

**A systematic review of topical steroid withdrawal in children diagnosed with eczema**

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**Conflict of Interest or potential competing interests:** The reviewer has a child recovering from topical steroid withdrawal after cessation of topical steroids used for eczema and has a blog that was eligible for inclusion in this systematic review.

**Review Registry:** PROSPERO International prospective register of systematic reviews CRD42015019001

**Abbreviations:** AAD-American Academy of Dermatology; AD-Atopic Dermatitis; NEA-National Eczema Association; RSS-Red Skin Syndrome; TS-topical steroid(s); TSA-topical steroid addiction; TSW-topical steroid withdrawal

**Key words:** adverse effects, children, eczema, topical steroids, topical steroid addiction, topical steroid withdrawal

**Contributor's Statement:**

Rosemarie Curley, MSPT conceptualized and designed the review, conducted literature searches, collected data, carried out all analyses, created all figures and tables, created data extraction forms and devised an information rating measure for the blogs, drafted the initial, revised, and final manuscripts, and approved the final manuscript as submitted. Others assisting in this process are listed in Acknowledgements. The reviewer agrees to be accountable for all aspects of her work.

**ABSTRACT**

**Background:** A 2015 study by the National Eczema Association Task Force concluded that topical steroid withdrawal (TSW) is an adverse effect that can occur with prolonged frequent use of topical steroids (TS) that occurs mostly in adult females. The authors stated that it is unclear whether children were less likely to develop TSW or that cases of TSW in children are just underreported.

**Objective:** The reviewer sought to assess the current evidence regarding TSW in children.

**Methods:** The reviewer performed a systematic review of literature and social media blogs about children experiencing signs and symptoms of TSW.

**Results:** The literature search yielded no studies meeting criteria. Of 142 blogs on TSW, 26 (18%) were child blogs meeting inclusion criteria. Length of TS use ranged from 2 months to 12 years. Primary reason reported for stopping TS was worsening skin condition despite higher potencies and increased frequency of application (70%). Most common signs and symptoms were increased redness, dryness, flaking, oozing, and pruritus beyond original lesion site (100%); shedding skin (96%); pain (93%); burning/stinging and swelling (85%). Growth delays were reported in 26% of subjects.

**Limitations:** Lack of studies on TSW in children, low quality of evidence, and potential parent and reviewer bias are limitations.

**Conclusions:** Children who stop using TS for eczema can develop signs and symptoms of TSW seen in adults. These signs and symptoms can last >12 months, even for the relatively short duration of use compared to adult usage. Unlike documented adult TSW cases, children in this review manifested full-body symptoms for 8-16+ months during the withdrawal process. The prevalence of this phenomenon is yet unknown, and clinicians and parents should be aware of this potential adverse effect of TS use, choose appropriate interventions, and closely monitor the application and effects of TS if used on infants and children.

**Key words:** adverse effects, atopic dermatitis, children, eczema, Red Skin Syndrome, topical steroid addiction, topical steroid withdrawal

Registered with 2015 PROSPERO CRD42015019001

## Introduction

For more than 60 years, topical steroids (TS) have been the mainstay of treatment for atopic dermatitis (AD) or eczema, and their efficacy has been established in over 100 different random clinical trials.<sup>1</sup> However, the clinical practice of reporting adverse reactions to TS is wanting, despite the importance of timely reporting, and the adverse effects of TS in medical literature have been downplayed or overlooked in practice.<sup>2</sup> One of these adverse effects is Topical Steroid Addiction<sup>2</sup> (TSA) and Topical Steroid Withdrawal (TSW), particularly in children.

In 1979, Kligman noted the increase in number and seriousness of adverse effects of TS with the emergence of more potent preparations, and he described TSA as an “insidious type of side reaction” because it frequently goes unrecognized and “the physician and patient fail to incriminate the steroid.”<sup>3</sup> Characteristics of TSA included continued use of a potent steroid for weeks or months, followed by a pattern of symptoms that occurred after withdrawal or cessation of the TS: erythema, exudation, pruritus, cracking, scaling, xerosis, skin thinning, telangiectasia, pustulation of the face, and intolerable discomfort, all of which took many months to resolve.<sup>3</sup> In 1999, Rapaport and Rapaport reported on TSA development from chronic TS treatment of eyelid dermatitis in 100 cases over an 18-year period.<sup>4</sup> They delineate various patterns of TSA and describe TSW symptoms in additional articles in 2003 and 2006, coining the terms “Red Skin Syndrome” (RSS) and “Red Burning Skin Syndrome.”<sup>5,6</sup> Fukaya’s 35-chapter book *Steroid Addiction 2010* was an appeal to the Japanese Dermatological Association to include information on TSA and rebound in its guidelines so that future cases of TSA/TSW could be prevented.<sup>7</sup> His website *Atopy Steroid Addiction in Japan* is the English translation of the book, which provides articles, references, and supplemental material on TSA and TSW for patients and clinicians.<sup>8</sup> Despite these admonitions, resources, and reported treatment of thousands of affected patients by Rapaport<sup>6</sup> and Fukaya,<sup>9</sup> TSA/TSW remained unacknowledged in the clinical setting and, if a clinician had heard of it, was considered “rare.”

In December 2013, in response to increasing numbers of patient inquiries, dermatologist reports of patient inquiries, and posts on social media sites about TSA and TSW, the National Eczema Association (NEA) formed a Scientific Advisory Committee Task Force to study TSA/TSW.<sup>10</sup> Their systematic review, published in 2015, concluded that TSW is an adverse effect that “generally occurs with the inappropriate prolonged frequent use of high-potency TCS” and reported that the majority of the subjects with TSW were adult females who used TS on their face.<sup>11</sup> Since the study involved primarily adult subjects, the authors stated that it is unclear whether children were less likely to develop TSW or that cases of TSW in children are just underreported.<sup>11</sup> Earlier studies on TSA and TSW by Kligman,<sup>3</sup> Rapaport,<sup>4,6</sup> and Fukaya<sup>12</sup> also involve primarily adult subjects, and the TS was used for other dermatoses in addition to eczema.

