes (often armpit and groin). The lymph nodes are moderately swollen, mobile, and not painful.

Digestive symptoms

The most common and earliest digestive symptom is **anorexia**. The patients lose their appetite at the same time they lose their joyfulness and sleep. This anorexia is sometimes so pronounced that it can be dangerous. The persistence of a good appetite has also been observed by Woringer in 3 of his patients who however, rapidly lost weight. Extremely rarely, an increase in appetite has been described.

In contrast, patients are very **thirsty**. This thirst is so intense that in one patient of Haulsalter, it suggested a diagnosis of insidious diabetes. Many authors attribute this thirst to the sweating. I think that the sweating is insufficient to explain the extreme cases I just described, and that this thirst has a neurological origin.

In many cases, an **excess of salivary secretion** has been observed. This symptom is common but not constant. Most of the time, this excess is more common at night than during the day.

The mouth mucosa is often red and swollen. Sometimes, a real stomatitis is observed, with ulcerations.

The loss of teeth is one of the strangest symptom of acrodynia. This sign has been reported by foreign physicians in particular in Australia (five out of 21 cases described by Zahorsky, 3/17 cases described by Rodda). The number of lost teeth varies. Some patients lose only one, more often several teeth fall. Most often, the gum closes over the tooth socket rapidly. However, sometimes a local infection starts, with pyorrhea.

Vomiting is often observed during the initial phase of acrodynia. Usually, it disappears early. However, it sometimes persists, as described by American authors.

Diarrhea has also been described in the initial phase, but also in the last stage. It is exceptional during the main course of the disease. In most cases, **constipation** is observed.

Urinary symptoms

Urine is rare, dark, and thick. Albuminuria has often been described. It is usually mild and transient. Sometimes, the albuminuria is observed in connection with pyuria, when acrodynia is accompanied with an infection of the urinary track: cystitis and pyelonephritis. Glycosuria has been described in some cases, mild and transient. It is the result of the hyperglycemia previously mentioned. Acetonuria has been mentioned by Byfield. I observed it too in some of my patients. An hematuria, mild and transient has been described by Parkes Weber.

I mentioned in my publication in 1928 the presence of **difficulties to urinate**. One child could not urinate for 24 hours and had a dilated bladder so that a catheter was going to be installed when spontaneous miction occurred. Another child kept saying "I need time, I need time!" This bladder paresis seems of interest to me because of its resemblance to infections of the CNS. It may also explain the frequency of urinary infections in acrodynia.

Respiratory symptoms

The respiratory system is most often unaffected, except for the nose and throat area. In many cases, **a runny nose is observed**, often accompanied by hypersalivation and watery eyes. Also, in many cases, a rhinopharyngitis is observed. The throat is red, the tonsils are swollen, and sometimes swallowing is difficult. This rhinopharyngitis, often accompanied by a slight elevation of temperature, is mostly observed at the beginning of the disease, before the other typical symptoms occur. I think this rhinopharyngitis is very common, and if searched for is almost always found. The duration is variable, usually only a few days, sometimes several weeks.

Bronchitis, either secondary to the rhinopharyngitis or by itself is common. It can lead to bronchopneumonia, most often fatal. It is one of the most common causes of death from acrodynia.

Sensory symptoms

The eyes are affected in acrodynia. The symptom most often observed is **photophobia.** It is most often present at the beginning of the disease and therefore may go unnoticed if doctors are called only at a later stage. Its intensity and duration vary: some children only blink when the light is strong, others dread all sources of light, hide their eyes behind their hands, or their head under their pillow. This photophobia contributes to the special positions young patients adopt. It usually disappears or at least diminishes greatly in 15 days.

There is usually no visible eye lesion, although some children may have conjunctivitis. I have observed it fairly often, but it is usually very mild and transient and therefore may go unnoticed.

Ears are usually unaffected. **Older children sometimes report buzzing of the ears**.

General condition-Temperature

Almost all the authors who have described acrodynia have mentioned the lack of fever. Higher than normal temperature seems to be observed only in the presence of infectious complications. Some physicians consider this a very important fact against an infectious origin of the disease.

More recently, more thorough observations indicate that a fever is often observed before the apparition of the neurological and cutaneous symptoms. In one of my patients, a 19-month old, a fever lasting 5 days preceded the symptoms of acrodynia. In another, a five-year old, a severe form of acrodynia was observed after a fever lasting about 3 weeks.

