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Dear Colleague,

My findings after treating so many eczema patients who have become addicted to topical corticosteroids and my inability to effect the necessary protocol changes in the various medical communities that care for them has led me to write the enclosed 8 commentaries as a "White Paper."

I ask your indulgence in reading my interpretation of this continuing problem in hopes of effecting a radical change in the treatment of eczema patients that will eliminate topical corticosteroid addiction.

Sincerely yours,



Marvin Rapaport MD

## Topical Steroid Addiction (TSA) – a White Paper

*Those who do not feel pain seldom think that it is felt.* Dr. Johnson

After 30 years of successfully curing 3200 patients with Red Skin Syndrome (RSS) and after 30 years of unsuccessfully convincing my colleagues that RSS is due to topical steroid addiction (TSA) I have decided to issue a “White Paper.”

A “White Paper” is an authoritative report or guide informing readers in a concise manner about a complex issue. Its purpose is to help readers understand an issue, solve a problem or make a decision. I am presenting the following white paper on topical steroid addiction in hopes of informing the public about its existence and persuading the medical community to take responsibility for its participation in TSA so that Red Skin Syndrome can be eliminated forever.

### Topical Steroid Addiction – a White Paper

The sequence of events that results in the vast majority of patients with Red Skin Syndrome is the misdiagnosis, mistreatment, and mismanagement of atopic dermatitis (eczema). The manifestations of eczema initially seen most commonly in children and rarely initially in adults are invariably mild and only in small areas of the skin. Conventional treatment begins with weak strength topical corticosteroid creams, lotions, and ointments. After a few weeks and the continued presence of the rash, stronger topical steroids are prescribed. The rash now flares up and down and a larger area of skin becomes involved. The beginning of addiction to the steroids is underway. The downward spiral continues and is met with more creams, allergy testing, food avoidance, more physician consults and more patient and parental anxiety.

The rash spreads. The child or adult becomes very itchy and if old enough to verbally express it describes a severe burning sensation to the skin. They continue to exhibit flashes of heightened redness in the skin followed by spontaneous diminution over days and always instantly clear with more steroids – this pattern of flares followed by application of topical steroids facilitates the addiction process. The evolution into addiction occurs within 4-8 weeks. The patients now have topical steroid addiction (TSA).

All of this is avoidable. The natural history of eczema is seen in the front of the elbows, behind the knees, sometimes in small areas of “slobber dermatitis” on the face of the infant, a mild eyelid rash in the adult, or mild hand dermatitis. Only after prolonged treatment with topical steroids does the rash spread.

Red Skin Syndrome was unknown before the introduction of topical steroids. Childhood eczema naturally resolved itself with warm baths, cold compresses, lubrication and sunshine. The children “outgrew” their eczema. The advent of topical steroids has created a devastating cycle of flaring and clearing that inevitably leads to topical steroid addiction and Red Skin Syndrome.

So, why do the treating physicians not recognize the obvious fact that the patients are getting worse despite their recommended conventional treatments? The science of careful observation and medical management has been replaced by “beliefs”, “suppositions,” “search for the hidden allergen,” “patient blame for not following orders,” and the insidious interference of pharmaceutical companies peddling their “newest” and “latest” cure for eczema.

## **Topical Steroid Withdrawal – TSW – The Difficult Process of Recovery**

*The human condition is such that pain and effort are not just symptoms which can be removed without changing life itself. - Hannah Arendt*

My “White Paper” appearing in Blog 28 discussed topical steroid addiction (TSA). What follows is a description of the patient’s process after the diagnosis of topical steroid addiction is made when he/she must totally withdraw from topical steroids to be cured. The patient completely stops using any and all steroids. Usually within days flares of redness and some edema occurs. The beginning of topical steroid withdrawal (TSW) is initiated and ultimately the Red Skin Syndrome (RSS) will be full-blown.

