

## Pearl S. Buck and Phenylketonuria (PKU)

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### ABSTRACT

In 1921, Pearl S. Buck gave birth to a daughter, Carol, who became severely retarded and was eventually institutionalized at the Vineland Training School in New Jersey. To help pay for her daughter's care, Buck wrote *The Good Earth* in 1931, and then other novels and biographies about her life in China, for which she was awarded the Nobel and Pulitzer Prizes, and honored around the world. Years later, she published *The Child Who Never Grew*, a short piece about her daughter's retardation that also revealed her desperate search for answers and good clinical care. Asbjørn Følling distinguished phenylketonuria (PKU) from other forms of childhood retardation in the mid-1930s, and new assays and biochemical findings eventually led to ways to circumvent the devastating effects of PKU. But for Carol Buck, these advances came too late. It was not until the 1960s that physicians confirmed that her severe retardation was caused by PKU.

**Keywords:** Pearl S. Buck, Carol Buck, Phenylketonuria (PKU), Mental Retardation, Asbjørn Følling, Vineland Training School, Rehabilitation, *The Child Who Never Grew*

She wrote many fine books and won notable prizes, but her major humanitarian work was with children, some of them sadly stigmatized like her own daughter.

(James A. Michener, 1992, p. xi)

Three months after her birth, the Sydenstrickers returned to Chinkiang (Zhenjiang), a port city on the Yangtze River in the Kiangsu (Jiangsu) province of China. There she was raised largely by her mother and a Chinese nurse, taught by a Confucian scholar, and had Chinese playmates. As would later be evident in her writing, these childhood experiences indelibly shaped her personality and philosophical approach to life.

In 1910, while her parents were on another leave to the United States, she enrolled in Randolph-Macon Woman's College in Lynchburg, Virginia. After graduating in 1914, she dropped her plans to stay in the United States and returned to China to tend her seriously ill mother.

After her mother's health improved, Pearl chose to remain in China and took a position as teacher in a boy's day school in Chinkiang. It was

### INTRODUCTION

Pearl S. Buck (1892–1973), the first American woman to win the Nobel Prize for literature (in 1938) and a previous winner of the Pulitzer Prize (in 1932 for *The Good Earth*), was born in Hillsboro, West Virginia. Her parents, Absolom and Caroline (“Carie”) Sydenstrickers, were Southern Presbyterian missionaries who were on temporary leave from China, and she was the fourth of their seven children.

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around this time that she met (John) Lossing Buck, an agricultural economist with a degree from Cornell University; he had come to China to teach American methods of farming. Following a brief courtship, the two were married in 1917 (Fig. 1). They then moved to Nanhsuchou (Nanxuzhou), a community in the rural Anhwei (Anhui) province.<sup>1</sup> Pearl secured work in this northern Chinese community as the head of a girl's school. After a short stay, the couple moved south to Nanking (Nanjing), where Lossing had an offer to teach agriculture at the university and where she found work teaching English. They would live there (albeit with interruptions caused by political unrest and other leaves from the university) from 1920 to 1933.



Fig. 1. Wedding Photo of Lossing and Pearl S. Buck, May 30, 1917. (Reprinted with permission from Pearl S. Buck International.)

<sup>1</sup>This area of northern China would provide the setting and agrarian peasant characters for *The Good Earth*, the novel that would win Buck international fame as a writer in 1931.

It was in May of 1920 that Caroline Grace Buck, who would be called Carol by her family, was born. She weighed seven pounds, eight ounces, and appeared to be healthy. Unbeknownst to her parents on her arrival, Carol would suffer from phenylketonuria (PKU), a genetic disorder which would render her unable to metabolize the amino acid phenylalanine and would severely hinder her later intellectual development.

### CAROLINE GRACE BUCK

Pearl Buck concealed Carol from the public for more than two decades. Her existence was circumvented in interviews, and friends were begged never to mention her existence to the press or, for that matter, to anyone. For example, the most she would reveal in her interviews was that she had "two little daughters. One is away at school and one . . . is at home with us" (Buck, as cited in Conn, 1996, pp. 111-112). She even did her best to suppress an article in the 1936 *Akron Times* in which Mrs. W.C. Lowdermilk, who had previously been a neighbor in Nanking, mentioned Carol's condition. These evasive actions probably served two purposes; first, they protected Carol's privacy, which Buck claimed was her sole motive. And second, they probably also protected Buck from the hurt that she must have felt as Carol's mother. Striving for perfection in everything she did, she had to be pained to no end by the thought of having a severely retarded daughter.

In a letter to one of her closest friends, she once confided:

It is not a shame at all but something private and sacred, as sorrow must be. I am sore to the touch there and I cannot endure even the touch of sympathy. Silence is best and far the easiest for me. I suppose this is because I am not resigned and never can be. I endure it because I must, but I am not resigned. So make no mention of her and so spare me. (Buck, letter to Emma Edmunds White, as cited in Jablow, 1992, p. 10)

It was not until May 1950 that Buck came forward to share Carol's condition with the world. *The Child Who Never Grew* was first published as a lengthy article in *Lady's Home Journal* and then

in book format that September (all quotes in this paper come from the 1992, second edition, of the book). This work serves to document not only Carol's difficulties, but also Buck's role as a mother struggling to accept her child's limitations. Lossing is noticeably absent. Buck writes about Carol as if she were a single parent – a frantic mother driven to use her own resources, both mental and financial, to properly care for her retarded daughter.<sup>2</sup>

