

The Gettysburg Review

SUMMER 2010

\$10



The British Cure

MARCH 19, 1968

I stood at a bus stop in a place I never thought I would visit: Newcastle upon Tyne in the north of England. I pulled my raincoat closer and looked down along the bleak row houses built on terraces on both sides of the hill. Several women wearing bandanas chatted in their musical northern voices. Unsure of which bus to take, I stood on tiptoe in my striped orange shoes to scrutinize the route sign. One of the ladies walked toward me. "Where are you off to, pet?" she asked. I smiled but ducked my head to hide the red, scaly skin on my face.

"I'm trying to get to the Royal Victoria Infirmary."

"You're just in the right place, yer'na." She settled her plastic purse on her arm. "You're a Yank then, are ya?"

I was a Yank. One of the few, presumably, who ever needed to know which bus to take to the massive hospital on Queen Victoria Road. That morning I had an appointment with Dr. Sam Shuster, a young dermatologist who proffered daring treatments for the severe skin condition, worse than psoriasis, that I have tolerated since birth. Shuster had already made a name for himself in the international world of dermatology, with which I was distressingly familiar. He practiced in Newcastle; I had come up to see him that day from Oxford, where I was studying for my MA in English.

This trip wasn't my idea. My parents, like any loving parents of a child with a physical problem, sought whatever medical advice they could find in what seemed to me a relentless search for a cure for my ailment, which is called ichthyosis. It is named for the dark scales that lie, with varying degrees of thickness, across my whole protesting body; *ichthys* is Greek for fish. Although as many as one in five thousand people have a mild form of ichthyosis, called ichthyosis vulgaris, my form—lamellar ichthyosis—is very rare; only about twenty Americans a year are born with it. It is lifelong. There is still no cure for ichthyosis, and there probably won't be until an effective gene replacement is developed. A genetic mutation, not well understood, is responsible. Like the gene for blue eyes, the ichthyosis gene is passed on from both sides of the family. It is recessive, so my parents, a handsome couple, had no idea they carried this gene

until I was born. Maybe their innocent guilt drove them to involve me in treatment after treatment.

This time, I would much rather have been back in Oxford, where I was beginning to make friends among my classmates. But I was a biddable young woman, even at twenty-two, so I kept the appointment.

Shuster pushed open the door without knocking, raised his prominent eyebrows, and thrust out his hand. "I'm Sam Shuster." A slight man with slender shoulders, he came directly to the examining table, where my feet dangled from under my hospital gown. He got right to the point. "I think we have something that can help you." *Okay*, I thought. *I've heard that before.*

"Let's take a look at you." He picked up my fingers, turned them over, and then moved to examine my back. I barely felt his hands slide over my rough skin. "You've used heavy doses of natural vitamin A and steroids, right?"

"Yes, that's right. The vitamin A worked best. But it threatened my liver, so we stopped it."

"What happened with the steroids?" He was looking into my ears.

"They gave me a moon face when I was thirteen."

"But it didn't really help your skin, right?"

"No, it didn't, not really." He didn't ask me what it was like to have an abnormally puffy face when I was a teenager, even though he had written about the psychological effects of skin diseases. I wasn't about to bring it up. I had never talked with a dermatologist—or anyone else for that matter—about how different I felt. It wasn't part of the program. Deep in denial, my parents and I treated my skin condition as a purely medical problem.

Shuster jerked a small stool from a corner and sat, leaning forward. "Well, I think the way to attack this problem is to hypothesize that your skin produces new cells too quickly. In normal skin, the outer layer sheds constantly, almost invisibly. In fact a new epidermis, that outer layer, is produced about once a month. But in lamellar ichthyosis, something interferes with this process."

I let him talk. In those days, a patient didn't normally question her doctor much. Accustomed to dealing with prominent dermatologists, I knew that even the best—compassionate men, passionate scientists—didn't have a simple cure for my problem. I glanced at the NHS header on the prescription pad that jutted from his pocket. *God bless the National Health Service*, I thought. *I'm getting all this for free.* "If the skin cells proliferate too quickly," Shuster continued, "the thing to do is slow them down. That's what methotrexate does. That's why we use it to slow down cancer cells. I think it may be just the thing for you."

Okay, that's logical, I thought. I didn't ask him how many people with lamellar ichthyosis he had treated with methotrexate. Probably none. So few people in the world even have lamellar ichthyosis that it is difficult for doctors to gather enough cases together in one place to experiment. Methotrexate had been used for psoriasis since about 1950, but physicians differed in their opinions about the drug. One of Shuster's colleagues at the Royal Vic, writing in the *British Journal of Dermatology* in 1968, reported that some dermatologists would not prescribe it under any circumstances because they believed it to be dangerous.

Squirring on the examining table, I nerved myself to ask the really frightening question, the one for which doctors never had a clear or comforting answer. "Are there side effects?"

He walked over to the desk and started scribbling notes. "Possibly. We'll do blood studies throughout the course of treatment . . . to be sure your liver and kidneys are okay. We'll watch the bone marrow." I tried to absorb the talk of threats to my vital organs, but I had heard warnings like this before, almost every time I started any powerful new treatment. I had a lot of practice in ignoring them. Perhaps I also had a lot of practice in forgetting how my body remembered the vitamin A crawling along my bones, which made me flinch with pain. Anyway, I didn't protest this new experiment. Certainly, Shuster must have thought the payoff would be worth the risk. With his hand on the door, he skipped to logistics. "Let's get you back up here during your spring vacation. We'll give you a powerful dose right away. Keep you under observation for two weeks. Dr. Vickers will have to follow up down in Oxford." He smiled, thanked me for coming, and shut the door.