Full-blown Red Skin Syndrome is manifested symptomatically by severe itching, burning, pain, edema, oozing of the skin, anxiety and frequently psychological depression. This can last anywhere from months to years depending upon the length of time steroids were used. The symptoms, the clinical rashes, the skin biopsy, the severe erythema do not correspond with any atopic dermatitis (eczema) findings. It is a different diagnosis entirely. It is not “bad or chronic eczema” it is Red Skin Syndrome and must be treated differently. Total withdrawal from topical steroids is the cure for Red Skin Syndrome and Red Skin Syndrome is the correct name for what has been diagnosed as bad or chronic eczema.

Because of the severity of the problems of Red Skin Syndrome many patients necessitate withdrawing from school or work for up to a year. There is a total inability to function. Others continue to work or go to school but they function at a very low level with severe symptoms 24/7. All necessitate professional medical support. Sadly, they do not obtain this support from our fellow physicians – instead they are met with obstinate arrogance worldwide. These physicians demand that their patients take more and more topical and systemic steroids. The suffering patients have had nowhere to turn for help and have initiated “self-help support groups” for comfort. Since no real medical help can be afforded in these groups the patients languish in a sea of patient suggested foods, bath products, creams, vitamins, Eastern medical procedures and an array of avoidances – all giving false hope because none address the problem. Conventional medicine has turned its backs on these patients who are in their dreadful state because of the arrogance of their doctors’ misguided management.

Despite having evaluated, examined, studied, diagnosed, treated and cured approximately 3200 patients over the last 30 years, despite 7 peer reviewed papers in the finest English speaking journals, despite numerous patient support groups, despite search engines listing TSA, TSW and RSS the number of severely affected patients has increased exponentially. I still treat 5-20 new patients every month who come from all over Southern California, many distant and near states in the USA, and from around the world. Most recently patients have flown in from Korea, Sweden, Singapore, Texas, Pennsylvania, Washington and various Canadian provinces. They come to see me in Los Angeles because their local treating physicians will only treat them with steroids despite overwhelming evidence that these medications severely worsen the problem. It is the ethical and moral responsibility of the medical community to acknowledge that Red Skin Syndrome exists and will cease to exist when topical steroids are withdrawn. Often the easy path is not the right path. Withdrawal is not easy but it is the right and only path to cure for patients already afflicted with RSS. When physicians change their course of treatment and stop prescribing topical steroids for lengthy and for early stage eczema then Red Skin Syndrome will finally be eradicated.

## **Topical Steroid Addiction (TSA) - Psoriasis, Seborrheic Dermatitis, and Atopic Dermatitis**

*Less is more.* Mies van der Rohe

There are three dermatological diseases for which patients are put on protocols of long-term (chronic) corticosteroid use; they are psoriasis, seborrheic dermatitis, and atopic dermatitis. Chronic steroid usage continues daily, weekly and yearly in many of the patients. In my experience all of the chronic users become addicted to the corticosteroids after varying periods of time.

For many decades psoriasis patients developed Red Skin Syndrome (RSS) and exfoliative dermatitis after prolonged topical steroid usage. If systemic steroids either intramuscular or oral were administered the process was hastened. The patients developed “pustular” psoriasis, total body erythema, burning skin, edema, and skin ooze. All were blamed on their “bad” psoriasis. An array of drugs were given to control this severe explosive psoriasis. Anti-mitotic, immunosuppressive, biological and other potentially dangerous medications were now being given for long-term usage. The long-term effects of these drugs is not fully known but lymphoma, cancer and severe infections have already been reported. These treatments were never necessary before the widespread usage of steroids.

Seborrheic dermatitis beginning with only a minor mild para-nasal erythema can eventuate into severe facial erythema, rosacea-like symptoms, severe unrelenting facial burning and at times suicidal ideations with the continual usage of steroids. Addiction again. The cause is unrecognized by physicians and more steroids are prescribed.

Our focus group – atopic dermatitis (eczema) performs exactly the same as psoriasis and seborrheic dermatitis when steroids are continually used. Addiction again. These patients suffer the most, probably because they usually apply the steroids over their entire bodies and for very long periods of time. Also systemic steroids are more widely administered to them.