## EARLY YEARS

In the 1950 edition of *The Child Who Never Grew*, Buck wrote that she did not know when Carol's intellectual development stopped (Buck, 1950/1992, p. 33). She informs the reader that there was nothing in her family history to suggest that her child, of all children, would fail to grow mentally. Further, Carol's early infancy yielded no hint of her future difficulties. In fact, it was the opposite, her wise demeanor, that impressed Buck early on:

I remember I said to the nurse, "Doesn't she look very wise for her age?" She was less than an hour old. . . . I remember when she was [three months old] that she lay in her little basket upon the sun deck of a ship. I had taken her there for the morning air as we traveled. The people who promenaded upon the deck stopped often to look at her, and my pride grew as they spoke of her unusual beauty and of the intelligence of her deep blue eyes. (Buck, 1950/1992, p. 32)

The concern that something was wrong with Carol, however, slowly built as the baby approached her third birthday. Unlike her peers, she still did not talk and her movements were poorly coordinated. Fearful, Buck fell back on stories from friends and neighbors of healthy

babies who were slow to talk and walk. PKU was unknown at the time, and decades would pass before her daughter's persistent eczema, which she tried to treat with vegetable and fruit juices, would later become one of the diagnostic signs the disorder.

By age four, Buck could no longer ignore her fears. "The hour of awakening to sad truth" hit hard. A visiting American psychologist was lecturing nearby on child development, and she now realized just how far behind other children Carol had fallen. She spoke with the lecturer, who

pointed out to me the danger signs I had not seen, or would not see. The child's span of attention was very short indeed, far shorter than it should have been at her age. Much of her fleet light running had no purpose – it was merely motion. Her eyes, so pure in their blue, were blank when one gazed into their depths. They did not hold or respond. They were changeless. Something was very wrong. (Buck, 1950/1992, pp. 36-37)

Other doctors were consulted and the general recommendation was that Carol should be taken to the United States for further testing and evaluation. Since Lossing was planning to spend a sabbatical year at Cornell, where he hoped to earn a master's degree, the trip back to the United States could serve both purposes.

Buck took Carol to child clinics, endocrinologists, and psychologists after they arrived in the United States. It was not until they visited the Mayo Clinic, in Rochester, Minnesota, however, that she achieved a greater understanding of Carol's condition. After a thorough examination, she was told that, for some unknown reason, her child's mind had definitely stopped growing – she was hopelessly retarded.

A compassionate doctor with a strong German accent begged her not to deceive herself about Carol's intellectual potential. He advised her not to be consumed by Carol's retardation, but to "find a place where she can be happy and leave her there and live your own life" (Buck, 1950/1992, p. 45).

Buck would later write:

I don't know of any blow in all my life that was as rending. It was as if my very flesh were torn.

<sup>2</sup>According to Janice Walsh (1992), the Bucks adopted daughter, Pearl Buck left her husband out of *The Child Who Never Grew* for multiple reasons. One was that the couple was already growing apart when the Carol was born. A second was that the author did not want to break up the narrative thread that held the story together. And a third reason was that Buck was still insecure and striving to show her independence.



Fig. 2. Carol and Janice Buck in 1925, shortly after Janice's adoption. (Reprinted with permission from Pearl S. Buck International.)

It was beyond belief, and yet I knew I had to believe it, and shape my life around the fact. (Buck, as cited in Harris, 1969, p. 119)

In what may have been an attempt to blunt the pain from this realization, Pearl and Lossing decided to adopt a second child soon thereafter.<sup>3</sup> In

<sup>3</sup>At the time of Carol's birth, it had been discovered that Pearl S. Buck had a uterine tumor, for which she underwent a hysterectomy. Although unable to have more biological children of her own, Pearl Buck would go on to adopt several additional children, the first of whom was Janice. Carol's disability did not appear to be a major contributor to Buck's decision to adopt her later children, especially those who were orphaned Asian-American children. According to Harris (1969, p. 125), her need to adopt was partly driven by the ever increasing loneliness in her life: "There was, of course, no comfort in the retarded child, for she did not respond in any way to efforts to train and teach her except to become tired and nervous."

The goal of finding homes in America for mixed children of American servicemen who had been stationed in Asia would become one of Buck's sacred missions. In 1949, she founded Welcome House, Inc., an adoption agency for salvaging hard-to-place children of mixed parentage. She always regarded Welcome House, Inc. as one of her most important contributions to humankind.

1925 a three-month-old infant from a small orphanage in Troy, New York joined their family. Later she would become Janice Walsh and would play an important part in telling the rest of the story (Fig. 2).

The decision was now made to find a good care-taking institution for Carol. Given that the extended family, not institutions, took care of the handicapped in China, the needed institution would have to be located in the United States. Once this was decided, and with Pearl unknowingly blaming Lossing for their child's problems, the issue became practical – how to pay for such care:

I had found out enough to know that the sort of place I wanted my child to live in would cost money that I did not have. There was no one to pay for this except myself. I must myself devise means to do what I wanted to do for my child. (Buck, 1950/1992, p. 59)

But before relinquishing day-to-day care of her daughter, Buck decided to take time off to try her best to teach Carol to read and write, to distinguish colors and notes, and to sing songs. In short, she wanted to know exactly what Carol could and could not do. Some of this parental evaluation took place in Nanking, some in Japan, and some

in Shanghai, as civil wars and xenophobia now made parts of China extremely dangerous for foreigners.