Also, during the main phase of the disease, a slightly elevated temperature can be observed in the absence of any infection, reminding Wykoff of tuberculosis.

Excerpts from Case Report of Heather Thiele, Acrodynia Survivor
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[Excerpted by Safe Minds, 7-26-01. Emphasis Safe Minds]

Source
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My name is Heather Thiele (nee Kemp) and I was born on 11th June 1949, the first born of twins. I was born at Bacchus Marsh Victoria, Australia. I weighed 6lbs 3oz at birth and was a healthy, thriving baby, until I reached the age of nine months, when I started to teeth. I had rather large teeth and was suffering with cutting them. To soothe my gums and relieve my distress, my mother used the commonly used teething powders readily available over the counter in corner stores and chemists throughout the country of Australia, and other English speaking countries at the time. The teething powder was rubbed on the gums or the tongue of the suffering infant.

Immediately, I became **lethargic, sensitive to noise, light and touch, lost my appetite and consequently lost weight alarmingly. I lost muscle tone** and I found it hard to hold my head up or sit, and although I was on the verge of walking, I became like a floppy doll. The skin on the soles of my feet and palms of my hands became bright pink and began to peel off. I would scream if placed in a bath, so my mother started "washing" me with olive oil and cotton wool. **I would rock myself from side to side in my pram or cot, and bashed my head against the walls.** Nothing seemed to pacify me, and **I would go for days without sleep**. My mother says my cry was more like the whimper of a frightened animal, and could last for periods of 24 hours or more, without a break. My hands turned "puffy" and it was this edema, along with the photophobia and pink extremities, that the doctor used to diagnose the condition as "pink disease".

I started to convulse and developed pneumonia regularly. I would recover from one bout to go down with another... The doctor gave my mother little hope for my survival, as so many babies with these symptoms were dying in the district.

… In the early 1950's the work of Dr. Joseph Warkany of the USA proved that the cause of the pink disease was the calomel in the teething powders and with Dr. Cheek's encouragement, the powders were

withdrawn from the market in Australia and the United Kingdom.. .. Once the powders were withdrawn from sale, the incidence of pink disease stopped immediately. I have a Sydney newspaper, which published a warning not to use the powders containing the calomel from July 1st 1874, following the death of a baby with pink disease. Yet it took another 80 years for the incidence of pink disease to stop. It is a shame so many hundreds, even thousands, of babies had to suffer and die because of slow action by the medical profession. I have documented cases of a family having 5 of their 10 children die from suffering pink disease, and many cases of two or three babies in the one family dying. Plus you have to consider the effects that having suffered such a horrific form of mercury poisoning at such an early age in life has had on each and every pink disease sufferer and their families.

… Eventually, I began to recover, although I was unwell until I was 7 years of age… I can remember the terrible nightmares I had until this time and being very **tired all the time**. I was particularly **clumsy and very shy as a child**. **I would sit in the corner of a room, reading a book or playing, and be quite unaware of all that was going on around me**. (Not a mean feat when you think that by this time, I had another two brothers, also twins, and baby sister, making our family of 10.) I did well at school only because I used to study so hard at all I did. As I write this in June 2001, I can say that **I have always lacked spatial judgment and fine motor skills**. I have trouble judging "how much of this would fit into this", doing up things like locks, seat belts, jewelry clasps, double clicking my computer mouse etc. I always say that I do everything in life twice: firstly, the wrong way and secondly, the right way!

I can remember being yelled at by a teacher when I was 8 years of age: "Look at me when I talk to you, you ignorant child". I have often felt as if I was on the "outside of life looking in." I have severe pain especially around my ribs in the connective tissue (costal chrondritis) and **cannot bear to be hugged by anyone**. **If I bump my leg against a piece of furniture, it really pains for days afterwards. I have no sense of direction**. If I park my car, it doesn't end up anywhere near where it should be. I have a rope hanging down from the carport roof to show where I should park the car, but still can't get it right! My husband gets so frustrated with me**. I go around turning down the sound on the TV and turning off lights in the house**. … **I can feel nauseated when I am in a crowd of people**, or if I am in a group of screaming children at a party e.g. **I still rock myself when I am distressed or worried. I have definite patterns of repetition and order in many things that I do**. Sometimes I wonder if these are more of a survival mechanism than an actual symptom of a disorder. I am so used to thinking out in advance the easiest way to do things so that I don't do mistakes, that **I have quite a reputation for being very organized.** The same people and friends, who compliment me for being organized in my life and ways, don't appreciate that this is the ONLY way I can cope with life! I have maintained a rather stubborn streak in my personality and a good sense of humour which both help at times!