When I left the Royal Vic that day, I had heard what I needed to hear and as much as I wanted to know. Shuster would have to deal with the redoubtable Dr. Renwick Vickers, professor of dermatology at the Oxford Medical School, who was my local dermatologist. Vickers had told me that he was skeptical about methotrexate. I wondered if he was even more skeptical about the younger, more ambitious northerner, but I wasn't going to get mixed up in medical politics. In my mind—where I lived much of the time—the whole business looked risky. When I weighed the odds that this powerful, toxic drug would actually bring my skin to a watery ripeness, I was as skeptical as any conservative dermatologist. But walking down the broad steps of the Royal Vic past the marble statue of the young Queen Victoria, I let my heart skip with an echo of hope.

On the train back to Oxford, I wrote to my parents. I tried to spell out the pros

Anne Kaier
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and cons of this treatment with as much clarity as my father, a successful lawyer, would expect.

Dear Mom and Dad,

I shall try to unravel what Shuster said. He has one more or less master plan. It's not to say he thinks he can once and for all lick my problem, but he thinks there's a possibility that this drug will, or might, control it. In any event, he thinks it's worth a try, and if I understand him correctly, it might prove a topical remedy, if not a complete or organic one.

There is, of course, a hitch. The bleedin' drug is toxic—affecting bone marrow, liver and kidneys—I presume rather like the affects of the vitamin A which I took so heavily about five years ago.

It seems this chap Shuster has an idea, seemingly a sound chemical idea, which may just do a lot of good and I'd rather do it now than wait around until July. If there's to be a toxic effect it would be better to get it over with in my vac than in the regular semester. Write and tell me what you think.

Love, Anne.

What did they think? How far into the future were they thinking? Would the side effects rule out using the drug for a long time? If so, why take it to begin with? Was I supposed to see my skin clear and then see it relapse? Looking back, I am amazed and angry that no one asked these questions. However, in 1968, dermatologists simply didn't have widely accepted information about the potential side effects of this drug. We were all operating in a world of trial and error. Perhaps my parents thought that any drug that would make their daughter better was worth trying. Perhaps they thought the doctors might then find something similar but not so toxic. I didn't keep the letters they wrote to me. Perhaps they downplayed their fears. Maybe my father, in his steady way, advised me to consider the risks, and then put them out of my mind. I can't imagine that they were too swayed by the rather arch tone of my letter, full of the Britishisms that came so easily through my ear and onto the page. I am sure they saw the worry beneath. I cringe a little when I read these letters now. I wince at their too-obvious attempt to hide real feelings under the scrim of witty language. This is not surprising. We didn't discuss serious problems for very long in my family. At home in Philadelphia, my brother got his draft notice as the war in Vietnam escalated. They never told me anything about it.

By the time I dropped my letter in the red mailbox outside the Oxford station,

I only wanted to shake off the entire business and get back to my room at St. Anne's College.

Students at Oxford University don't enroll in the university as such. They enroll in one of the thirty colleges, although Oxford University issues the degrees. In the late sixties, five of those colleges admitted women, only women, in fact. I chose St. Anne's, in part because of the name. I arrived at Oxford in a roundabout way. When I told my parents I wanted to pursue graduate study in England, my father remembered that a Jesuit friend of his had earned an MA at Oxford. The friend was eager to promote his alma mater and arranged to have the entrance exams sent to Manhattanville, my college in White Plains, New York. Somehow I passed the tests, and my father was able to afford the surprisingly modest tuition.

In Oxford, I lived in one of the Victorian houses on St. Anne's campus. It was a sand-colored brick house without central heat. I put shillings in the gas heater in the fireplace. Like a parking meter, it would take only so much money. So the heat ran out in the middle of the night. But I had an early morning helper. Back then, men were not allowed on the college grounds after 10:00 PM. However, my window opened directly onto Woodstock Road. Anyone who wanted to evade the night watchman could just raise the sash and slip out. Rob, the long-limbed guy who was sleeping with the girl upstairs, regularly left through my window just before dawn. On his way out, he would put another shilling in the meter.

His girlfriend, another Anne, had befriended me in my first semester. A Jewish girl from London, she probably felt as much an outsider at Oxford as I did. She and Rob and I used to roam the back streets of the medieval city center in search of cheap Indian food or cafés where flaky sausage rolls warmed us in the damp Oxford mist. Once, after we had eaten at the King's Arms, a slightly scruffy student pub, Rob ambled into busy Broad Street and flung one arm around Anne and one around me. I stiffened a little, unused to the male smell in his work shirt.

Just hanging around with a guy, even a man as safe as a friend's boyfriend, was new to me. In my girls' Catholic high school, the typical Irish Catholic repression of sexuality found a willing acolyte. My principal, a nun responsible for our "Catholic marriage preparation" course, once told me she didn't like to be touched. Since I thought no one wanted to touch me anyway, I shriveled inward from the skin that thickened the nerve ends of my fingers and arms and breasts. I withdrew into the sanctioned regions of my very capable brain.

Even in the swinging sixties, I didn't date. For better or for worse, my parents discouraged me from even trying to go out with boys. Perhaps they wanted to protect me from what they saw as inevitable rejection. "Marriage isn't every-

thing," my mother used to tell me. Perhaps this comment betrayed her regret that as a married woman in those days, she had little chance of a career herself. I think she tried to imply that I had the intelligence to support myself as an English professor. But when I heard her say that, more than once, I also learned to believe that marriage was only for elegant, beautiful women like her. It wasn't for me, at least not until I was cured. So I felt skittish and awkward around men. I knew very few men during my college years. At Oxford, Rob, who loped around town like a friendly pony, helped ease my nervousness.