Buck discovered that her daughter could be taught to write her name, sing simple songs, and read very simple sentences with concerted effort. But progress was torturously slow and frustrating, both for mother and child. Turning to the fundamental issue of whether Carol was even capable of understanding what she was doing, Buck would later write:

I happened to take her little right hand to guide it in writing a word. It was wet with perspiration. I took both her hands and opened them and saw they were wet. I realized then that the child was under intense strain, that she was trying her very best for my sake, submitting to something she did not in the least understand, with an angelic wish to please me. She was not really learning anything.

... She might after much effort be able to read a little, but she could never enjoy books. She might learn to write her name, but she would never find in writing a means of communication. Music she could hear with joy, but she could never make it. (Buck, 1950/1992, p. 62)

## VINELAND

In 1929, a few months after Carol's ninth birthday, Buck traveled with Carol and younger sister Janice, who was then four, back to the United States. The primary goal of this trip was to locate a suitable institution for Carol. This action was necessitated by Carol's increasingly frequent behavioral outbursts and need for attention, as well as because of the increasingly militant political disarray spreading through China.

Buck wrote:

In the midst of these years I made a swift journey to the United States to put my invalid child into a permanent school. The decision had been hastened because I foresaw a future in China so uncertain in terms of wars and revolutions that the only safety for a helpless child was a life shelter. (Buck, 1954, p. 249)

After an extensive search of American institutions, she selected the Training School at Vineland for Carol. It was located in southern New Jersey, north of Philadelphia and east of Trenton. Then, dropping her daughter off and after a short visit to New York, she returned to China accompanied only by Janice.

She later explained that Vineland was chosen because of the kindness shown to its residents. In addition, it had a stellar history as a training school, especially with birth-injured children (e.g., those with cerebral palsy). Moreover, it was a cutting edge research institution – the first in the United States to use the Binet Test for measuring intellect and the site where the Social Maturity Scale had been devised.

It was with this knowledge about Vineland, and some words about the pain involved in placing one's child in someone else's care, that Buck's short narrative, *The Child Who Never*



Fig. 3. Carol Buck in 1933 at age 13. (Reprinted with permission from Pearl S. Buck International.)

*Grew*, ends. Buck did not see Carol again for three years, confessing in private that, at times, she wished her daughter would just die (Fig. 3). In a published interview, however, it is only her maternal guilt that is revealed:

I left her all alone for three years and that, I know now, was wrong for me to have done. It was wrong for her and for me. After all, she had never been separated from me before and for it to be so sudden and so complete was hard on us both. True I paid a woman friend to go and see her, and she reported to me each month, but it was not the same as visiting her myself. I vowed I would go back and see her at least once a year. (Buck, as cited in Harris, 1969, p. 144)

#### A NEW LIFE IN THE UNITED STATES

With Carol at Vineland, Buck thought she might now spend her summers in the United States and winters in China. Her plans for the future, however, would be dramatically altered over the next few years. On the same June day in 1935, she first divorced Lossing<sup>4</sup> (“free of all obligation to me or my children”) – who she accused of withdrawing from her and their children – and then married Richard Walsh, her recently divorced editor (Buck, as cited in Harris, 1969, p. 173). Buck’s home would be in America from now on.

<sup>4</sup>Although the couple stayed married for 18 years, from the start Pearl Buck had realized she should not have married Lossing, who was not addicted to books and, in her mind, was not her intellectual equal (“Did you ever try to live just with a handsome face?”; Buck, quoted in Harris, 1969, p. 82). Following the couple’s divorce, there was almost no communication between Lossing and Pearl S. Buck. In addition, Janice was forbidden contact with Lossing.

Lossing eventually became acting dean and instructor in Agricultural Economics, Farm Management, Rural Sociology, and Farm Engineering at the university in Nanking. He remarried after their divorce, now choosing a Chinese wife. The couple would raise two bright children with no signs of PKU. Highly regarded and honored for his contributions to agriculture in China, Lossing died in 1975.

Of these decisions, she wrote:

There were personal reasons, too, why I should return to my own country. It is not necessary to recount them, for in the huge events that were changing my world, the personal was all but negligible. My invalid child, nevertheless, had become ill after I left, and it was obvious that for her sake I should live near enough to be with her from time to time. The grey house, too, had ceased to be a home for family life, in spite of my efforts, for the distances between the man and woman there had long ago become insuperable. There were no differences – only a difference so vast that communication was impossible, in spite of honest effort over many years. . . . Now the difference had come to include the child who could not grow and what should be done for her. . . . It was time for me to leave China. (Buck, 1954, p. 291)

Most of Buck’s life would now be spent in a large, renovated farmhouse outside Philadelphia in Perkasio, Pennsylvan. Later in life she would move to Vermont.

We learn that Carol occasionally visited Perkasio from Buck’s *Treasure Book*, her collected but unpublished notes about her interactions with her children. A recurrent theme is her own struggle to not to be engrossed by any of her children; to have her own life and her freedom. The following passage about Carol dates from 1940:

This is a beautiful day. Carol is at home – I like to have her here but all sense of flesh, my flesh, is gone. I feel toward her as tenderly as ever, but I am no longer torn. I am, I suppose, what may be called “resigned” at last. Agony has become static – it is true but I will not disturb it or allow it to move in me. (Buck, as cited in Harris, 1969, p. 279)

#### CAROL AT VINELAND

More is learned about Buck’s interactions with her retarded daughter and Carol’s life and development at Vineland in the 1992 edition of *The Child Who Never Grew*. This second edition

contains a sixteen-page "Afterward," written by Janice Walsh. In addition to becoming Carol's legal guardian in 1973, her adopted sister became an active member of the Board of Directors of the Training School at Vineland and served as President of the Pearl S. Buck Foundation. Moreover, she had trained as an occupational therapist who specialized in working with the mentally retarded.