Eczema is often diagnosed in infancy or early childhood, and many individuals outgrow it.<sup>13,14</sup> For those who do not, TS use is generally part of the long-term treatment or

maintenance plan.<sup>2</sup> Due to the chronic nature of eczema, resulting in prolonged use of TS during the course of a child's life, and in light of the documented adverse effects of TS<sup>2,3</sup> and TSW research in adults, it is prudent to investigate the possibility of TSW in children and study its sequelae in this most vulnerable population.

The objective of this systematic review was to: determine if TSW manifests in children after cessation of the TS used for their eczema; present caregiver reasons for stopping TS; outline the signs and symptoms of TSW in children; identify duration of TSW and treatments used; identify the type of support provided by health care practitioners; and identify the source of support during TSW and information on TSW management.

Due to the anticipated lack of literature on TSW in children, one source of current evidence available to the reviewer is social media: blogs written by the parents of children undergoing TSW. One may equate the quality and evidence level of these blogs to patient self- or informal case reports, but in absence of solid research on TSW in children and with the recent acknowledgement of TSW by the NEA in a study prompted by social media reports, the blogs can provide valuable information about TS use in children that is not obtainable in the lab or clinical setting.<sup>15</sup> The parent is caring for, treating, and observing the child 24 hours per day, 7 days per week, and 365 days per year, so the documentation and photos on the blogs may provide insight and important details to help create a more definitive picture of TSW in children and stimulate formal research from which evidence-based practice in the management of TSA/TSW can be established.

For the purposes of this paper, the following terms, definitions, and concepts apply:

- 1) Eczema and atopic dermatitis (AD) are used interchangeably.
- 2) Topical steroid(s) (TS) is equivalent to topical corticosteroid(s) (TCS).<sup>13</sup>
- 3) Topical Steroid Addiction (TSA) is defined as “the situation in which the skin develops more severe or diverse skin manifestations after the withdrawal from TCS than at preapplication”.<sup>13</sup>
- 4) Topical steroid withdrawal is the act of stopping or “withdrawing” TS used in treatment. Topical Steroid Withdrawal (TSW) is the group of signs and symptoms that results from cessation of TS, as well as the term for the recovery process after stopping TS.
- 5) “TSA/TSW” is used when appropriate to more accurately reflect the context in which it is used.
- 6) TSA and TSW are also referred to as Red Skin Syndrome.<sup>5,6</sup>
- 7) Recovery from TSA and TSW does not necessarily result in elimination of the underlying eczema or skin condition for which the TS was initially prescribed.<sup>16</sup>
- 8) A “TSW blog” is a website on which an individual or a parent/caregiver documents his or the child's experiences during TSW, often including detailed descriptions and photographic progression of the symptoms.
- 9) “Long-term” is defined as 24 months or longer.

- 10) This review may use layman's terms to preserve the description of signs and symptoms and be consistent with the terminology used in the blogs. The parent-authors are not formally-trained skin specialists, and it is the hope of this reviewer that the professional reader will suspend judgment and allow this relaxing of dermatological terms in the interest of gaining information and insight about TSW in children.

**Methods.** This systematic review was registered with PROSPERO International prospective register of systematic reviews (CRD42015019001). The reviewer searched PubMed, ClinicalTrials.gov, and Cochrane Library for literature from January 1, 1954 to May 21, 2015. Additional searches were conducted using JSTOR, Google Scholar, Science Direct, and OVID. Safari (Apple Inc., Cupertino, CA) and Google Chrome (Google Inc., Mountain View, CA) web browsers and Google (Mountain View, CA) and Yahoo (Sunnyvale, CA) search engines were used to gather any social media blogs from January 1994 to May 2015 about TSW and about children with eczema who have stopped TS use. Search terms used were related to topical steroid withdrawal in children, eczema, red skin syndrome, topical steroid addiction, topical steroids, red sleeves, infants, eczema, effects of long-term TS use in children with eczema, treatment during TSW, and atopic dermatitis in children. Only literature written in English was considered. English was the preferred language for blogs, but non-English blogs with a language translator available on the blog were also considered.

Search strategies are outlined in Table I and II. All captured titles and blogs were to be screened by the reviewer. The same reviewer examined studies from the systematic review on TSW by Hajar, et al<sup>11</sup> and screened the blogs for relevance using inclusion/exclusion criteria.

**Table I.** Search strategy for literature

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1. Searched PubMed, ClinicalTrials.gov, and Cochrane Library between January 1, 1960 and April 2, 2015.
  2. Search terms used were related to topical steroid withdrawal in children, eczema, red skin syndrome, topical steroid addiction, topical steroids, red sleeves, infants, eczema, effects of long-term TS use in children with eczema, treatment during TSW, and atopic dermatitis in children.
  3. No results were found. Search was rerun with dates of January 1, 1954 to May 21, 2015.
  4. No results were found that met the inclusion criteria.<sup>a</sup>
  5. Examined references number 15-48 from NEA task force study on TSW by Hajar et al.<sup>11</sup>
  6. None of these studies met the inclusion criteria.<sup>a</sup>
  7. Searched JSTOR, Google Scholar, Science Direct, and OVID<sup>b</sup>.
  8. No studies from this search met inclusion criteria.
  9. Result: 0 studies for inclusion in the systematic review.

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*TSW, Topical Steroid Withdrawal; NEA, National Eczema Association*

<sup>a</sup> 1) Language: English 2) Relevance: articles must pertain to TSW in children diagnosed with eczema or AD. 3) Studies should involve only children ages birth to 17 years 30 days, inclusive, who were using topical steroids (TS) for the treatment of eczema or AD and then stopped TS use (the age refers to the age of the child at cessation of TS use). 4) Study design: Due anticipated low number of studies on "topical steroid withdrawal in children," all study designs were eligible for inclusion.

<sup>b</sup> Additional search suggested by reviewers of this manuscript 8/2015.