The day after I returned from Newcastle, all three of us sat in the narrow Cadena Café on Cornmarket Street, drinking thick coffee. For a while we talked about the recent demonstrations protesting the war in Vietnam. While Rob and I rehashed stories about how the mounted London police had charged crowds in front of the American Embassy, Anne had been curling one strand of black hair against her thin white face. "So what was it like in the frozen north?" she asked.

"It's the ugliest town in all of England."

"Yeh, commercial. Bringing coals to Newcastle. All that sort of thing."

"That's for sure. Soot over everything." I smoothed the table cloth. "The townspeople are friendly though."

She clouded her coffee with more milk. "Well, it was alright for you there, then, was it?"

"Yep. Well, they all speak with that lovely, uncouth north-country accent. You can't understand half of what they say, but it sounds so musical."

"So can they help you, then?" asked Rob, rubbing the top of his head.

"Dunno. We'll have to wait and see."

I never talked much about my skin, even though it was there for all to see. I had been brought up to ignore it; I had no idea about how to set anyone at ease about it. I rallied every bit of Irish American charm to distract people from my red hands, to make friends despite the white flakes that marred my delicate fingers.

These days, I talk about my skin when I first get to know people, so the question of what is wrong with me can be answered quickly and laid to rest. But I can't change the past. That afternoon in Oxford we fell silent, finished our coffee, and walked back past the still domes and crumbling stones of the ancient city.

Dr. Vickers's office was located in the Radcliffe Infirmary, a famous hospital whose Georgian front turned a blank face to the Woodstock Road across the street from St. Anne's. A few days after my return from Newcastle, I went to see him, wondering if Shuster had called him and persuaded him to supervise the follow-up for this treatment. In his office, Vickers came around from his desk in a

starched, white lab coat, each cloth-covered button tucked in its hole. "How've you been doing?" His fingers tapped the thick scales on my forearm, which I regarded as if it were an unexplored field, bumpy with hillocks.

"Fine. Just fine. Newcastle's really an interesting city. I liked it up there."

"Umm. Any change in the nails?" Vickers always asked about nails. The moons told him something I didn't understand, didn't want to know about.

"No, not really."

He seemed satisfied, went back to his desk, and sat sideways behind it, resting his right arm parallel to the front edge. At fifty-seven, his hair was graying.

"I've talked with Dr. Shuster about his plan."

"Good. Good. I'm glad you did."

"Miss Kaier, methotrexate is a very powerful drug. It can have adverse effects on the liver. We'll have to monitor the triglycerides in your blood to be sure the liver and kidney function remains normal." It sounded like he was willing to go along. My mother would be pleased. "We also have to worry about potential effects on your ovaries. If you were pregnant or likely to become pregnant, it would be cause for worry." He leaned toward me, and his eyes softened.

I jerked my gaze to the blank yellow walls, the rim of stone window. "No, no, that's not, that's not a problem." In my mind, I fled. To talk about sexuality, conceiving children—these things seemed utterly remote from me.

He sat back. "All right, then. I'll get in touch with Dr. Shuster. When you come back from Newcastle, make an appointment and we'll set up a schedule for blood tests."

So the plan crystallized. I would go back to Newcastle within the week, when spring break began. Instead of staying in Oxford and reading in the library, or maybe going up to London to visit Anne's family, I would be in a ward at the Royal Vic.

NEWCASTLE, MARCH 25, 1968

The women's dermatology ward of the Royal Vic stretched long and narrow as I unpacked at its far end. Fluorescent lights ran like railroad lines along the ceiling of the white room. Concentrating on my task, I pulled out the screeching metal drawer in the white side table and put away my underclothes and book of Keats's poems. In the background I heard a high, lyrical north-country laugh. Although I wasn't really sick, I changed and got into bed like everyone else. Curtains on racks above each bed, which provided for rare occasions of privacy when the doctors came by, stood tightly furled against the wall. I took up my book, but pretty soon

Mrs. Pierce, the dark-eyed, middle-aged lady in the bed next to mine, broke into my silence. In gently round tones I can't possibly reproduce, she asked me where I was from and what "they" were going to do for me. She must have called me "pet" with every breath. Pretty soon we were joined by Peggy, a teenager with a beehive hairdo who flopped on my bed and bemoaned her yellow hospital gown. Mrs. Pierce and Peggy taught me the critical things I needed to know about being in a British hospital, including the fact that the nurses were called "Sister." That night, I wrote to my parents:

Well, here I am ensconced in the Royal Vic. Hospitals are in a way like small towns—everybody knows all the local gossip. In my part of the ward are an older woman and a young girl, both quite friendly and willing to clue me in on the local goings-on—when the head nurse is around and when we are free of her apparently iron control, who are the nice interns etc. The Matron (the feared Head Nurse) came around this evening after dinner (*absolutely* uneatable) and said rather too cheerily, "Well, ladies, and how are we all today, feeling better, uh?"—such-like goo. Anyway, the place seems livable.

After dinner, Dr. Shuster came by, briefed his retinue of interns on my condition, snapped the curtains closed, and watched as one of his assistants administered my first shot of methotrexate. When he had gone and the lights were out, I tried to sleep, but my hands drummed the metal sides of my bed. I held my face an inch above the rough sheets, afraid to feel it swell with the terrible moon face that steroids had once given it, afraid to feel it burst as my cheeks protested the toxic drug that swam through my blood. When I finally drew up my legs and curled on my side, I saw the quiet light at the nurse's station far down the corridor. Her shadow kept her company as she stood over her desk.