Janice informs the reader that her mother, who died from lung cancer at age 80 in 1973, made her last visit to see Carol at Vineland during the summer of 1972. In retrospect, Janice acknowledges that she was less than an ideal mother to her children. Buck herself once said that she valued the relationship between man and woman more than that between mother and child. She even added: "I enjoyed my children, and still enjoy them as human beings and as individuals, but not because I'm a 'mother'" (Buck, as cited in Harris, 1969, p. 186).

Pearl Buck never considered herself a maternal person, but rather an understanding woman with responsibilities. Consistent with this role, she served as a major fundraiser for Vineland and an activist spokesperson for its residents. She not only contributed money to build a new two-story dormitory with a porch and wading pool for Carol and fifteen other girls, but also assigned the royalties from the first edition of *The Child Who Never Grew* to the school.

In her comments, Janice Walsh makes the point that the child who never grew did in fact show some growth at Vineland. To quote:

She never learned to read or write, but she did learn to color, write her name, and verbalize her needs. She also learned to sew simple projects and to master many self-care skills that enhanced her independence. She learned to bathe and dress herself with some supervision, to tie her shoelaces, to be independent in toileting and tooth brushing, and to comb and brush her hair with verbal reminders. She also became skilled at using a fork and spoon . . . (Walsh, 1992, pp. 97-98)

In addition, Carol continued to develop her skills in music. She learned to play her phonograph and use her radios (though they often dropped and broke). She would also hum along to the music.

When it came to sports, her abilities were good for someone afflicted with PKU. She could roller skate, shoot baskets, and run in Special Olympics events. She also had a tricycle, which she continued to ride around the grounds at Vineland until she passed away in her seventies.

Nevertheless, Carol did not do well in vocational training, which included placing her in a supervised workshop at Vineland when she was in her fifties. Her three biggest problems were: (1) her short attention span and inability to focus on her work; (2) the fact that she quickly became frustrated when parts did not fit together easily; and (3) her need for more intensive guidance. In short, she had profound learning disabilities.

With regard to speech and language, even as an adult, we learn that

Carol's speech was not clear, and since I did not see her daily, I often found it difficult to understand her sentences. But when she spoke in clear, single words, I could usually understand what she was trying to express. She seemed to understand me quite well, but I had to keep the communication simple. (Walsh, 1992, p. 101)

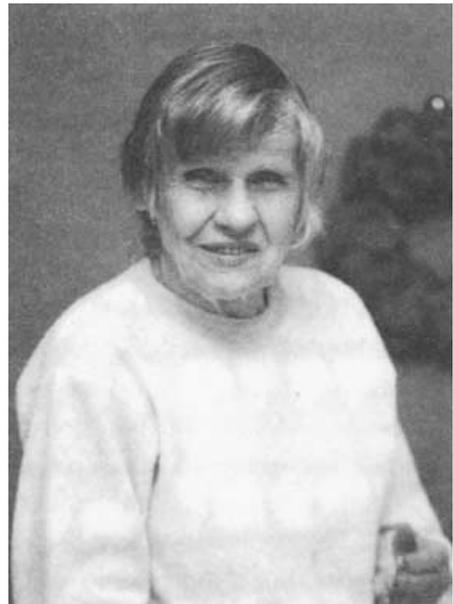


Fig. 4. Carol Buck at age 70. (Reprinted with permission from Pearl S. Buck International.)

In 1991, Carol Buck, like her mother two decades earlier, was diagnosed with lung cancer (Fig. 4). She underwent several operations and was given chemotherapy. Nevertheless, she still succumbed to the disease, dying in her sleep on September 30, 1992. She was buried at Vineland, which had been her home for over sixty years.

#### CAROL'S EFFECT ON PEARL S. BUCK'S CAREER

According to Buck, because her husband thought that sending their retarded daughter to an expensive, private institution was a waste of his hard earned money, she was compelled to meet all the expenses herself. The alternative, which she was never prepared to accept, was to turn Carol over to some free but depressing state institution and then forget about her as a person. In his authorized biography of Pearl S. Buck, Theodore F. Harris wrote: "She was alone in her care for the child. It became entirely her responsibility to provide for the child's future" (1969, p. 123).

Desperate to secure the necessary funds, Buck approached the Presbyterian Mission Board in New York. Mrs. John H. Finley, a member of the Board and the wife of an executive of the *New York Times*, was so "moved by the story of a brave young mother trying to care for a retarded child alone" that she provided a \$2,000 loan (Harris, 1969, p. 138). In addition, the Board agreed to pay \$500 if the struggling young mother would write a children's story about missionaries (Conn, 1996). These finances gave Buck the time and freedom she needed to try to make a success of herself as a writer. Soon Pearl S. Buck would be a household name, and she would be able to provide all of the financial support ever needed for Carol with her writing.

Buck's daughter Janice wrote that Carol "was one of the primary impetuses that spurred my mother to write" (Walsh, 1992, p. 106). Peter Conn, one of her biographers, added:

Whatever other motives compelled Buck to sit down at her typewriter every time she could reserve ten minutes or a quarter-hour from household chores, her fears about Carol [not

being properly cared for] were the most urgent. It goes only a little too far to say that Pearl S. Buck's entire career as a writer was anchored in her anxiety for her child. (1996, p. 102)

Buck herself had this to say:

... I was in the United States with my retarded child, for whose care and future I was solely responsible. For her sake I needed money, for I knew all too well the cost of lifelong care for such a child. ... I was well paid as teachers go, but now I had to earn much more. A Christian organization said to me: "If you will write a book for children with a Christian ending, we will give you five hundred dollars."