**Table II.** Search strategy for blogs on topical steroid withdrawal

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Used Safari and Google Chrome web browsers and Google and Yahoo search engines

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1. Accessed TSW blog lists from ITSAN.org<sup>a</sup> and 2 other established TSW blogs<sup>b</sup>
2. Searched internet for social media blogs from January 1994 to May 2015 about TSW and about children with TSW and/or eczema who have stopped TS use
3. ITSAN.org forum member blogs: 70
4. After crosscheck with <http://topicalsteroidwithdrawal.blogspot.com/?wref=bif>: 30
5. After crosscheck with <http://byebyesteroids.blogspot.co.nz/p/tsw-warriors.html>: 13
6. After checking the web for more TSW blogs Google: 20
7. Check the web for more TSW blogs: 5 (Safari)
8. Check the web for more TSW blogs 4 (Yahoo)
9. Total blogs: 142 (Sum of lines 3-8) (as of 4/23/15)
10. Screened 142 blogs for inclusion with age criteria: between birth and 17 years 30 days old, inclusive
11. Total child TSW blogs to assess for eligibility for review: 31 (as of 4/23/15)
12. Assessed 31 child blogs for eligibility<sup>c</sup>
13. Searched internet for additional child TSW blogs: 0 (as of 5/2/15)
14. Total child TSW blogs for review: 26<sup>c</sup>

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*TSW, Topical Steroid Withdrawal*

<sup>a</sup> <http://itsan.org/> had a list of TSW blogs which was accessed in March and April 2015. The organization remodeled its website in May 2015. The list can now be found under “ITSAN forum-Member bloglist”.

<sup>b</sup> LJ (<http://topicalsteroidwithdrawal.blogspot.com/?wref=bif>) and A.

(<http://byebyesteroids.blogspot.co.nz/p/tsw-warriors.html>) published a list of TSW blogs which they updated as new blogs were discovered.

<sup>c</sup> Excluded 5 TSW blogs: 3 were parent resources; 1 was no longer accessible; 1 was too difficult to follow and establish a TS-TSW relation.



**Study selection criteria****Inclusion criteria**

1. Language: English
2. Relevance: articles must pertain to TSW in children diagnosed with eczema or AD.
3. Studies should involve only children ages birth to 17 years 30 days, inclusive, who were using topical steroids (TS) for the treatment of eczema or AD and then stopped TS use (the age refers to the age of the child at cessation of TS use).
4. Study design: Due anticipated low number of studies on "topical steroid withdrawal in children," all study designs were eligible for inclusion.

**Exclusion criteria**

1. Subjects over 17 years 30 days of age when stopping TS use
2. Studies involving use of oral immunosuppressants in addition to or in absence of TS
3. Studies that followed patients for less than 24 months

**Blog selection criteria****Inclusion criteria**

1. Subjects between birth and 17 years 30 days old who have used TS for treatment of eczema or AD and have stopped using TS because they were no longer effective in managing the eczema, and their skin condition was worsening
2. English language or translator application available on the blog if not in English
3. Relevance: must pertain to TSW in children diagnosed with eczema or AD.
4. Time frame, objective measures, photos, treatments reported
5. The general setting is the child's home environment where the author of the blog, the parent, is able to observe, treat, and care for the child 24 hours per day, 7 days per week, 365 days per year.

**Exclusion criteria**

1. Lack of written documentation or photos depicting signs and symptoms of TSW
2. Resource or information blogs on children with TSW
3. Subjects older than 17 years 30 days old at cessation of TS use
4. Subjects using oral immunosuppressants in addition to or in absence of TS

**Data extraction**

Data from the included blogs were compiled onto a data extraction form on Google sheets (Google, Mountain View, CA), which includes the fields presented in Tables III-XIX and Figures 1, 3, and 5. The reviewer and assistant corresponded with blog authors, when necessary, for clarification of information reported in the blog, and this is noted.

**Risk of bias assessment**

**Studies:** No studies meeting inclusion criteria were identified.

**Blogs:** Due to the nature of a blog, some bias by the blog author is expected. Therefore, extreme care was taken to extract impartial information and use objective data and evidence from photo documentation from the blogs. In addition, the reviewer created a tool in an effort to rate the quality of information found in the blogs. Quality is defined as the basic information present in the blog that is needed to create a picture of TSW in the

child. This Information Rating (IR) (Figure 1) rates the blogs based on the presence of 6 basic elements, assigned 1 point each. The sum of points from elements 1-6 constitutes the IR, with the maximum rating of 6. An IR of 6 suggests a more definitive picture of TSW in the child. Blog elements include:

- 1) History;
- 2) Description of signs/symptoms;
- 3) Pictures;
- 4) Temporal relationship between stopping TS and TSW/RSS signs and symptoms (ie, TSW followed cessation of TS);
- 5) Treatments/methods used in TSW; and
- 6) Other: objective measures, detailed procedures, helpful tips, or other organized/systematic quality to the information.

Blog elements	Point value	Points scored
1. History <sup>a</sup>		
A. Age began TS	0.1	_____
B. Indication for TS	0.1	_____
C. Age stopped TS	0.1	_____
D. Reason for stopping TS	0.2	_____
E. Location of initial TS application	0.1	_____
F. Location of final TS application <sup>b</sup>	0.1	_____
G. Frequency of TS use <sup>c</sup>	0.1	_____
H. Duration of TS use <sup>d</sup>	0.1	_____
I. TS features: Types/potencies of TS <sup>e</sup>	0.1	_____
2) Description of signs/symptoms	1	_____
3) Pictures <sup>f</sup>	1	_____
4) Temporal relationship between stopping TS and TSW/RSS signs and symptoms	1	_____
5) Treatments/methods used in TSW <sup>g</sup>	1	_____
6) Other <sup>h</sup>	1	_____
<b>Sum of blog elements 1-6 is the information rating.</b>	<b>IR =</b>	_____

*TS, topical steroid(s); TSW, Topical Steroid Withdrawal; RSS, Red Skin Syndrome*

<sup>a</sup> Sum of items A-I, with maximum of 1 point for history

<sup>b</sup> Prior to TS cessation

<sup>c</sup> Initial prescription of TS and just prior to TS cessation

<sup>d</sup> Total length of time TS were used from initial to final application, including calm periods in between

<sup>e</sup> First applied and last applied types of TS before TS cessation; other corticosteroids used prior to TSW, eg, oral, IV, injected

<sup>f</sup> 0.5 points if pictures are present; 0.5 points if pictures show progression or other objective quality

<sup>g</sup> 0.5 points if mentioned; 0.5 points if details are provided

<sup>h</sup> Objective measures, detailed procedures, helpful tips, or other organized/systematic quality to the information

**Figure 1.** Calculating Information Rating (IR). Blog elements are on lines 2-34 of the data extraction sheet

**Data Synthesis**

Data were combined at the aggregate level and evaluated using descriptive methods.