So, why is this addictive problem not recognized? Addiction is not recognized because doctors would necessarily have to acknowledge their participation in the development of the addiction, patients would necessarily have to undergo the difficult painful process of withdrawal, the pharmaceutical companies would not be able to introduce new drugs to a large group of patients, and in our pharmaceutically driven culture everyone would prefer the easy quick fix. Change is always difficult. The easy path is not always the right path but only the difficult path of complete withdrawal from steroids offers cure.

## **Topical Steroid Addiction and Red Skin Syndrome – The Elephant in the Room**

*The world gets better every day and then worse again in the evening.* Kin Hubbard

“An elephant in the room” is an English metaphorical idiom for an obvious truth that is either being ignored or not being addressed. The idiomatic expression also applies to an obvious problem or risk no one wants to discuss. It is based on the idea that an elephant in the room would be impossible to overlook. In 1814 a poet named Krylov wrote a fable titled “The Inquisitive Man” which tells the story of a man who goes to a museum and notices all sorts of tiny things but fails to notice an elephant in the room.

I strongly suggest that an elephant has been living in dermatology clinics for over 30 years. There is no such entity as “bad” eczema, “bad” psoriasis, or “bad” seborrheic dermatitis, only corticosteroid addiction and the resulting Red Skin Syndrome. The simplicity of this observation has allowed me to cure over 3200 patients.

Physicians are focusing on the little things and do not see the elephant in the room. They focus on disparate symptoms and do not see the elephant that connects them. In each case, whether psoriasis, seborrheic dermatitis or atopic dermatitis, the elephant that connects the seemingly different conditions is the Red Skin Syndrome that inevitably develops after long-term steroid use. The escalation to anti-mitotics and immunosuppressants further compromise the patient, the National Eczema Association NEA disingenuously claims that RSS is a rare condition, the drug companies continue to “study” RSS patients with expensive more powerful and side-effect ridden drugs, and the physicians continue to prescribe the dangerous new drugs while still maintaining the steroid usage. This will never work.

The elephant in dermatology clinics is the Red Skin Syndrome caused by topical steroid addiction and confirmed by the 3200 patients that I have cured, the approximately 10,000 patients cured as reported in support groups (ITSAN and other Facebook Topical Steroid Withdrawal Support Groups), and the massive army of patients who have discontinued steroids on their own accord after searching the Internet for a cure including a mass of patients living in Taiwan and Korea. These staggering numbers should influence even the most doubtful practitioner to reconsider his/her conventional diagnosis and treatment.

## **Red Skin Syndrome (RSS) – Suffering**

*There is somebody wiser than us, and that is everybody.*                      Napoleon

In his 1992 book titled Intoxicated By My Illness Anatole Broyard wrote, “Illness is primarily a drama and it should be possible to enjoy it as well to suffer it. Suffering and joy are often more complimentary than oppositional; each requires the other.”

There is *transformative suffering* and this recognizes that suffering can be the foundation of insight and creativity. The opposite of transformative suffering is *useless suffering*. Useless suffering anticipates no transformation; it only breaks people. RSS patients suffer uselessly 24/7. Their useless suffering is wholly created by the misdiagnosis mismanagement and mistreatment of their skin and the outdated protocols followed by those who treat them.

RSS patients can assuage their suffering by seeking connection with the stories of others who are also suffering with RSS. Their shared experience creates a community that helps them feel less lonely and less crazy. The opposite of this dynamic is found in isolation because suffering intensifies when people feel alone. Support groups like ITSAN, Topical Steroid Withdrawal Group and the NEA have performed well in this area. Indeed, both the reader and the writer in these groups benefit. The reader finds solace in finding others who similarly suffer and the writer finds relief in telling the world what he/she has gone through. Suffering is alleviated somewhat by community but cure is obtained only through appropriate medical intervention that ends the conditions that impose it.