Thus I contracted for *The Young Revolutionist*. I returned to China then and first wrote *The Good Earth* because it was in my mind, waiting. Then, reluctantly, I fulfilled my contract for *The Young Revolutionist*. (Cited in Harris, 1969, pp. 84-85)

Prior to *The Good Earth*, which appeared in 1931, Buck had shown promise as a writer. Writing was a talent that, she says, she developed because she did not have American friends or a close family in China, where she became increasingly lonely. Her literary career began at about age ten with stories, articles, and poetry for the *Shanghai Mercury*, a British newspaper that offered cash prizes to children for their contributions. She also won prizes for fiction and poetry while at Randolph-Macon Woman's College, although her major area of study had been psychology.

*The Good Earth* was not Buck's first book, although it was by far her most famous book. A year earlier, she published *East Wind: West Wind*, which she learned was accepted for publication while she was in New Jersey dropping Carol off at Vineland. Although it did not create a stir, the editor who accepted it was Richard Walsh of the John Day Company in 1930. Walsh not only encouraged Buck to write more, but was also the person who came forth with the title for her next book, *The Good Earth*. Buck's own title for the masterpiece that really launched her career had been *Wang Lung*.

*The Good Earth* remained on the bestseller list for almost two years, helped in part by the



Fig. 5. Pearl S. Buck receiving the 1938 Nobel Prize. King Gustavus V, then king of Sweden, is also pictured. (Reprinted with permission from Pearl S. Buck International.)

publicity surrounding the 1932 Pulitzer Prize that it received. It played a major role in Buck's getting the 1938 Nobel Prize in literature, and is still selling strong as a classic of American (really world) literature (Fig. 5).<sup>5</sup> Grossing over a million dollars (Buck hoped it would make \$20,000), its proceeds allowed the author to settle debts and establish a substantial (for the time) \$40,000 endowment at Vineland for her retarded daughter.

Buck would write over 70 books in her career (for an extensive bibliography, see Harris, 1969). Her first eight novels dealt with China and the Chinese people, often peasants who for the first time became "real men and women" to her less-

<sup>5</sup>The 1938 Nobel Prize was given to Buck not just for *The Good Earth*, but for "rich and genuine epic portrayals of Chinese peasant life, and for masterpieces of biography." The prize for literature was not shared. There was also only one prize for physiology or medicine in 1938, and it went to Enrico Fermi, the famous physicist.

than-worldly Western readers. Early on she also wrote biographies of her mother and father, and translated Chinese classics, such as *Shui Hu Chuan* (*All Men are Brothers*, 1933).

After her Nobel Prize, more of her books dealt with contemporary American life than with Asia, although Asia was still fertile ground for some of her stories (e.g., *Dragon Seed*, 1941; *Imperial Woman*, 1956). Because her output was so immense, she published some of her non-Asian novels under the pseudonym John Sedges, so as not to flood the market with Pearl S. Buck books during the 1940s. Her books about China, however, were always those most associated with her and sought after, and several were made into films (e.g., *The Good Earth*, *China Sky*, *Dragon Seed*, *China Flight*).

Despite her success as a writer and Carol's plight in stimulating her to write commercially, Buck would later lament to her friend Polly Small:

I would gladly have written nothing if I could have just an average child in Carol. Average children seem such a wonderful joy to me – I wouldn't ask for a clever, bright child if I could have had her just average. (Buck, a letter to Polly Small; cited in Conn, 1996, p. 132)

## RETARDATION IN BUCK'S OTHER WRITINGS

Most writers base their best novels on their personal experiences. Hence, it is fair to ask whether children with retardation appear in Buck's stories and more autobiographical works. The answer to this question is "yes," without qualifications.

In *The Good Earth*, which is about a Chinese peasant who amasses a fortune by accumulating land and skillfully farming it, we read that the protagonist, Wang Lung, and his dutiful wife, O-lan, had a retarded baby girl. The child, who is never referred to by name, was a source of great sorrow and heart-felt pain to her compassionate father.

Wang Lung had, therefore, at this time no sorrow of any kind, unless it was this sorrow, that his eldest girl child neither spoke nor did

those things which were right for her age, but only smiled her baby smile still when she caught her father's glance. Whether it was the desperate first year of her life or the starving or what it was, month after month went past and Wang Lung waited for the first words to come from her lips, even for his name which the children called him, "da-da." But no sound came, only the sweet, empty smile, and when he looked at her he groaned forth, "Little fool – my poor little fool –". And in his heart he cried to himself, "If I had sold this poor mouse, and they found her thus they would have killed her." (1931/1994, p. 161)

Wang Lung's daughter's retardation was so profound that family members had to feed her. They also had to take her outside to feel the warm sun and then back in the house at night or when it rained. She would laugh without understanding when others would cry, and would spend hours at a time folding or twisting a small piece of cloth. "She saw no one who came and went and knew no face except her father's and her mother's" (1931/1994, p. 199). In his later years, it would anger and offend the kindly Wang Lung that his snobbish daughter-in-law would "not suffer the poor fool near her" and would even remark: "Such an one should not be alive at all" (1931/1994, p. 298).

Peter Conn, in his cultural biography of Pearl S. Buck, would write: "The nameless child, who serves throughout the novel as a symbol of humanity's essential helplessness, is Pearl's anguished, barely disguised memorial to Carol" (1996, p. 124). To the extent that this thought may be true, the operative word would have to be "disguised." Indeed, Buck did not mention Carol by name or reveal her mental deficiencies in her early, more autobiographical writings.