**Primary Outcome**

Clinical features of TSW in children:

1. Subject factors: demographics; age started TS; indication for TS; measures taken before stopping TS; age stopped TS; length of time used TS; length of time off TS or duration of TSW; allergies
2. Topical Steroid (TS) factors: locations of initial and final application; type/potency of TS; instructions for application; reasons given for continuing TS; reason(s) for stopping TS
3. Signs and symptoms after stopping TS
4. Duration of TSW symptoms

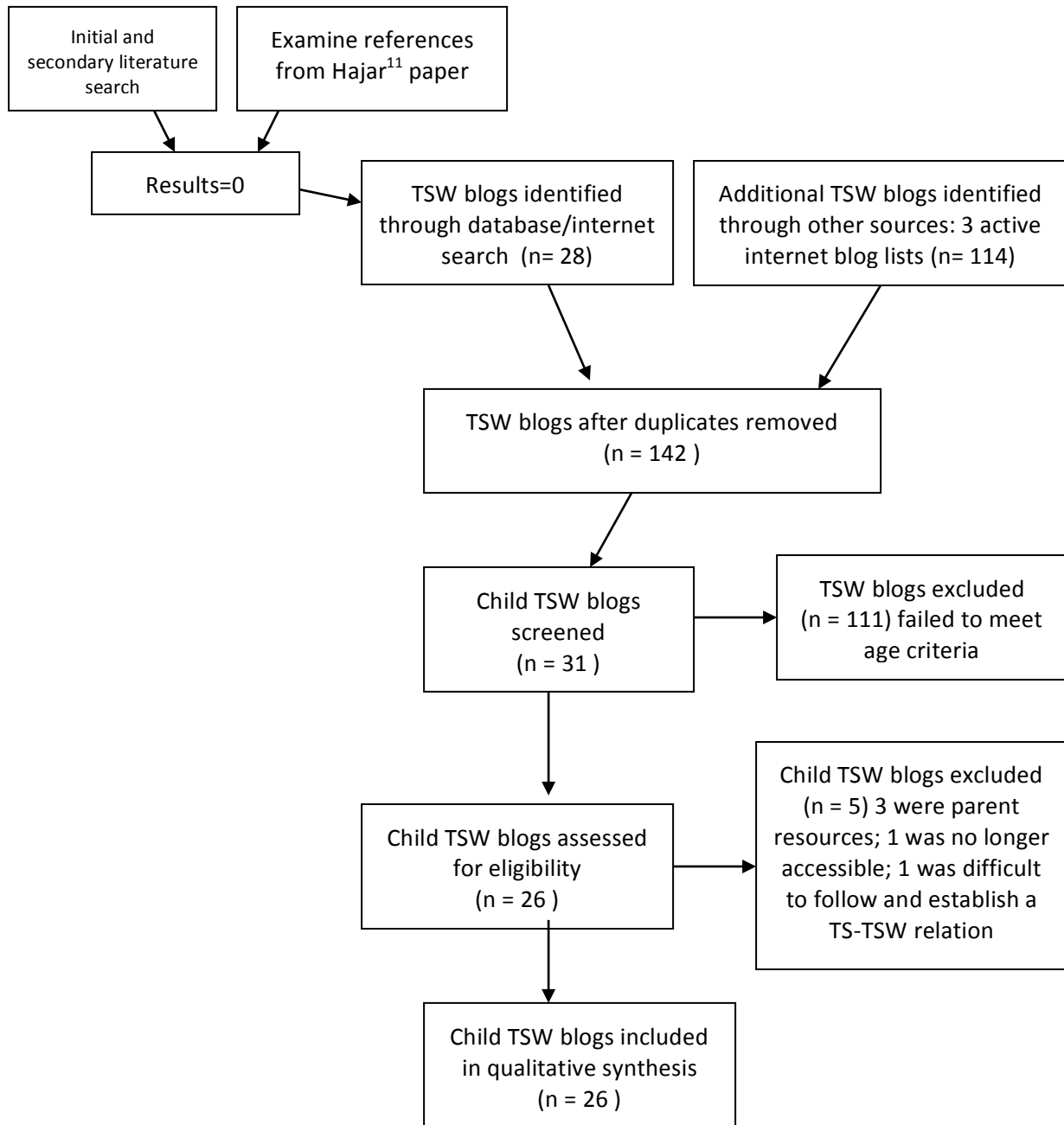
**Secondary Outcome**

1. Treatments employed during TSW/RSS
2. Source of caregiver support and information regarding TSW
3. Interactions with healthcare providers: diagnosis; instruction on appropriate use of TS: dose, frequency, duration
4. Provider factors: TSW diagnosis; treatment prescribed for worsening skin condition; support for TSA/TSW

**Results**

There were no formal research studies that fit the inclusion criteria and none specifically involving TSW in children or TSA/TSW as the effects of long-term topical steroid use in children with eczema. The NEA's systematic review on TSW reported that only 7.1% of their cases were patients 18 years or younger, of which 0.3% were younger than 3 years old.<sup>11</sup> Examination of these 34 studies to see if any child cases would qualify for this review resulted in none meeting the inclusion criteria.

There were 142 TSW blogs found which were screened for children's blogs. Using age criteria (birth to 17 years 30 days) resulted in 31 children's blogs, of which 26 (18%, n=142 blogs) met inclusion criteria (Figure 2). The blogs were listed as they were identified and numbered 1-26. The oldest blog was started in February 2012 and the most recent was March 2015. The IR for the 26 blogs ranged from 2.6 to 6, with the median being 5 (Table III).