## **Red Skin Syndrome (RSS) – Ongoing Grief**

*Only one who is in pain really senses nothing but himself.* Hannah Arendt

There are many losses to grieve in life including the quality of one's life. In her groundbreaking 1969 book, "On Death and Dying," Dr. Elizabeth Kubler-Ross describes the five stages of grief that patients experience as they approach physical death. The Red Skin Syndrome (RSS) patients experience the same five stages of grief as their condition worsens and their lives become unbearable. RSS patients, despite starting with a benign disorder, eventually develop a severe malady and endure all the inevitable phases that the author describes. Their suffering is completely unnecessary and their grief is totally avoidable.

The five phases are:

### **1. DENIAL**

In the first phase of grief RSS patients try adjusting to the idea of a severely altered lives. Despite being told that the disease is chronic and for life they really don't accept it. They entertain fantasies of things somehow working out. They see hidden glimmers of hope. This is the phase when they are most susceptible to reaching out to any and all who will listen.

### **2. ANGER**

Anger is expressed in many different ways. Anger can be directed at God or the Universe and expressed in comments like, "Why am I cursed?" "Why can't anything ever work out for me?" Anger can be directed toward other people who don't understand or agree with their anger. Anger can be directed at the Internet, health gurus, or the medical profession. Anyone or anything can become victims of their rage because no matter where the patients turn they continue to get worse and their anger mounts.

### **3. BARGAINING**

Bargaining often accompanies denial. RSS patients have the vague hope that through negotiation they can make this awful thing go away. They bargain with The Powers on High promising to be a better person, giving up favorite foods and pleasures and often going the route of the mystic. During this stage they may take up a new interest in astrology, tarot cards or any type of black magic that promises to alleviate their severe discomfort. They search for a wide array of alternative medicines because traditional professional medical care has failed them.

### **4. DEPRESSION**

Depression surfaces in varying forms just like anger. Patients will stay in bed all day, will not go to work, will not socialize and continually exist on the verge of tears if not outright crying. There is an overarching feeling of hopelessness and their sleep is severely impaired.

### **5. ACCEPTANCE**

In this phase RSS patients accept their fate and either continue going from doctor to doctor or they may stop seeking medical care all together. They are making peace with their problem.

The traditional professional medical community has failed RSS patients and facilitated their grief by being unwilling to acknowledge that Red Skin Syndrome is completely curable through withdrawal from steroids. These patients need not grieve.

## Topical Steroid Addiction (TSA) – A Challenge for Change

*Only one who is in pain really senses nothing but himself.* Hannah Arendt

My “White Paper” (Blog 28) issues a challenge to all involved in caring for the community of suffering TSA patients to change their misguided course. All the dermatologists and practicing physicians, all the patient support groups, all the eczema societies, all the editors and peer reviewers of the journals in which my papers were published, and finally the President and Board of Directors of the American Academy of Dermatology are being addressed and challenged to make a seismic shift in their attitudes. Will there be a willingness and open mindedness to change the existing long-term pattern of misunderstanding misdiagnosis and mistreatment? The eczema support organizations particularly the National Eczema Association (NEA) are challenged to change their approach to this problem and stop asking for more donations, funding, trips, or legislations to beg for more unnecessary research. They must be willing to absorb the decrease in funding from pharmaceutical companies and other public and/or private sources. The answer is already here: NO steroids and the patients need to be directed to appropriate and caring physicians to aid them through their withdrawal process to cure. No further data is needed. No more money is required.

3200 cured patients demonstrate that there is no “bad” eczema warranting newer and potentially more dangerous interventions. Instead, the worsening conditions of patients’ eczema are due to the prolonged usage of corticosteroids – the misguided dermatological standard for five decades. All 3200 of my patients were treated with only one changed variable – the cessation of all corticosteroids – and they were all cured.

## Red Skin Syndrome (RSS) – Topical Steroid Addiction – A Conspiracy of Silence

*We hold the power and bear the responsibility.* Abraham Lincoln

It appears that appearances are more compelling than facts in contemporary America. Despite my thirty years of careful observation and investigation, scientific research, and appropriate medical reporting, an alarming increase in corticosteroid addiction in the atopic dermatitis patients persists.

A conspiracy of silence has prevented mainstream America from receiving the cure for topical steroid addiction and the resulting Red Skin Syndrome. Those who care for RSS patients hold the power and bear the responsibility for making the cure for this public health problem known.