The ice was not broken until 1950. "I have been a long time making up my mind to write this story," wrote Buck in the opening sentence of *The Child Who Never Grew*. The world-famous author would from this time forth no longer be as secretive about Carol or as reticent to make retardation a theme in other published works.

Buck continued to reveal some of the suffering that she experienced as the mother of a re-

tarded child in *My Several Worlds*, published four years later, in 1954. The major theme of this semi-autobiographical book was to contrast the Chinese and American societies in which she had lived.

But even more worthy of note is *The Gifts They Bring*. In this 1965 book, written with Gweneth Zarfoss, people with mental retardation are presented in an unusually positive light. No longer presented as embarrassments or burdens to society, the mentally handicapped are portrayed as "beautiful minds" and overlooked contributors to the world in which we live.

Passages about having a retarded child can also be found in *The Time is Noon*, one of Buck's more revealing autobiographical novels. This deeply personal and even "confessional" work was published in 1967, although most if not all of it had really been written in the mid-1930s. By the time of its publication, the Western public was decidedly more accepting of mental handicaps. The heroine, Joan Richards is the daughter of a demanding, narrow-minded priest. After Joan gives birth to a retarded son, her personality and outlook on life changes, and she abstains from any further sex with her husband. Here one does not have to look particularly hard under the surface to encounter Pearl and Lossing Buck.

At one point in the hybrid autobiography-novel, Buck shares the moment in which Joan is first told that her child is destined to a life of mental retardation. In drafting this very intimate passage, Buck drew directly on her own experiences:

"Dr. Crabbe, where is his mind?"

The pain of waiting for birth was nothing to the pain of this waiting. All of life, all the world, stopped, faded, was nothing. In all the world there was nothing but this tiny room, this old man, this child, herself. But he did not answer for a long time. At last he began to put on the garments again, slowly, carefully, to fasten them expertly, securely. At last when the child was dressed, he looked at Joan, his face a twist of wrinkles.

"His mind was never born, Joan – my dear child –" (1967, p. 287)

Later in the novel, a woman gives poor Joan some advice that Buck herself might have found too emotionally difficult to follow:

“You can’t ever put him away anywhere,” said Mrs. Mark. “That’s what folks don’t understand. Putting his body away wouldn’t help. You can’t put your child away from your heart. Besides, you don’t want to miss everything of him just because you haven’t all of him. He’s got his own ways. He’s Paul. Don’t measure him by other people. Just take him as he is. If he talks, those few words he’ll say will mean more to you than anybody’s.” (1967, pp. 330-331)

## UNDERSTANDING PKU

Pearl Buck did not learn the reason for Carol’s retardation for some forty years. As told by Janice Walsh:

On one of my brief visits home, sometime in the 1960s, Mother told me that she had learned the reason for Carol’s mental retardation. Carol had an unusual disease called PKU (phenylketonuria). This condition resulted from an inability to metabolize phenylalanine, an essential amino acid. In addition to causing mental retardation, PKU was associated with blond hair, blue eyes, eczema of the skin, and an overpowering musty odor, which was perhaps due to the inability to absorb or process protein. (Carol had all of these attributes.) Mother explained that the condition was inherited, and must have been present in both her genes and Lossing’s genes. When we learned about PKU, a method of diagnosing the condition by testing urine samples from the diaper had recently been developed. (Walsh, 1992, p. 96)

In this context, it is important to date PKU as a distinct disease entity. The first evidence that PKU could be differentiated from other forms of childhood retardation was provided by Asbjørn Følling, a Norwegian doctor and biochemist, in 1934 (Christ, 2003). In that year Følling was approached by Mrs. Borgny Egeland, who was searching for an explanation for the apparent failure of her two children to development men-

tally. Følling’s description of one of the children, a six-year-old girl, could easily be taken as a description of Carol. She was found to be

very restless, always fluttering about from one thing to another without issue. She is able to say some words which are understood by her family but she does not talk in sentences. Likes to play, alone or with other children, and to listen to music (her paternal relatives are very musical). (A. Følling et al., 1945, p. 9)

A check of the urine of these children for ketones produced an unexpected result. Typically, when a solution of aqueous ferric chloride is added to urine it turns purple-burgundy if ketones are present, otherwise the mixture turns red-brown. Adding the ferric chloride to the urine of the Egeland children, however, resulted in a dark green color. Although initially perplexed, Følling was determined to identify the anomalous substance in the urine that was responsible for this unique reaction. Several months later, he was able to isolate and identify the substance. It was phenylpyruvic acid.

Wondering whether the phenylpyruvic acid might in some way be related to the children’s mental impairment, Følling made arrangements to test urine samples from some 400+ mentally impaired patients from nearby institutions. He was able to identify an additional eight individuals who, along with the Egeland children, all shared two key traits – all were mentally retarded and all secreted high levels of phenylpyruvic acid in their urine. Følling called their condition *imbecillitas phenylpyruvica*. The shorter term *phenylketonuria* would be coined just a few years later by the English geneticist, Lionel Penrose, and this term, or PKU, would be widely accepted (Penrose & Quastel, 1937).

Noting that his sample included three pairs of siblings, Følling suggested that the condition was probably hereditary. In a follow-up study, he confirmed this hypothesis and provided convincing evidence that PKU is transmitted by a recessive autosomal gene (Følling et al., 1945).

Drawing on his knowledge of biochemistry, Følling concluded that increased levels of phenylpyruvic acid in the urine reflect an inability to metabolize phenylalanine, a common amino acid.