NEWCASTLE, MARCH 26, 1968

In the morning, with no effect whatsoever from the methotrexate, I set off to explore the hospital and to find, if possible, something good to eat. Hospital food in the north of England in the sixties consisted of peas mashed to a gritty green blob and mystery meat. At home in Philadelphia, the Chop Shop café at the University of Pennsylvania Hospital served cheeseburgers and Cokes. Surely I could find somewhere to buy a sausage roll at least. What I found instead was the Vietnam War, reported in the *Times of London*, which I bought for a shilling in the hospital gift shop along with a bar of Cadbury's chocolate. Back on my bed, I read about Bobby Kennedy, stumping in L.A. and—pushed left by his presidential

rival Senator Gene McCarthy—finally proclaiming his opposition to the war. The *Times* reporter wrote about the expected effect of Kennedy's move: "One California Democratic Congressman told me he expects Senator Kennedy to get twice as many votes as the next man in the state primary election on June 4, and that he expects President Johnson to come in last."

How isolated I felt from the momentous events happening at home! Anne and Rob and I had only read about the demos in London, when Vanessa Redgrave had led crowds in an antiwar rally. I was entirely too shy to march with other students at Trafalgar Square. The hospital, three hundred miles north of London, seemed a closed world. No one had a radio. If there was a phone on the ward, I don't remember where it was. Although I had glimpsed a TV way down in a room off the men's ward, I hadn't ventured that far from Peggy and Mrs. Pierce. But I had time to fill, so I read the paper from cover to cover.

NEWCASTLE, MARCH 29, 1968

Sitting in bed, I wrote to my parents:

Sam Shuster, blast him, has gone off on a 10-day vac. But it really doesn't matter. He's left another chap in charge of me, whose name I don't know, but who says he saw me at Penn a few summers ago. By the time Shuster gets back, I'll have had another methotrexate shot and we can tell what's happening. So far, I have had absolutely no toxic effects. Not a thing. Something, however, is making my face pretty gorgeous—lovely & deep soft. They're using a different cream on it but after long experience with creams, I rather doubt that any cream could work so fast. Shuster says that if the methotrexate is working, it would show earliest on my face, since it is in the best condition and would show the turnover of skin the fastest. Well, we'll see. It's honestly much too early to tell anything for sure, so don't get excited . . . but at least nothing *bad* has so far happened.

Writing with a calligraphy pen in black ink, I tried to give my distant parents what they needed: reassurance, information, hope. My mother, so elegant in her fashionable linen sheaths, believed you had to elbow, even connive your way to what you wanted in life. She had relied on her brains, beauty, and luck to maneuver herself out of Depression-era Indiana into a happy marriage on Philadelphia's Main Line. With fierce intelligence and intense maternal love, she had fought for my health since the day I was born. She wanted nothing so much as to see her

daughter's skin soft, clear, normal. Only when it shone smooth and healthy, she believed, would any man want me. All her upbringing as a pretty, but fatherless, girl looking for a husband made her see beauty as an unquestioned prerequisite in the marriage market. So far, I didn't have the goods. Of course I felt ugly in comparison with her, but perhaps I was secretly glad I didn't have to compete with her for physical grace. I put off the whole question of marriage to some future era in which I would be cured. In the meantime, I had an excellent brain and, with a good education, a chance at an academic life. So I lived in my head. My father, gentler, happier, and willing to take a backseat when it came to the children, mainly wanted me to be safe. In my letters from England that spring, I did my best to please them both.

NEWCASTLE, MARCH 31, 1968

As I worried less about the side effects of the drug, I began to think about how much studying I needed to do. At Oxford, semesters are punctuated by six-week "vacations," which are filled with assigned reading and papers due when the next term starts. I was intensely eager to impress one of my teachers, a man named John Jones, who sat in a big green leather chair in his rooms in medieval Merton College and talked with me about poetry as if I were his equal. I looked forward to returning to Oxford with a brilliant paper for him.

So, I finagled a private room. It huddled in a corner just off the men's ward. It had a window, a small bed, and silence. A private room was a rarity in the public National Health Service hospital—surely beyond the means of Mrs. Pierce and Peggy and the men who were being treated in the big ward next to me. I thought I just wanted to get my work done, that the constant conviviality of the women's ward wore on me, that I needed some solitude. All these things were true, but I also think another reason impelled me to seek refuge. It was almost impossible for me to admit we were all suffering from skin diseases. I had been so alone in mine and so divorced from my body, I pretended I didn't have ichthyosis at all. In part, this may have been a simple coping strategy taken to extremes. If I didn't think about my body, I didn't have to think about how itchy I was. If I just refused to notice the constant changes in my skin, the flaking and redness that varied day by day, they were easier to deal with. I had absolutely no one to talk with about my skin except my dermatologist who, despite his kindness, stuck to medical issues. In the fifties and sixties, in my middle-class Catholic world, there was no psychologist or counselor or even school nurse in whom I could confide. At home my

disease ranked as a taboo subject. We all ignored it. So, these friendly northern women, who knew they were in hospital to treat their psoriasis or eczema, were a threat to my understanding of myself and my own body.

My parents—loving, elegant, determined not to dwell on my problem—doubtless paid for the private room. That evening I wrote breezily:

This morning I moved into my private room and it's blissful. Less noise, no horrible neon lights. However, I still eat with my ward mates, and Mrs. Pierce has kind of appointed herself as my foster-aunt and tells me to go to sleep, calls me "pet" and gives me oranges and apples on which I've literally been living. At this point, I could definitely do with a gin and tonic and a steak!

PS. As of this morning, my scalp is completely clear, due to the acidic cream which they've had on it constantly. It's terrific. Hasn't happened for years.

Looking back, I notice I slid the news about my scalp into a postscript. Anything to escape a direct gaze at my body. Even in a letter, three thousand miles away, it was hard for me to bear my mother's inspection, the ferocity of her love, her desire for me to get better. Those lights in the women's ward were fluorescent, of course, not neon. So often in my life I have needed to simply hide, to flee from the eyes of strangers and even parents into a world in which no spotlight can find me naked and peeling.