- 1. IT APPEARS THE NEA TASK FORCE IS DISINGENUOUS IN THEIR COMMITMENT TO PUBLIC HEALTH:** The National Eczema Association (NEA) created a task force that sponsored and funded a physician review to ascertain if topical steroid addiction actually exists, to define steroid addiction, to explore the clinical findings, and to determine how common addiction is. Their narrow review of the literature examined only 34 articles that they fully admit are limited by low quality evidence, variability in the extent of data, and the lack of studies with rigorous steroid addiction methodology. Their review conspicuously failed to include my own comprehensive paper analyzing 1500 patients. All of the items the task force was charged to find answers for had already been answered and documented in my detailed paper directly contradicting the NEA who refused to identify topical steroid addiction leading to RSS as the dominant problem of all eczema patients. Instead, they concluded that topical steroid withdrawal is “likely” due to

misuse of steroids but is a rare and minor problem only seen on the face and in the groin. Theirs is a grievously wrong conclusion that ignores the 10,000 patients suffering with RSS today. Truthful findings would have eliminated the need for the existence of the NEA. Shame on the NEA and the authors of their disingenuous review.

2. **IT APPEARS THAT ITSAN AND THE TOPICAL STEROID ADDICTION SUPPORT GROUP VALUE MEMBERSHIP AND FUND RAISING ABOVE PUBLIC HEALTH:** International Topical Steroid Awareness Network (ITSAN), The Topical Steroid Addiction Support Group and other smaller private groups are attempting to increase their membership, solicit more contributions, sell more items and acquire more company sponsorship. They have failed to see that their public health mission is to find medical care for their followers to cure their plight not to aggrandize their organization. A recent trip to Washington to plead for legislation to allow RSS to become an “orphan disease” is pure folly. Keeping the organization going appears to be the prime reason for ongoing advertisements. I implore them to return to their original status as a Facebook support group and continue to guide their ailing followers into appropriate medical care hands.
3. **IT APPEARS THE DRUG COMPANIES VALUE PROFIT ABOVE PUBLIC HEALTH:** Instead of finding cures for diseases the drug companies are attempting to find new diseases for their new drugs including biologicals, monoclonal antibodies, and anti-mitotic. Pure science requires the atopic RSS patients cease the use of steroids when they enter into research projects. Pharmaceutical companies have RSS patients continue their use of steroids during the study and that completely skews the results. This poor scientific methodology is a conflict of interest and makes pharmaceutical studies on RSS useless. Further, since they have not looked at the literature about RSS nor recognized its existence they insist that they are studying and treating “bad eczema” patients.
4. **IT APPEARS THE ACADEMY OF DERMATOLOGY SACRIFICES PUBLIC HEALTH BY VALUING DRUG COMPANY RESEARCH ABOVE INDEPENDENT FINDINGS:** The Academy of Dermatology disseminates pharmaceutical company sponsored research, papers and lectures at the meetings of the Academy and in their journals instead of independent research. Why are there no oversight and questioning of methodology or conflicts of interest? If the peer reviewed journals that I am discussing did not find my papers’ findings appropriate and above reproach then let them either retract the results of my work or concur with my findings using the editorial mode and stop this charade.
5. **IT APPEARS THAT DERMATOLOGISTS HAVE GOTTEN LAZY AT THE EXPENSE OF PUBLIC HEALTH:** My fellow dermatologists continue to write prescriptions for the corticosteroids that continue to endanger RSS patients. Why have they also continued to write prescriptions for the “new” side-effect ridden drugs that I mentioned above and needlessly expose the patients? In a recent Academy of Dermatology Journal article looking again at a new drug intervention, the drugs cited as being used previously by these RSS patients included systemic corticosteroids, cyclosporin, mycophenolic acid, azathioprine, phototherapy, methotrexate, interferon gamma, omalizumab, and calcineuin inhibitors and this was only in six patients. My evaluation of the patients’ histories was that they were all steroid addicted.