When I go to type out words, they get mixed up. "That" is typed as "hatt" for example. I am OK if I write by hand. I cannot do things like shuffle cards, do up seat belts, do up jewelry clasps etc. **When I am interrupted in a task or speech, I lose all track of where I was up to before the interruption. I find it hard to remember books and articles I have just read. I have to make notes and go back to the article time and time again to remember the basic thoughts of the article. However, I am marvelous at remembering dates. I am terrible at remembering people's names and faces.** I often can't remember the name of an article, which worries me as I get older (Alzheimer's?). Recently, I was with my daughter and kept calling her by my grand-daughter's name, and telling her to put something into the car when I meant shopping basket. I recently saw a program on TV about the recognition of faces. I thought at the time that this is what I have problems with.

Some of my problems seem to "come and go" in intensity, but I notice **they are worse when I am stressed.** I own a café, and when we get busy I have to literally "check" myself and "go down a gear" in my actions, and really concentrate on taking orders etc. I will take an order down as three black coffees and one white, when it should be the other way around. I constantly have to double check orders so that I

don't make mistakes. Both my husband of many years and my staff get very cranky with me when I make mistakes, and this adds to my frustration. I think pink disease people must be very frustrating to live with. **I have noticed many of us have had more than one marriage and many are now divorced and living on their own. I know I prefer my own company than being with a crowd or even a couple of people**.

I also have **no strength in my arms**, when holding things above my shoulders, or stacking things onto shelves. I am a hopeless swimmer for this reason. This seems to be common amongst pink disease people.

Another thing I have noticed, is that I have had what I might describe as "hot flushes" all my life. Even as a child when I made a mistake or was embarrassed, **I'd flush in the face and come out in a hot flush over my body. I have never been good at speaking in front of an audience or being the centre of attention.** I do not self promote myself.

… We do not have any obvious signs of our disabilities, and look quite "normal". Most of us seem to be rather determined, intelligent and hard working, so we do not draw attention to the daily struggle we have to function in this world. ..Others really have to spend a day or so with me to see that I do have problems performing normal every day tasks. I will go to open a door and have to take two or three attempts to grab the door knob etc. Or I will go to place a plate on a shelf, and miss the shelf completely, grazing my knuckles. I often have bruises on my body from bumping into things and I don't remember doing it.

I have mentioned only the things I do not have in common with other members of my family, as I do appreciate that some things, like a tendency to suffer arthritis, are genetic. I am one of eight children and have a large extended family. No other members of my family have the problems and issues I have mentioned.

… When I would go horse riding, **my feet would go numb and I had always had all these other things happening, like drifting when I walked, stumbling, getting things back to front when I typed etc.**

… Over the years, I have tried to get medical and government organizations interested in our case, to no avail. It appears to me that most people consider the pink disease story as something that children "got" years ago, like measles, and it had no long-term effects. It is a long forgotten story to everyone but the people who suffered it or maybe a parent who watched a child fade away from the condition or its complications. I have letters from mothers whose babies died with pink disease in hospital and they weren't even told where the baby's body went. Many mothers in particular, as it was often the mothers who nursed the babies in those days (first half of last century), still talk of the terrible struggle they had to bring their babies through pink disease or the heartbreak they suffered when their babies died. **The doctors at the time did not know the cause and many mothers were told it was a venereal disease their husbands brought back from the wars, or the baby was "spoilt" or they were overanxious.** And then there is the guilt many mothers feel on learning it was the teething powders that caused pink disease.

… I have learnt my capabilities in life and stick to those things. **I'd rather do something I know I can do well, than try new things**. For example, **I am fairly good at math** and my bookwork for my business. In Australia, we have a new tax system being implemented this year, and I have learnt it all well. I **find if I have a more uncluttered style of home and workplace, I am able to function better.**

I will continue to endeavour to educate all that "should know better" about the long forgotten pink disease children and what we have endured. I feel strongly that I was meant to survive so I can make this my "purpose in life".