NEWCASTLE, APRIL 1, 1968

Nevertheless, I had been stealing glances into the men's ward where the lads with their husky voices shambled about rather embarrassed about being in hospital. Many covered their hospital johnnies with old red bathrobes from home. I noticed their pockets hid brown paper bags, which they fondled covertly except when Sister strode into the ward. This evening, after she had given me a second shot of methotrexate—in the fanny, no less—I quietly followed the men and Peggy in her orange fuzzy slippers down to the lounge just off the men's ward. There, anchored to the green wall, the only TV on the dermatology floor promised movies, drama, escape. We scattered onto steel chairs in our robes, some of us smelling of the tar used to treat psoriasis, me with my scalp smeared with stinging lotion. Occasionally one of the lads would take a swig from whatever hid in his woolen pocket. Out of the corner of my eye, I watched one of the younger guys suck on the brown lip of his bottle. *Newcastle Brown Ale*, I thought, *that's what they've got!* Their friends or families must have smuggled in a few bottles during Sunday visiting hours. "Yer sweetie bring ya that?" Peggy asked one of the

younger guys, scraping her chair nearer to his. He grinned, looked around for the matron, and then offered us both a sip. Soft and dark with the slightest ting along the tongue, it went down easily.

We turned back to the BBC news. As Peggy and her new friend teased each other, my eyes finally focused on the strangely familiar face of President Johnson. What was Lyndon doing here? My contemporaries and I generally despised Johnson. We hated him for the war, for the killing, and particularly for the draft. My college roommate's nineteen-year-old brother, conscripted into the infantry, had been killed two weeks after he had arrived in Vietnam. My brother's roommate from Harvard died in the same manner, in the same place, at twenty-two. As far as I knew, my brother himself remained safe in law school, but how long could that last? I looked around at the Newcastle lads and thought how unaffected they were sitting in their robes. On the screen, Johnson seemed to be meandering, even mumbling in his thick Texan accent. I clenched my teeth, shook my head a little, dreading the thought of him in the White House for another four years. Then I heard him say, "I shall not seek, and I will not accept, the nomination of my party for another term as your president." My shoulders hit the back of the chair. It was over! At least Johnson was over. Now we could elect Bobby Kennedy or McCarthy, someone who would put an end to the war. I exulted, but the lads barely seemed to notice. American politics boiled far away from Newcastle Brown, from the ward, from the endless waiting for skin to clear so we could go home.

NEWCASTLE, APRIL 3, 1968

Sitting in bed reading Keats, I surreptitiously fingered my cheeks. The skin on my face seemed to be thickening again. My scalp seemed tighter as it labored to hold the extra layers. The methotrexate was supposed to slow down the production of skin cells so my skin would slough off normally, slowly. What was happening?

Later that afternoon a group of doctors and interns jammed into my little room. Shuster remained on vacation, but it seemed that every other dermatologist in Newcastle was there to take a look. The handsomest of Shuster's medical residents, a Swede from Uppsala, smiled and asked, "Does anyone else in your family have this condition?" He parted the hair on my scalp.

"No. Just me. Are you from Sweden?"

"Yes, I am. Can you show me your legs?" I fished my legs out from under the sheet. He pushed up my pajama pants, and the others leaned in to get a closer look.

"I visited Stockholm once, with my family. On a summer trip when I was

about fifteen. What a lovely city. Rather splendid actually. But I've never been farther north. Except to Bergen, on that stunning Norwegian fjord."

"Oh, yes. It's lovely in Norway. And what treatments have you used before this?" *Lord*, I thought, *hasn't he read the bloody chart? Do I have to go through the whole litany again?*

"Tar, tar on my skin and then exposure to UVB. Ultraviolet light, is that it? I used to stand in a light box, like a tanning box."

"And did that help?"

"Not really."

"What else did you use?" He lifted up a foot and felt the thick skin between my toes, like clumps of bark on a tree.

"Vitamin A was the most helpful. Except, of course, for the side effects." I wanted to talk about Norway, not tar treatments. I wanted to remember the lovely Scandinavian light in midsummer when I walked around Bergen harbor and my father bought me a brightly painted mug. Mostly, I wanted to be taken for the charming, intelligent young woman I was. Especially by this good-looking Swede. But I was gold for these doctors. Lamellar ichthyosis is so rare, they had probably never seen a case and probably never would again. This was their chance. *Well*, I thought, *I may as well get something out of this audience.*

"So what do you think, gentlemen? Will methotrexate do me any good?" One of the British interns patted the side of my bed.

"I read about a child who had your complaint. She was treated with this drug and after eight months—I think it was eight months—she cleared up. So we'll have to wait and see, right?"

Eight months! I thought I had signed on for two weeks in Newcastle to see if large doses of the drug would help soften my skin. I didn't want to wait eight months to see if it was going to have any effect. The young man must have seen my face fall. "Well, maybe the dose given to a child was smaller than what you're getting." The Swede smiled and began to turn toward the door.

"Dr. Shuster will be back soon." The others crowded out, and he closed the door firmly behind him.

I straightened my bed clothes and clipped my legs closed like a pair of scissors. After years of seeing eminent dermatologists, I was used to being examined. But like many patients, I hated it—although I had a hard time admitting that to myself. In my mind, I began to retool the story of the Swede, reworking it into something to amuse my mother the next time I wrote to her.

NEWCASTLE, APRIL 5, 1968

I had convinced the doctors and the matron to let me out for the day. The sooty streets of Newcastle seemed alive with sunshine, and I rejoiced in the smells of petrol and coffee. I found a tea shop and feasted on a rum tart. Then I went to the movies. In the art deco cinema, I settled into *Half a Sixpence*, a big musical filmed in garish Technicolor.