**Figure 2.** Flowchart for Topical Steroid Withdrawal (TSW) literature and blog selection. PROSPERO CDR42015019001

**Table III.** Child Topical Steroid Withdrawal blogs included

Blog number <sup>a</sup>	Information Rating <sup>b</sup>	Blog start date <sup>c</sup>	Blog end date <sup>d</sup>
2 <sup>17</sup>	6	2/2014	ongoing
4 <sup>18</sup>	6	8/2013	ongoing
3 <sup>19</sup>	5.9	6/2014	ongoing
15 <sup>20</sup>	5.9	7/2013	3/2014
17 <sup>21</sup>	5.9	10/2013	ongoing
23 <sup>22</sup>	5.8	1/2013	ongoing
13 <sup>23</sup>	5.7	5/2013	ongoing
19 <sup>24</sup>	5.7	10/2013	ongoing
25 <sup>25</sup>	5.7	3/2014	ongoing
24 <sup>26</sup>	5.6	5/2014	ongoing
8 <sup>27</sup>	5.4	2/2012	ongoing
18 <sup>28</sup>	5.3	5/2014	7/2014
5 <sup>29</sup>	5	4/2012	ongoing
10 <sup>30</sup>	5	6/2013	9/2013 <sup>e</sup>
21 <sup>31</sup>	4.8	7/2012	2014
11 <sup>32</sup>	4.6	8/2013	ongoing
14 <sup>33</sup>	4.3	4/2013	ongoing
9 <sup>34</sup>	4.2	5/2013	ongoing
12 <sup>35</sup>	4.1	9/2014	ongoing
1 <sup>36</sup>	4	4/2014	ongoing
16 <sup>37</sup>	4	10/2013	5/2014
6 <sup>38</sup>	3.9	4/2012	10/2013
22 <sup>39</sup>	3.7	5/2014	11/2014
26 <sup>40</sup>	3.4	3/2015	ongoing
7 <sup>41</sup>	2.6	4/2013	4/2013
20 <sup>42</sup>	2.6	12/2013	ongoing

*TSW, Topical Steroid Withdrawal*

<sup>a</sup> There are 26 included blogs but 27 subjects because blog 24 has 2 siblings in TSW. Start date is the date on which reporting on the child's TSW began if the blog was already in existence before TSW.

<sup>b</sup> Calculating Information Rating; Figure 1.

<sup>c</sup> When parent started the blog; does not equal start of TSW.

<sup>d</sup> Date of last entry if >6 months from 5/2015; does not equal end of TSW.

<sup>e</sup> Returned to TS use (correspondence with caregiver) and worsening eczema for 1.5 years; currently trying a different method and reports promising results.

**Primary Outcomes--clinical features**

**Subject factors.** Demographics (Table IV). There are 26 blogs but 27 subjects (14 male, 13 female) because one blog was about TSW in two male siblings. The subjects were from the United States (US), the United Kingdom (UK), South Africa, Canada, and United Arab Emirates (UAE). The 18 US subjects came from at least 11 different states. One blog provided a language translator.<sup>38</sup> Mild or severe allergies were reported in 12 (44%), and asthma was reported in 6 (22%) subjects, 5 of whom also had allergies (Table V).

**Table IV.** Demographics<sup>a</sup>**Location (country) (n=27)**

USA	UK	South Africa	Canada	UAE	Other
18	4	1	1	1	2

**USA child Topical Steroid Withdrawal cases by state (n=19)**

3 (each)	Colorado, North Carolina
2 (each)	California, Georgia
1 (each)	Florida, Illinois, New York, Oregon, South Carolina, Texas, Virginia
2	Unknown

**Gender (n=27)**

14	Male
13	Female

**Ethnicity (n=27)**

17	white/Caucasian <sup>b</sup>
2	Indian
2	Hispanic
1	Filipino/Caucasian
1	Hispanic/Caucasian
1	Jamaican/German
1	black/Japanese
2	Unknown

*TSW, Topical Steroid Withdrawal; USA, United States; UK, United Kingdom; UAE, United Arab Emirates*

<sup>a</sup>n=27 for 26 blogs because 1 blog was about 2 siblings with TSW.

<sup>b</sup>Includes 6 subjects from UK, South Africa, and Canada based on photographs

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**Table V.** Allergies, asthma, or digestive issues prior to Topical Steroid Withdrawal<sup>a</sup>  
no. (%) (n=27)

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9 (33)	No mention of allergies or digestive issues
8 (30)	Mild or questionable allergy or severity not reported
4 (15)	Severe allergies with need for Epi pen
6 (22)	Asthma <sup>b</sup>
2 (7)	Mild food sensitivity or digestive issues
1 (4)	Family History of allergies
1 (4)	No allergies or digestive issues

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<sup>a</sup> Child may have more than one issue; some blogs did not mention these issues

<sup>b</sup> 5 of the 6 children with asthma also had allergies

**TS Factors.** The age at which subjects were prescribed TS ranged from 2 months old or younger to 8 years old, with 15 of 27 (56%) subjects prescribed TS at 12 months or younger (Table VI). TS use ranged from 2 months to 12 years in 21 (78%) subjects. Parents sought physician care for eczema (70%) and other presentations (30%) of skin rashes, bumps, redness, and pruritus (Table VII). All presentations were diagnosed as eczema and prescribed TS. Types of TS initially prescribed and those used just prior to TS cessation are listed in Table VIII. Several subjects were prescribed more than one TS. Those who were prescribed tacrolimus or pimecrolimus used them briefly then discarded them due to the black box warnings. Of the 11 types of TS initially prescribed, 8 (73%) were of mid-strength to high-strength potency.