Although Følling, along with biologist Karl Closs, would soon confirm this hypothesis (Følling & Closs, 1938), several years would pass before the precise mechanisms responsible for this abnormality would be fully understood.

We now know that homozygous carriers of the PKU gene are unable to produce an essential enzyme, phenylalanine hydroxylase, thereby disrupting the process of converting phenylalanine into tyrosine, a neurotransmitter precursor. The phenylalanine hydroxylase molecule is either absent or mutated in individuals with PKU (Friedmen et al., 1973). This genetic-based abnormality occurs in approximately 1 per 10,000 individuals (Smith, 1985). In addition to severe cognitive impairments, individuals with PKU display an increased incidence of epilepsy (Jervis, 1937; Paine, 1957), microcephaly (Corsellis, 1953), and motor abnormalities (Jervis, 1937; Følling et al., 1945; Cowie, 1951; Paine, 1957), as a result of consuming food containing phenylalanine.

The precise biochemical mechanisms responsible for the brain damage seen with PKU were unknown during Carol's lifetime, and they are still not fully understood. Today, the belief is that excessive phenylalanine competes with some neurotransmitter precursors, possibly tyrosine and tryptophan, thereby affecting production of one or more neurotransmitters (Diamond et al., 1994; Thompson, 1995). Consistent with this hypothesis, but possibly only part of the story, reduced levels of dopamine have been found in the cerebral spinal fluid of individuals with PKU (Lou et al., 1985).

The idea that PKU syndrome might be circumvented by restricting intake of food containing phenylalanine began to circulate in the 1950s, when Carol was in her 30s (e.g., Bickel et al., 1953). It is now known that infants and young children who are kept on phenylalanine-restricted diets throughout childhood and adolescence can be spared many of the adverse consequences (including mental retardation) associated with untreated PKU. Unfortunately, dietary changes later in life do not help those individuals, like Carol, who are profoundly retarded by PKU in early childhood.

Although Pearl Buck learned that Carol's mental state could not be reversed, having a biomedical

explanation for Carol's condition seems to have had two effects on the world-famous author and social activist. On the one hand, she finally had an answer to the question "why?." She must have been relieved to learn that her daughter's condition had nothing to do with poor mothering. But on the other hand, she now knew that her own genes, like those of Lossing, did in fact contribute to Carol's severe mental disability.

## IMPACT

After leaving Carol at Vineland and making a success of herself through her writings, Pearl S. Buck came out of the closet to work hard on the behalf of mentally retarded children. She not only became an active member of the Board of Directors at the Vineland Training School but also chaired the Governor's Committee for the Mentally Retarded in the State of Pennsylvania. Her efforts had a stimulating effect on others in the public eye.

One such person was Eunice Kennedy Shriver, sister of President John Fitzgerald Kennedy. She wrote about her retarded sister Rosemary, who like Carol loved music, the need to help retarded people become useful citizens, and the Joseph P. Kennedy Jr. Foundation for the mentally retarded, in the *Saturday Evening Post* in September, 1962. Citing the fact that retardation can occur in any family, "poor or rich, of doctors, lawyers, writers, men of genius, presidents of corporations – the President of the United States," she specifically singled out the ground-breaking efforts of Pearl Buck. In her words: "Nobel prizewinning novelist Pearl Buck, in a small volume called *The Child Who Never Grew*, has written a moving account of her efforts to find a good life for her mentally retarded daughter" (p. 72). Later in her article Shriver even mentioned how PKU was discovered:

Sometimes the persistence of an individual parent is the instrument which breaks important new ground. The Norwegian mother of two severely retarded children trooped from doctor to doctor with the story that her children's diapers "smelled different." She was scoffed at. One doctor even suggested she consult a psychiatrist for her own sake.

But she was right. Her children's retardation was caused by phenylketonuria, or PKU, a disorder that brings an excess of a certain acid to the system. The acid gives a distinct odor to the urine. Not until one doctor finally took the trouble to investigate this mother's improbable "evidence" was the nature of PKU discovered. Today it can be detected by simple tests, and cured before it damages a child. (p. 74)

Buck's efforts also had an effect on the wife of French President Charles de Gaulle, who said she had carried a similar cross on her back and experienced the same sorrow as did the American author (Conn, 1996). Another individual who seemed to be influenced by Buck, and who was also mentioned by Eunice Shriver, was actress Dale Evans Rogers, the wife of cowboy actor Roy Rogers. She wrote a book in 1953 describing a child in their family who had Down's syndrome. This book by a greatly admired American movie and television star had exceptionally high sales and further helped to change attitudes about the retarded (see Trent, 1994).

Throughout most of her adult life, Buck thought children provided the greatest opportunity for improving mankind, and looked upon retarded children, like Carol, as being among the most needy. Nevertheless, and in a way consistent with her own personality, she felt more comfortable working with parents than with children. As she explained it, the first step had to be for the parents to accept the child's condition; a later goal would be to have these children accepted in the wider community.

Numerous awards were given to Buck for her efforts with the retarded. There were also countless letters of thanks. One of the more visible tokens of appreciation was a hand-painted doll from Japan, awarded to her by the Association of Parents of the Mentally Retarded in Japan. This doll was proudly put on display at the Pearl S. Buck Foundation in Philadelphia.