Made in the wake of *The Sound of Music*, *Half a Sixpence* stars song-and-dance man Tommy Steele in the improbable story of a sales assistant who inherits a fortune, forgets his chambermaid girlfriend for a rich woman, loses his fortune, and marries his girlfriend after all. The movie is mostly forgotten, and even in 1968 the big show tunes seemed hardly credible to a young woman who listened to Bob Dylan day and night. But I was on leave from hospital life and hungry for sensation. A contemporary review by Renata Aldler in the *New York Times* sums up the film's visual effects: "It should be visually fascinating to anyone in a state that I think is best described as stoned." After the grim, green walls of the Royal Vic, the swimming, filtered psychedelic colors were a feast for my eyes.

What did I think of the beauty of the young actresses—both forgotten now? At a level deeper than where I consciously lived, it can only have hurt. These, after all, were not only movie stars, but peaches-and-cream British movie stars. No one can match the manufactured beauty of screen actresses, especially filtered by caressing lights, but skin-deep beauty is still prized, still a ticket to success and, in the opinion of some dermatologists, a sine qua non of self-esteem, particularly for women. Ours is a culture in which blemishes of the face can unfairly signal blemishes of the soul, and in which a skin disease can produce fear, even, perhaps, instinctive shunning. At about the same time that I sat in that theater in Newcastle, doctors used methotrexate to treat a child with ichthyosis in Illinois because, according to her dermatologist, "the little girl in question was a complete social outcast due to the severity of her disease. Despite higher than average intelligence, the local public school refused to accept her." Thank God I never had such an extreme experience. Such a child would have legal protection now. However, everyone with a disease of the skin has to tangle with the deep fears that often glare behind stares in the street. Leaving the cinema that night, I danced with denial—as always. Denial of the flaking skin there before my eyes. But surely I also wanted to be as beautiful as those young British actresses—or at least as ordinary as the young women in their beehive hairdos who rustled down the smoky streets.

NEWCASTLE, APRIL 8, 1968

In the morning, Dr. Shuster came to my room to evaluate the progress of the drug. Although there didn't seem to be any dramatic change in the appearance of my skin, my face did look somewhat better, and Shuster didn't give up easily. "This drug works slowly and cumulatively," he told me as I steeled my shoulders against the back of the bed. "I want you to continue on a lower dose. Dr. Vickers can follow you down in Oxford. I'll get him to set up a program of weekly shots. Then we'll see."

"So what do you think is happening?"

"I don't know exactly. We have to give it time." Looking into my body was like looking down a headland on a misty day. Something was happening there, some dance of drug and cell, but neither he nor I, certainly, had any clear idea what it was. So I could only wait. If I was nervous about what Dr. Vickers might say, I didn't mention it.

That night the lads and Peggy gave me a farewell party in the TV room. We snuck sips of Newcastle Brown Ale and watched a flick starring Frank Sinatra. I guess the guys' families had brought them more ale when they visited on Sunday afternoon, but not one man hoarded his precious brew.

OXFORD, APRIL 9—JUNE 19, 1968

Back in Oxford, I drank cheap South African sherry in the dark pubs with Anne and Rob, followed the American elections in the *Times*, wept at Bobby Kennedy's assassination, heard that my brother had providentially failed his Army physical, and wore my Irish fisherman's sweater to keep myself from checking my skin. One afternoon, I followed my usual route past the yellow walls of the great university library and down narrow Magpie Lane that took me to my lesson with Professor Jones in Merton College, one of the oldest Oxford colleges. Just at 3:00 PM, I ran up the stone steps of his entryway in the inner quadrangle, knocked on the door, and found him looking out at a row of lime trees in the garden. Without turning toward me, he remarked in a rather whispery voice, "The lime trees were here before we were born and they'll be here after we die." Then he flung himself into his chair, swung his legs over the side, and turned cheerfully to hear my lesson. I didn't quite know how to answer. I certainly couldn't dispute him. Level with my gaze hung a severe portrait of novelist Iris Murdoch, painted by Jones's wife. Iris made me squirm in my seat, but I read out my paper on Keats, which intrigued and pleased him. I walked home quickly, now and then trailing my hand against the sandy stones of old college walls.

Throughout April and into early June, Dr. Vickers's nurse dutifully gave me the shots of methotrexate. For a while, I thought we would just continue, hoping that the drug would have a good effect on me. I showed up at the Radcliffe Infirmary, got my shot, and went about my business as the summer gradually spread over Oxford.

I even began to feel more at ease with the young men in my classes. We battled wits, joked around, and studied together. In a seminar held in one teacher's study, I made friends with a slender guy from Canada when we both felt the butt of the instructor's anger purely because we were North Americans. A renowned professor at St. Anne's, her wit sharpened when her servant brought her a glass of gin promptly at five. One day, she stood in front of her mantel, clutched the cut glass tumbler, and looked down at the students who sat at her feet. Her memories of the Second World War quickly crystallized. "We British stood alone against the Germans and yet the bloody North Americans think they won the war for us," she ranted. My Canadian friend and I sank deeper in our chairs. I dared not look at him for fear a glance would betray some secret complicity in this heinous behavior in which our compatriots had allegedly engaged. Out in the parking lot, he swung a long leg over his bicycle and then leaned back on the seat. "Well, Anne, looks like we're set to ace *this* class."

"Yeh, right." I fiddled with his bike bell and then grinned at him. "Maybe we better practice our posh Brit accents."

"Nah, she'll be too addled to notice." He shrugged his shoulders. "See you next week, doll."