**Table VI.** Age at initial and final topical steroid application (n=27)

<b>Age</b>	<b>no. (%)</b>
<b>Age started topical steroids</b>	
Birth-2 months	5 (19)
>2-4 months	4 (15)
>4-8 months	3 (11)
>8-12 months	3 (11)
>12-24 months	4 (15)
>24 months-3 years	2 (7)
>3-8 years	3 (11)
Unspecified	3 (11)
<b>Age stopped topical steroids</b>	
5-7 months	2 (7)
13-19 months	3 (11)
23-26 months	6 (22)
>3-4 years	3 (11)
5-7 years	2 (7)
8-10 years	4 (15)
12-13 years	3 (11)
16 years	2 (7)
Unspecified	2 (7)
<b>Total length of time used topical steroids<sup>a</sup></b>	
2 months	1 (4)
11-12 months	2 (7)
17-18 months	2 (7)
2-3 years	5 (19)
5 years	2 (7)
7-8years	4 (15)
>8-9 years	4 (15)
12 years	1 (4)
Unclear	6 (22)

<sup>a</sup>Total time includes breaks due to calm periods

**Table VII.** Indication<sup>a</sup> for topical steroids (n=27)

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no. (%) Signs and symptoms prior to first topical steroid prescription	
19 (70)	Eczema, cradle cap, facial eczema
3 (11)	Fine rash on cheek, heat rash, small red patches on cheeks
2 (7)	Bumps on left leg like mosquito bites; small raised bumps crook of elbow, wrists, behind knees
1 (4)	Contact dermatitis, blister on cheek
1 (4)	Unbearable itchy and rashy patches on upper thighs and lower abdomen
1 (4)	Skin very red but not flaky or dry, always itchy

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<sup>a</sup>All of these presentations were diagnosed as eczema and prescribed topical steroids.

**Table VIII.** Types of corticosteroids and topical immunosuppressants used initially and at topical steroid cessation n=26 blogs

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no. <sup>a</sup> (%)	
<b>Initial topical steroids prescribed<sup>b</sup></b>	
9 (35)	Unspecified
8 (31)	OTC 1% hydrocortisone
5 (19)	Triamcinolone 0.1%
3 (12)	Clobetasol
1 each	Hydrocortisone valerate, desonide, fluocinonide 0.05%, fluocinolone body oil, mometasone, fluticasone propionate, alclometasone dipropionate, betamethasone
<b>Other corticosteroids prescribed<sup>c</sup></b>	
<b>8 (31)</b>	<b>Oral<sup>c,d</sup></b>
<b>6 (23)</b>	<b>Inhaled<sup>c,e</sup></b>
<b>2 (8)</b>	<b>Intravenous or injected<sup>c,f</sup></b>
<b>Topical Immunosuppressants</b>	
5 (19)	Tacrolimus/pimecrolimus <sup>g</sup>

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<b>Topical steroids used at time of topical steroid cessation</b>	
9 (35)	Unspecified
6 (23)	Triamcinolone 0.1% ointment
3 (12)	Fluocinolone scalp/body oil
3 (12)	OTC hydrocortisone
2 (8)	Wet wrap therapy with betamethasone dipropionate; triamcinolone on body; desonide on face
2 (8)	Desonide
1 each	Clobetasol, betamethasone, mometasone, fluticasone propionate, dexamethasone
<b>Other corticosteroids</b>	
1 (4)	Inhaled
<b>Topical Immunosuppressants</b>	
1 (4)	Tacrolimus <sup>g</sup>

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*TS, topical steroids*

<sup>a</sup>Indicates number of blogs reporting the TS.

<sup>b</sup>Several subjects were prescribed more than one TS at initial diagnosis of eczema.

<sup>c</sup>13 blogs reported oral, inhaled, or injected/IV corticosteroids--one of which had all 3, and one had oral and inhaled corticosteroids.

<sup>d</sup>Description of course: 1-"4 tapering courses"; 3-took it "once or twice"; 4-unspecified

<sup>e</sup>5 children used inhaler intermittently for asthma; 1 used for walking pneumonia.

<sup>f</sup>1 injected for dental procedure; 1 received 4 rounds IV in hospital for worsening skin condition.

<sup>g</sup>Some were prescribed both TS and tacrolimus or pimecrolimus prior to or after TSW and used it just briefly due to black box warnings.

**Instructions** for initial TS dosage, frequency, and duration were unspecified in 16 (59%) cases. In 11 (41%) blogs that reported, providers' instructions for TS varied from "a few times per month" to two to multiple times daily for a range of 3 to 30 days, or "until it clears the skin". Frequency of application increased to daily use in at least 11 (41%) subjects prior to TSW. Final TS usage routine was unclear in 16 (59%) cases (Table IX). Locations of application of TS increased from primarily classic eczema targets (41%) to full-body or spread beyond the original site in at least 15 (56%) subjects (Table X). Prior to TS cessation, 13 (48%) subjects had received oral, inhaled, or injected/intravenous (IV) corticosteroids in addition to TS for eczema (Table VIII).

**Table IX.** Dosage, frequency, and duration of topical steroid use (n=27)

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no. (%)	
<b>Initial topical steroid usage (instructions as prescribed by healthcare provider)</b>	
1 (4)	3, 7, or 14 days on with same number days off
1 (4)	Use TS until flare calms down, then switch to pimecrolimus for maintenance
1 (4)	Multiple times per day
1 (4)	3 times/day for 5 days
1 (4)	Daily for 5-7 days
1 (4)	Daily for 1 month
2 (7)	A few days/month
3 (11)	2 times/day until it goes away; daily until it clears skin; as much as needed
16 (59)	Unspecified
<b>Final usage routine before stopping topical steroids</b>	
9 (33)	Increased to 1-3x per day, daily, because eczema did not clear and/or skin worsened; doctors prescribed more potent TS; several types applied to different body parts based on potency and absorption
2 (7)	Daily Wet Wrap Therapy with TS <sup>a</sup>
1 (4)	Used "dime-size amounts" of OTC TS over 2 months
16 (59)	Unspecified

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*OTC, over the counter; TS, topical steroids; WWT, Wet Wrap Therapy*

<sup>a</sup> 1-3x per day for 3 months<sup>36</sup> and 1-2x almost daily for 2 years<sup>40</sup> with fewer than 12-24 days without WWT with TS (clarified via correspondence).

