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I N T R O D U C T I O N

THE BASICS

If the demonstrated potential of UVA1 light to improve the lives of lupus sufferers were more publicly known, if research concerning both benefits and risks were accurately presented, if critics were fair, if our pharmaceutical industry didn't hold excessive power over medical research and practice, if patients were motivated to take more responsibility for their own well-being, Lupus Underground would not have needed to be written — if UVA1 light didn't alleviate fatigue, it wouldn't have been.

A few weeks after the 9/11 terrorist attacks my body underwent an internal siege of its own. Lupus hit hard. My immune system went berserk. I became, in effect, allergic to myself.

After surviving the initial flare, much of the next two and a half years was spent researching a constant series of vexing new symptoms, ever on the lookout for safe and effective treatments.

In December of 2003, I boarded a New Orleans-bound sleeping car to check one out: The U.S. Food and Drug Administration (FDA)-approved clinical trial of Dr. Hugh McGrath Jr., a Professor of Rheumatology in the Department of Medicine at Louisiana State University. His treatment method, unlike all others, did not involve highly toxic drugs. McGrath used light — ultraviolet light.

McGrath, 68, began experimenting with ultraviolet (UV) wavelengths and lupus cells in the late 1970s, moved on to mice in the 1980s, then humans in the 1990s. While shorter UV wavelengths activated the disease, he observed that the longest band of UV wavelengths, called UVA1, mitigated the disease. The majority of lupus patients he eventually treated showed remarkable improvement. In 2001 a research team in The Netherlands published a study which claimed even better results using UVA1 than McGrath in lowering disease activity. [See Appendix B for key lupus/UVA1 research studies.]

During a quick tour of his New Orleans lab, McGrath demonstrated his UVA1 light appliance — basically, a specially outfitted commercial sun

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tanning bed. He turned it on and I cast my swollen, achy hands under its soft light for no more than 20 seconds. Surprisingly, it felt soothing. Not a lot. But enough to notice and convince me I needed to try it.

McGrath, however, refused my entry into his tightly controlled clinical trial. It was limited to local patients, he said. Once back home, with the encouragement of my own physician, and after spending nearly six more weeks researching and exactly \$4,920.48, I built my own UVA1 light appliance.

Although not pretty, given all the heat-resistant duct tape used to attach the acrylic filter, it works. And works well. My 8-bulb, 120-volt residential sun canopy matches the therapeutically effective radiation levels of the 24-lamp, 220-volt commercial sun bed in McGrath's lab.

The primary components of both devices — the lamps and filter — are the same. More than 20 years ago, they were originally developed for the sun tanning industry in Europe. So in February of 2004, I began work on my own tan.

McGrath's New Orleans patients typically received 20 minute exposures per side, two or three days per week. My own doctor suggested cutting that down to 10. I cut it to five. Despite the fact UVA1 radiation is as close to visual light, wavelength-wise, as you can get and still be called ultraviolet, it's still radiation.

The caution was rewarded. After a total of only 10 minutes I ended up slightly sunburned. McGrath's research standard of 40 minutes total would have fried me. However, five minutes per side was also all it took to provide near immediate relief of my fatigue. The energy lupus hijacked more than two years ago was back. Forget the sunburn.

Overall, McGrath's patients (about 54 total, he said, as of the Summer of 2004) also often reported fatigue as the first symptom to go, but never immediately, usually after a week or two of treatments. Reduced joint pain, inflammation, fever, morning stiffness, improved cognitive function, and decreased photosensitivity are also commonly cited.

In addition to fatigue relief, I've found UVA1 effective in reducing joint pain, inflammation and morning stiffness. After the initial flare fevers weren't an ongoing problem, so I can't attest to its effectiveness in that regard. But as for cognitive function, when I sat up after the first exposure and looked about the room, I experienced a new found sense of

clarity. Not visual, but mental. And again, not a dramatic change, but enough to notice. It was as if a slight breeze had come along and swept away a cobweb from my brain that I didn't even know was there. This past summer, I've also noticed a reduction in my photosensitivity, enough to relax my dress code a bit.

At the start of my first summer trying to live with lupus, while I knew I had a need to cover up, my body didn't quite understand exactly how much. Thinking long pants and a long-sleeved shirt would suffice, I went for a short walk along Evanston's glimmering lakefront one bright June day and ended up hobbling back home after my very own personal solar flare. In 15 minutes both knees gave out and I was crippled with pain.

The rest of my summer days were spent close to home. When I did venture out I donned a broad brimmed white hat, large sunglasses, and chemically treated cotton or tightly woven polyester clothing from New Zealand designed to block UV. For complete protection, a liberal amount of sun block was applied to what was left exposed. I even buttoned the shirt's collar. On 95 degree days, I looked like a homeless pimp.

Being a research scientist and not an entrepreneur, McGrath finally got around to applying for a patent on his innovation after it was too late. Patentability is lost if more than one year before the patent application filing date, the invention was described in a printed publication. It was a few years after McGrath first published his findings in a scientific journal that he decided to apply. Consequently, the use of UVA1 light as a therapy for lupus is now in the public domain.