Theodore F. Harris (1969, p. 297) tried to summarize Buck's multi-faceted life in a single sentence when he wrote: "Everything this woman has accomplished in her life has been her answer to the world on a subject that concerns her." Janice Walsh had this to say:

As a public figure, she was able to reach out to all peoples of the world, and show her compassion and concern. She was able to leave a legacy of simple caring for all mankind who would listen and accept her challenge. Would this legacy have been different if she had not given birth to Carol? It is impossible to say for sure, but I think that the answer is "yes." (Walsh, 1992, p. 107)

Buck clearly knew the power of the pen and how influential she could be in drawing attention to human tragedies, raising money for research, and disseminating information. Within her lifetime, she witnessed first-hand the advances that were made in detecting and treating the biochemical disorder that afflicted her daughter. Had she lived longer, she would have been pleased to discover that medical scientists are still working hard to learn more about PKU, its effects on the brain, and its prevention.

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#### REFERENCES

- Bickel H, Gerrard AJ, Hickman EM (1953): Influence of phenylalanine intake on phenylketonuria. *Lancet* *ii*: 812.
- Buck PS (1930): *East Wind: West Wind*. New York, John Day Co.
- Buck PS (1933): *All Men Are Brothers*. New York, John Day Co.
- Buck PS (1941): *Dragon Seed*. New York, John Day Co.
- Buck PS (1950, May): The Child Who Never Grew. *Ladies Home J*, pp. 35, 146, 147, 150, 152, 156, 159, 160, 163-165, 167, 169, 171.
- Buck PS (1950): *The Child Who Never Grew*. Vineland, NJ, The Training School at Vineland.
- Buck PS (1954): *My Several Worlds*. New York, John Day Co.
- Buck PS (1956): *Imperial Woman*. New York, John Day Co.
- Buck PS (1967): *The Time is Noon*. New York, John Day Co.

- Buck PS (1992): *The Child Who Never Grew*. Bethesda, MD, Woodbine House, 2nd edition.
- Buck PS (1994): *The Good Earth*. New York, Pocket Books. (Original work published 1931, New York, John Day Co.)
- Buck PS, Zarfoss GT (1965): *The Gifts They Bring: Our Debt to the Mentally Retarded*. New York, John Day Co.
- Christ SE (2003): Asbjørn Følling and the discovery of phenylketonuria. *J Hist Neurosci* 12: 44–54.
- Conn PS (1996): *Pearl S. Buck: A Cultural Biography*. Cambridge, UK, Cambridge University Press.
- Corsellis JA (1953): The pathological report of a case of phenylpyruvic oligophrenia. *J Neurol Neurosurg Psychiat* 16: 139–143.
- Cowie VA (1951): Phenylpyruvic oligophrenia. *J Ment Sci* 97: 505–531.
- Diamond A, Ciaramitaro V, Donner E, Djali S, Robinson MB (1994): An animal model of early-treated PKU. *J Neurosci* 14: 3072–3082.
- Følling A, Closs K (1938): Über das Vorkommen von l-Phenylalanin in Han und Blut bei Imbecillitas phenylpyrouvica. *Hoppe-Seyler's Zeit Physiol Chem* 254: 115–116.
- Følling A, Mohr OL, Ruud L (1945): Oligophrenia phenylpyrouvica. A recessive syndrome in man. *Skrift Norske Vitenskapsakademi I Oslo. I. Mat Nat Kl* 13: 1–44.
- Friedman PA, Fisher DB, Kang ES, Kaufman S (1973): Detection of hepatic phenylalanine 4-hydroxylase in classical phenylketonuria. *Proc Natl Acad Sci* 70: 552–556.
- Harris TF (1969): *Pearl S. Buck: A Biography*. New York, John Day Co.
- Jablow MM (1992): Introduction. In: Buck PS, ed., *The Child Who Never Grew*. Bethesda, MD, Woodbine House, Inc., 2nd edition, pp. 1–23.
- Jervis GA (1937): Phenylpyruvic oligophrenia: Introductory study of fifty cases of mental deficiency associated with excretion of phenylpyruvic acid. *Arch Neurol Psychiat* 38: 944–963.
- Lou HC, Güttler F, Lykkelund C, Bruhn P, Niederwieser A (1985): Decreased vigilance and neurotransmitter synthesis after discontinuation of dietary treatment for phenylketonuria in adolescents. *Eur J Ped* 144: 17–20.
- Michener JA (1992): Foreword. In: Buck PS, ed., *The Child Who Never Grew*. Bethesda, MD: Woodbine House, Inc., 2nd edition, pp. i–xi.
- Paine RS (1957): The variability in manifestations of untreated patients with phenylketonuria (phenylpyruvic aciduria). *Pediatrics* 20: 290–331.
- Penrose LS, Quastel JH (1937): Metabolic studies in phenylketonuria. *Biochem J* 31: 266–274.
- Rogers DE (1953): *Angel Unaware*. Old Tappan, NJ, Spire Books.
- Shriver EK (1962): Hope for retarded children. *Sat Eve Post* 235: 71–75.
- Smith I (1985): The hyperphenylalaninaemias. In: Lloyd JK, Scriver CR, eds., *Genetic and Metabolic Disease in Pediatrics*. London, Butterworths, pp. 166–210.
- Thompson AJ (1995): Phenylketonuria: An unfolding story. In: Robertson MM, Eapen V, eds., *Movement and Allied Disorders*. New York, John Wiley and Sons Ltd., pp. 83–103.
- Trent JW Jr (1994): *Inventing the Feeble Mind: A History of Mental Retardation in the United States*. Berkeley, CA, University of California Press.
- Walsh JC (1992): Afterword. In: Buck PS, ed., *The Child Who Never Grew*. Bethesda, MD, Woodbine House, Inc., 2nd edition, pp. 91–107.

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