**Table X.** Locations of initial and final topical steroid applications (n=27)**Initial application**

no. (%)

6 (22)	Face, cheek, and/or scalp
5 (19)	Creases of elbows, wrist, knees, ankles, and/or neck
3 (11)	Other: neck; stomach and inner thighs, 1 leg
2 (7)	Face and body
11 (41)	Unspecified

**Final application**

14 (52)	Full body, face, and/or scalp
1 (4)	Spread to areas never affected with eczema before
1 (4)	Behind knees, on elbow creases, top of feet/ankles
11 (41)	Other

In 2 cases reporting wet wrap therapy (WWT) with TS,<sup>36,40</sup> failure of the skin to clear was attributed to the parents “not applying enough TS” and “not doing it right” despite the parents’ compliance to the original prescription of 1-3x daily WWT with TS for 10-11 weeks in one case and almost daily for 2 years in the second case.

While still using TS for treatment, caregivers took numerous varied measures to manage their children’s eczema (Table XI). At least 93 healthcare providers seen by 21 children recommended continuing TS despite no improvement in skin condition or worsening of skin condition and concern voiced by the parent, and no blogs reported providers who recommended TS cessation before they stopped TS (Table XII and Figure 3).

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**Table XI.** Measures taken to address worsening eczema before stopping topical steroids

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Consulted with pediatricians, general practitioners, numerous dermatologists and allergists, alternative medicine practitioners

Cared for by dermatologists, allergists, and other healthcare practitioners in prominent hospitals and institutions in Georgia (high dose IV steroids in hospital) and Colorado (WWT with TS 1-3 times daily for 9-10 weeks and 1-2 times almost daily for 2 years, as prescribed by the specialist)

Some children underwent extensive testing to rule out causes for worsening eczema and/or growth delays, including but not limited to: allergy and food intolerance tests; blood, stool, and urine testing; gastrointestinal workups; genetic testing; tests for adrenal insufficiency and HPA axis suppression

Basic eczema prevention protocol: hydrate skin, moisturize, remove triggers, bleach baths, file fingernails down, cotton gloves at night

OTC and prescribed medication for itching, allergies, skin infection

Environmental changes: ripping up carpet; getting rid of pets; use of dye-free, fragrance-free products; dust mite prevention; installed Microsilk tub, whole-house air purifiers, crawlspace dehumidifiers, in-house humidifiers; sold house; moved to different state

Dietary alterations: GAPS diet, elimination diets, allergy diets, leaky gut diet, autoimmune diet, anti-inflammatory diet, all-organic/non-GMO diets, other

In addition to TS, tried various lotions, creams, oils, ointments-OTC, prescription, homemade balms, silver, essential oils

Internet researching for information and pictures of children/people who resembled their children and their symptom; treatments for itch; searching for help

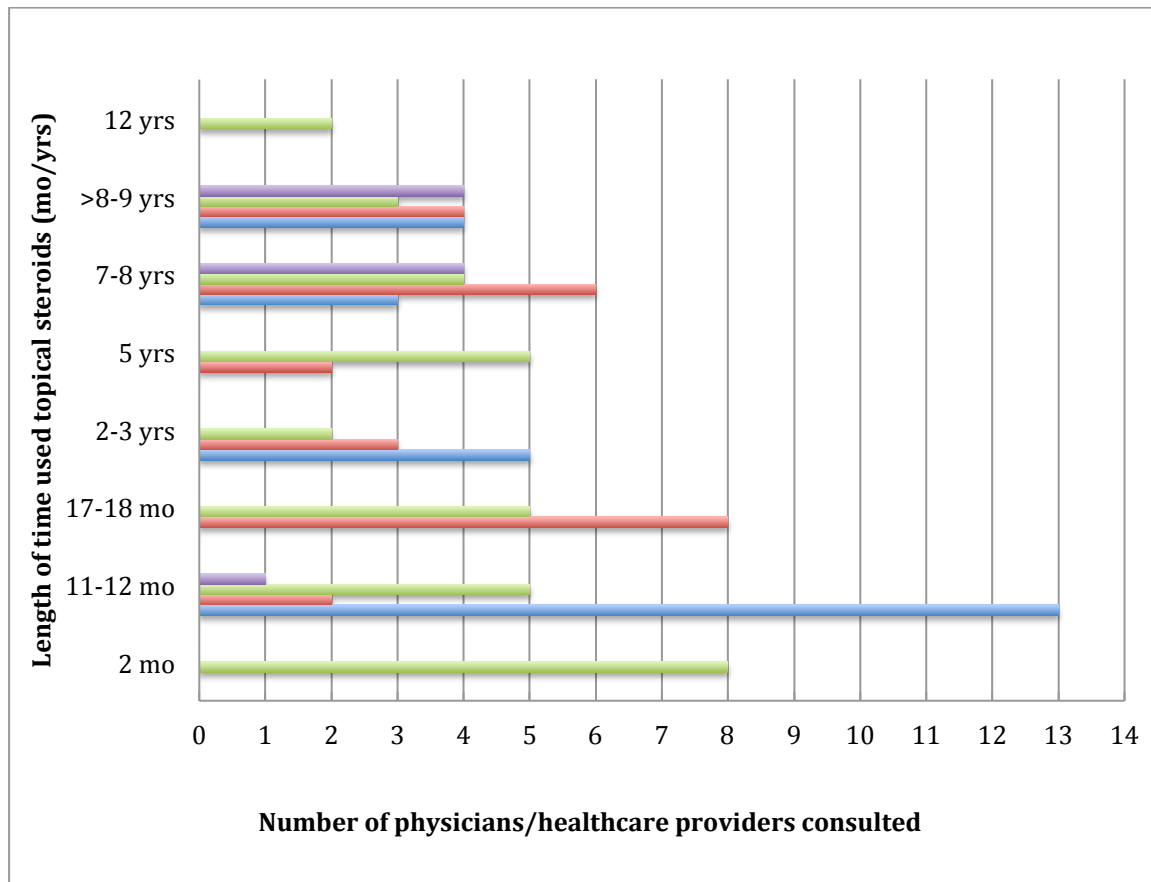
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*WWT, wet wrap therapy*

**Table XII.** Utilization of medical system  
no. (%) (n=26 blogs)

5 (19%)	Unclear how many doctor were consulted
20 <sup>a</sup> (77%)	Consulted with at least 2 providers; 1 consulted at least 13 different providers; 2 reported “many doctors”; median=4 providers consulted
1 (4)	Admitted she did not believe in doctors but saw at least 1
0	Primary pediatrician/GP/dermatologists recommended stopping TS as a treatment for the worsening eczema

<sup>a</sup> Minimum number of doctors consulted in 21 blogs: 1,2,2,2,2,3,3,3,4,4,4,4,4,5,5,5,5,6,8,8,13 median: 4 (at least 93 doctors seen by 21 children recommended continue TS despite no improvement in eczema.) The number of doctors seen was not discernible in the other 5 blogs.