That, plus the fact the UVA1 light equipment employed uses off-the-shelf technology, has kept the medical device industry from beating a path to McGrath's laboratory door. If he had their support, McGrath would not now be bogged down on the road to FDA approval — stuck in Phase II multicenter clinical trials with only one research center, his own. Unless more open, this proven effective treatment with no known toxic effects, stays there.

Historically this is not a radical treatment. It should not be approached with undue caution. Hippocrates, the "Father of Medicine," used the sun as a curative agent in ancient Greece. And even he likely wasn't the first.

More recently, in 1903 Dr. Niels Ryberg Finsen received one of the first Nobel Prizes in medicine for his use of UV light in the treatment of a disease called lupus vulgaris, or tuberculosis of the skin. His work gave birth to the medical specialty of phototherapy. [See Appendix A.]

Researchers like McGrath then are not so much blazing new trails as rediscovering fertile ground overgrown with weeds. Fertilized, intentionally or not, by the pharmaceutical industry. That is not to say I am unaware of the significant lifesaving contributions to our collective health this industry has made during the past 100 years. But it is to say the industry's financial and political clout so permeates our western culture, any treatment not shaped like a pill is, well, hard to swallow.

While I am not a patient of McGrath's, he has given generously of his time to help me understand his work. My sincere thanks for the patience he has shown by never tiring of my persistent questions, or being put off by my more challenging ones. He's a Georgetown University-trained M.D., an extremely gifted and dedicated researcher, and knows as much about lupus, if not more, than any other specialist out there.

I am, however, a reporter. Not a partisan zealot. I've never taken McGrath's word as final.

There's an old motto of the famed, but now defunct Chicago News Bureau that nicely conveys my research approach — "If your mother says she loves you, check it out."

To that end I turned to Frederick Urbach, M.D., Emeritus Professor of Dermatology at Temple University, a pioneer and renowned expert in the photobiological effects of UV. He happily agreed to answer a long series of questions via e-mail. Our Q&A exchange was going to be the basis of a complete chapter for this book. "It'll give me something to do," he said. "I'm retired and don't like it very much."

My very first question was "What am I doing to my body? Am I giving myself skin cancer or what?" Urbach, who knew both McGrath and the UVA1 lupus research, said in sum, "No." Based upon the known photobiological effects of UVA1 light, and the relatively low dose of radiation employed, "there is no real risk to humans from (UVA1) therapy" for lupus, he said.

As for the treatment itself, "I have no question that it works," said Urbach. Yet the notion of clinical improvement after UVA1 is both

provocative and contradictory to the maxim that UV harms lupus patients, so “When (McGrath) first started treating patients, I almost fell off my chair,” he declared.

“Any idea how or why it works?” I asked. “It alters the immune status. Has an effect on antibody cells. That’s as close as I can come to explaining its effectiveness,” he said. “The mechanism of the effect no one has investigated ‘cause it’s very expensive.”

Given his extensive knowledge I couldn’t believe “has an effect” was all that he could say. I got the impression Urbach was holding something back. So I repeatedly pushed the point, and the obviously frustrated Urbach eventually complied: “IT KILLS IMMUNE CELLS,” he bel-lowed. “And that’s good?” I asked. “For lupus patients,” he said. “But you should talk to McGrath about this.” You’ll find McGrath’s thoughts on how UVA1 might help normalize immune responses in Chapter 4.

Urbach provided other much needed scientific clarity during our several telephone conversations and initial e-mails. But before he could complete the entire Q&A assignment, the good doctor passed away on July 8, 2004. He was 82 years young and couldn’t fail to engage you, even over the phone, with his gregarious personality.

His publications were numerous, as were the awards for his research work, including the prestigious Finsen Medal of the Association Internationale de Photobiologie, and the Lifetime Achievement Award of the American Society for Photobiology.

Born in Vienna, Austria, he sounded like a scientist born in Vienna should — straight from central casting. I like to think of him as the ‘Sigmund Freud of UV light,’ having spent a lifetime teasing out the secrets of our sun’s rays. My lessons were cut woefully short.

I also need to acknowledge and thank Chris O. Costas, M.D., referred to often in this book as “my doctor.” On staff at St. Francis Hospital in Evanston, Illinois, and board certified in pediatrics, internal medicine and infectious diseases, he’s not a lupus expert. But he is among the finest physicians I’ve met in my life, and got into the business, I think, simply to help people. He has taken wonderful care of me for more than 15 years, and was the doctor who initially hit upon the diagnosis of lupus after others were stumped. For his creative thinking, compassionate care and encouragement, I am indeed indebted.

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As important as the gratitude I need to convey is this warning: Regular sun tanning beds, booths and canopies — the ones you’ll find at tanning parlors across the country, or that can be purchased today for residential use — are dangerous for lupus patients. The rays emitted by these devices, even if advertised as “UVA,” can trigger symptoms and make the disease much worse.

Lastly, this is not a book about lupus per se. It’s a book about a long-ignored, drug-free, non-patentable, counter-intuitive therapy that I know works for me, and has reportedly helped others. While some disease basics get covered, my assumption has been that you or someone you know has lupus, and as a self-motivated individual have already done your homework. If you’ve recently been diagnosed, this isn’t the first book you should read. In that regard, the best I’ve come across is *The Lupus Book: A Guide for Patients and Their Families*, by Daniel J. Wallace, Oxford University Press.

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