It wasn't the only time my American background caused me trouble. Things I had taken for granted—such as a plentiful supply of Cokes and lots of hot water—ran up against English realities. I could buy Cokes, fearfully expensive, in the variety shop across the road from St. Anne's. But a plentiful supply of hot water was another matter. Perhaps the British still remembered the wartime limits of three inches in the bathtub. The thought of luxuriating in a full bath of hot water may have been simply too much.

One June evening, I lay in just such a bath, gazing out at the flowering trees, feeling the warmth of the water sink into my skin and soothe it. Of course, I was thoughtlessly using up everyone else's hot water. I was vaguely aware that the door tapped loose against its jam. We never locked it. Anyone who wanted to use the bathroom simply knocked first. I lay idly, enjoying the heat and letting my hand stray to pucker a nipple. I compounded my concupiscence by turning up the tap with my foot. As the water sang out, an assistant dean, who must have been

working late, walked right in through the unlatched door, strode across the cold tiles of our bathroom, and shut off the tap. "That's enough!" she said. I guess her mind was on the next water bill, but as she turned and left, my eyes suddenly awoke to my poor naked body. There I lay, flushed from the heat, but still covered with thick scales that looked rather like a tortoise shell. There was no getting around it. The drug wasn't working. I stepped out of the tub, wrapped my terry robe around me, and trod heavily downstairs to my room.

A few days later, Dr. Vickers read me the riot act. Leaning forward at his desk, he ticked off the potential side effects: "This drug could upset your production of cells, not only skin cells, but also blood cells. There's a risk of leukemia. Also, it could affect your ovaries."

I sat silent, trying to memorize this list as if it were a summary of publication dates for the great English poems. But I knew the jig was up. I couldn't hold out against this. Perhaps I didn't want to any longer. Vickers smiled a little. "I think you should consult with your doctors at home, back at the University of Pennsylvania." My American dermatologist, Dr. Shelley, had met Vickers at international conferences. "Dr. Shelley is aware of the dangers of this drug."

Outside, I headed toward the center of town, kicking the pavement. I passed the Martyrs' Memorial whose lacy Gothic tracery belied the burnt flesh of the men who died at the stake there, and pounded around the corner where the Victorian facade of Balliol College stood in the sunshine. Here my fears, deeply buried, caught up with me. What was I doing? What if this drug did ruin my body? What if it caused leukemia or destroyed any chance of having kids? I never expected to have children. It wasn't in the game plan, at least not until I got cured and could attract the right man, but Dr. Vickers's candor had forced me to confront fears so instinctive that I could no longer shake them off.

By the time I clicked open the door to Blackwell's Bookshop, I had a plan. Dr. Vickers wanted me to consult Dr. Shelley, the very dear, very conservative dermatologist who had treated me for years back in Philadelphia. My parents trusted Shelley implicitly. If I got my mother to call him, Shelley would be likely to confirm the dangers of the drug. I would have an ally.

When I got back to my room in St. Anne's, I wrote to my parents on the familiar blue air-mail paper. After repeating the list of dire side effects, I summed it up:

Dr. Vickers is really very loath to give me this methotrexate. It does worry me somewhat, and I wish you'd talk to Shelley about it again. I certainly don't want

to overestimate the dangers, and yet I don't want to do anything too risky either. I know how circumspect Shelley is, and that's reassuring, but try to get him to be blunt and tell you the whole story about these toxic effects. I myself still feel fine and Vickers is doing frequent blood counts to watch out for anything.

Mom, thanks for the check. I took it right to the Midland Bank. I'll probably go out and get myself a pretty, frilly summer frock with the money. I kind of fancy something all sweet and feminine with ribbons and bows!

My mother always wanted me to be dressed well, to be fashionable. I don't recall what I did with the money—maybe I found a summer outfit; maybe I bought a book—but I didn't wait long to call home. On Sunday afternoon, I dialed collect from the public phone outside my room. After some chat about Mom's recent fifty-fifth birthday, I got to the point.

"Did you talk to Shelley at all?"

"Your mother did," said Dad from the phone in our hallway at home. Talking on the extension in her blue chintz bedroom, Mom reported, "I called him on Friday."

"What did he say?"

"He's very cautious about the drug," she admitted. "But I hate to see you give it up too soon."

"I know. But look, what did he tell you about the side effects?"

"Pretty much the same as Dr. Vickers told you over there."

"Well, I'll have to think about what to do. Whether to keep on taking it or not."

Dad cleared his throat. "You have to determine what you think is right, honey." Mom didn't give up that easily. "Call up to Newcastle. Talk with Dr. Shuster first. See what he thinks."

I hung up knowing that this was the end. I would speak with Shuster all right. But I wasn't going to let myself be persuaded into anything more. I had done what was expected of me. I had tried the methotrexate. It hadn't done any appreciable good. I had had enough.

On June 19, I wrote to my parents:

This will have to be quick 'cause I have to get back to my books, but I want to put a few things down while I remember.

1. I called Sam Shuster and he agreed that if the methotrexate hadn't done any good so far, it most probably wouldn't and that there was no benefit to be had from continuing with it so I stopped it.

2. No, I didn't even think of sending wedding presents to my friends in the States who are getting married this summer. Mom, please do. I trust your ingenuity completely—maybe a flower pot would do for Sarah. Karen's address is 125 East 84th Street and her last name is spelled Orth-Pallavini. Thanks.

So this latest in a long line of treatments came to an end. Of course I was dissuaded by the threat of side effects, and the word *leukemia* surely scared my parents, but I also think I wanted to shake off this most recent experiment with my body, to be free in Oxford and enjoy it, to learn and hang out with my friends. The beauty of the city absorbed me and distracted me from my itchy, scratchy skin, and I began to push my sleeves up to the elbow.

FALL/WINTER, 1968

I lost touch with the Canadian guy after the seminar ended, but in the fall, I met a quirky, red-haired Brit whose fair skin stretched translucent and freckled over the thin temples of his face.

David had been on a bus tour with Anne Mason's mother, so when he came to Oxford to work as a fact-checker for the Oxford University Press, he called Anne. She thought David horribly ungainly and wanted nothing more to do with him after the obligatory lunch the three of us ate together. But I looked kindly on the way he trailed after us as we tried to say good-bye in the street. Perhaps I sensed his essential loneliness.

That winter, he took me to classical music concerts and talked for hours afterward about composers and musicians. One evening we listened to the great violinist Yehudi Menuhin play in a small concert hall. Afterward, we walked to the pub for a pint. "Ohhh," said David, flapping his arms strangely close to his chest, "he played the Beethoven divinely, don't you agree, darling? But did you ever hear him play the Brahms?" I hadn't, but I hadn't been called *darling* before either, so I let him meander on until we reached the Bird and Baby, and he stopped talking long enough to order us drinks at the bar. While he waited, I slipped into the ladies' room and soaked my hands in hot water until I could stretch them and feel the soap through the softened skin. Then I worked a smear of moisturizer into them. Back in the front room, David had wedged his skinny legs underneath a table. "Over here, over here," he called. He handed me a glass of sherry. "Do you know C. S. Lewis used to come to this place? Oh yes, and Tolkien and all the rest of them. Sat over there and talked about religion and *Narnia* and

.....

The Lord of the Rings. They came every week. Ohhh, they had *enormous* discussions. Well, Oxford pubs are loaded with history, obviously. Do you know the story about the Trout out on the river? No? Well!”

Unused to listening to lonely men chatter, yet sensing I had to hear him out, I squirmed in my miniskirt while my eyes swept the polished wood of ancient booths clustered near the tiny bar. When he finished his oration, David leaned toward me. “How’s my sweet girl?”

“Fine. Oh, fine.” I caressed the dents in our table and then very slowly slid my fingers forward to touch the fair hair on his hand. I could feel it quiver in my palm, could sense the warmth beneath.

“Oh, *that’s* rather nice,” he said. “Do I get a kiss?” I licked my lips to soften them, and we kissed across the table. His mouth felt wet and rather cool on mine.

After another drink and some gossip about his job at the university press, he walked me home. On our way back to St. Anne’s, he put his thin arm around my shoulder, and I rubbed my head against the shine of his suit.

Finally, I had someone to take to college parties; once, a girl having a twenty-first birthday bash actually invited us as a couple. Occasionally, David took me to see his other friend in Oxford, a guy he knew from his college days in Wales. When we were leaving after dinner in this man’s comfortable flat, David talked for at least twenty minutes with his hand on the doorknob of what he took to be the front door but really opened a closet. Our host and I exchanged amused glances while I tried to nudge David toward the street.

Mostly we wandered around Oxford—its squares, lanes, cobbles. One night, he persuaded me to sing “Swing Low, Sweet Chariot” to him while walking over moonlit Magdalen Bridge; I could feel his warm hand move around my waist as I sang, and I gently put my arm on his. After a few moments, his body heat penetrated through the thick outer layer of my skin into the nerves of my hand.

A few nights later, I packed some frilly pink lingerie my mother had given me and walked with him down the length of his quiet street. His flat overlooked the back garden. When we finally managed to get into bed together, he took off his glasses and kissed me, our tongues touching quickly. The lingerie that pooled by the side of the bed shone satiny, but my belly and arms and breasts lay peaked with little clumps of thickened skin. As I watched, David carefully patted my thighs. *He has to pat me*, I thought. *He’s patting me*. I knew I should be feeling strokes, long and lingering, but nevertheless there I was, in bed with a man. I smiled and moved my thighs gently. His penis hovered over me like an ivory wand. I looked away and rested my hands on his thin back. Gradually, my hands

softened in his light sweat, and I felt the muscles of his shoulders move. When he finished, I slipped on my nightgown and lay next to him while the heat of his body sank through my skin to spread its peace across my waiting flesh.

The next morning, I walked back down his street alone, clicking my heels against the pavement while the early light seemed to flow up at me between the low stone houses.

In June 1969, I went home to do a PhD in the U.S., having decided that David was too quirky a man to keep me in England. Although he had proposed marriage—"I *would* marry you, you know," he told me—I couldn't imagine spending more than the occasional day or two in his company. But through our awkward lovemaking, a new image of my body slowly began to uncoil in my mind. I began to see that I too could be desired—and I learned that beneath the rough surface of my skin lay blood and flesh, which warmed to my lover's flank.

EPILOGUE

In the eighties, I finally found a less toxic drug—a synthetic vitamin A—which calmed and softened my skin. I also found a good therapist and began to break through the shibboleths of denial to acknowledge my condition. Although I never married, as I came to enjoy my relieved body, I had other, more passionate, love affairs.

David still calls me on my birthday. He talks on and on as he did in the late sixties, and I listen to his chatter. Beneath his feathery voice, I hear Rob and Anne laughing in the café, I hear my heels clipping on Professor Jones's stone staircase. Although I have returned to England many times since 1969, I have only been a visitor. For those two years, I lived there not as a native but as part of something larger than the closed worlds I had known at home. It is easy to remember Oxford with joy. Perhaps because I lived there when I was young, when every stone wall and college garden shimmered on the nerves of my eyes, I see it still. But forty years later, I am also delighted when snatches of north-country dialect come into my head, when once again I smell the mixture of coffee and petrol in the street, when in my mind's eye, I see Peggy and the lads with their Newcastle Brown, and I remember the lady at the windy bus stop who straightened her bandana and came over to help a lost Yank find her way.