**Figure 3.** Minimum number of physicians/healthcare providers consulted while using topical steroids for eczema. A report of “many doctors” was given the value of 4. If a specific number of doctors were not mentioned, it was given a value of at least 2 (assuming pediatrician and dermatologist). When several different providers were mentioned, the minimum number discernible was recorded on the chart. Reported in 21 blogs; number unclear in 5 blogs.

“Worsening eczema/skin condition” and “TS no longer controlling eczema despite higher potencies and frequency of application” were the reasons for stopping TS in at least 19 (70%) cases (Table XIII). Caregivers in 9 blogs explain “why it’s not just eczema anymore” in Table XIV.

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**Table XIII.** Caregiver reasons for stopping topical steroids (n=27)

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no. (%)

- 19 (70) Worsening eczema/skin condition; eczema spreading to other parts of body; TS no longer controlling eczema despite higher potencies and frequency of application
- 2 (7) Did not feel right continuing TS/started to think child did not have eczema; gut feeling she needed to stop because child could not seem to manage without them
- 1 (4) Subject said her eczema was driving her crazy, doctors just kept prescribing stronger and stronger steroids, and she wanted to try to get off steroids.
- 1 (4) Wanted to use more natural remedies and did not like the side effects associated with TS
- 1 (4) Internet search for "steroid cream side effects"; found <http://redskinsyndrome.squarespace.com/> JB’s blog<sup>a</sup> and ITSAN<sup>b</sup>; search internet for eczema pictures and pictures that looked like the child's symptoms
- 3 (11) Unspecified

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*TS, topical steroids*

<sup>a</sup> J B. Steroid Red Skin Syndrome. Available at: <http://steroidredskinsyndrome.blogspot.com/> Accessed on 5/26/15.

<sup>b</sup> International Topical Steroid Awareness Network. Available at: <http://itsan.org/> Updated 5/24/15. Accessed on 5/26/15.



**Table XIV.** Why it is not just eczema anymore: 9/26 blogs mentioned TSW vs. eczema

5	“Chasing the rash all over his/her body”; spreading rashes
2	“Did not look like the original eczema”; no eczema pictures on the internet looked like the child's eczema
2	Not typical eczema: full-body symptoms, not just skin

*TSW, Topical Steroid Withdrawal*

**TSW signs and symptoms.** Not all 26 blogs reported each of the features (Table XV and Figure 4). 100% had photographs or video documenting at least one or more of the signs and symptoms. The most common signs and symptoms were increased redness, dryness, flaking, oozing, and pruritus beyond original lesion site (100%); shedding skin (96%); pain, “zingers” (93%); burning/stinging and swelling (85%); and “red sleeves” (63%) (Figure 4). Growth delays were reported in 7 (26%) subjects prior to stopping TS. Of the 7 reporting growth delays: 2 had oral; 2 had inhaled; 1 had intravenous (IV); 1 had oral and inhaled; and 1 had oral, inhaled, and injected corticosteroids in addition to TS used for their eczema. All 13 school-aged subjects missed from a few days/weeks to a year of school.

**Length of time off TS and TSW duration.** Length of time off TS = (duration of TSW + transition to just eczema). Length of time off TS is the entire length of time since the subject’s last TS usage. Duration of TSW is the length of time TSW symptoms manifest themselves in the individual after stopping TS. Transition to just eczema is the rest of the time after TSW symptoms stop and either clear skin remains or the underlying eczema returns in original or classic eczema sites.

The first several months of TSW consist of constant manifestations of adverse signs and symptoms (Table XV). In later months of withdrawal, there may be periods of less inflamed skin alternating with episodes of more inflamed skin with a return of signs and symptoms present in early TS. This later phase is a “TSW flare.” A TSW flare differs from an eczema flare in that the symptoms are still full-body manifestations of TSW signs and symptoms: oozing, flaking/shedding, redness, itching, edema or hyperesthesia. Hair may still be thinned and sleep cycle/insomnia still altered.

**Table XV.** Signs and symptoms<sup>a</sup> of topical steroid withdrawal

Feature	no. of subjects	% of subjects	n=27
<b>Signs</b>			
Redness	27	100	
Swelling/edema	23	85	
Dryness, flaking, cracked skin	27	100	
Thin skin	18	67	
Shedding/peeling skin	26	96	
Oozing/crusting	27	100	
Swollen lymph nodes	7	26	
Elephant skin	7	26	
Growth delay <sup>b,c</sup>	7	26	Blogs 1,3,4,6,15,19,26
Hair loss (scalp, eyebrows, body)	7	26	
Red Sleeves (arms and/or legs)	17	63	
<b>Symptoms</b>			
Burning/stinging	23	85	
Increased itching	27	100	
Pain/"zingers"/"stingers"	25	93	
Tightness	13	48	
Hyperesthesia	8	30	
Decreased tolerance to lubrication	9	33	
Decreased tolerance to water	11	41	
Cold or hot all the time	11	41	
Exacerbation with heat/sun	7	26	
Sweat stings	7	26	
Fatigue	11	41	
Insomnia/altered sleep cycle <sup>d</sup>	20	74	
Other <sup>e</sup>			
<b>School-aged children</b>			n=13
Missed school time <sup>f</sup>	13	100	

<sup>a</sup> Reported or observed in photo documentation

<sup>b</sup> Stopped meeting milestones, growth stopped, stopped gaining weight

<sup>c</sup> Prior to topical steroid cessation: 2 had oral; 2 had inhaled; 1 had IV; 1 had oral and inhaled; and 1 had oral, inhaled, and injected corticosteroids in addition to TS used for their eczema

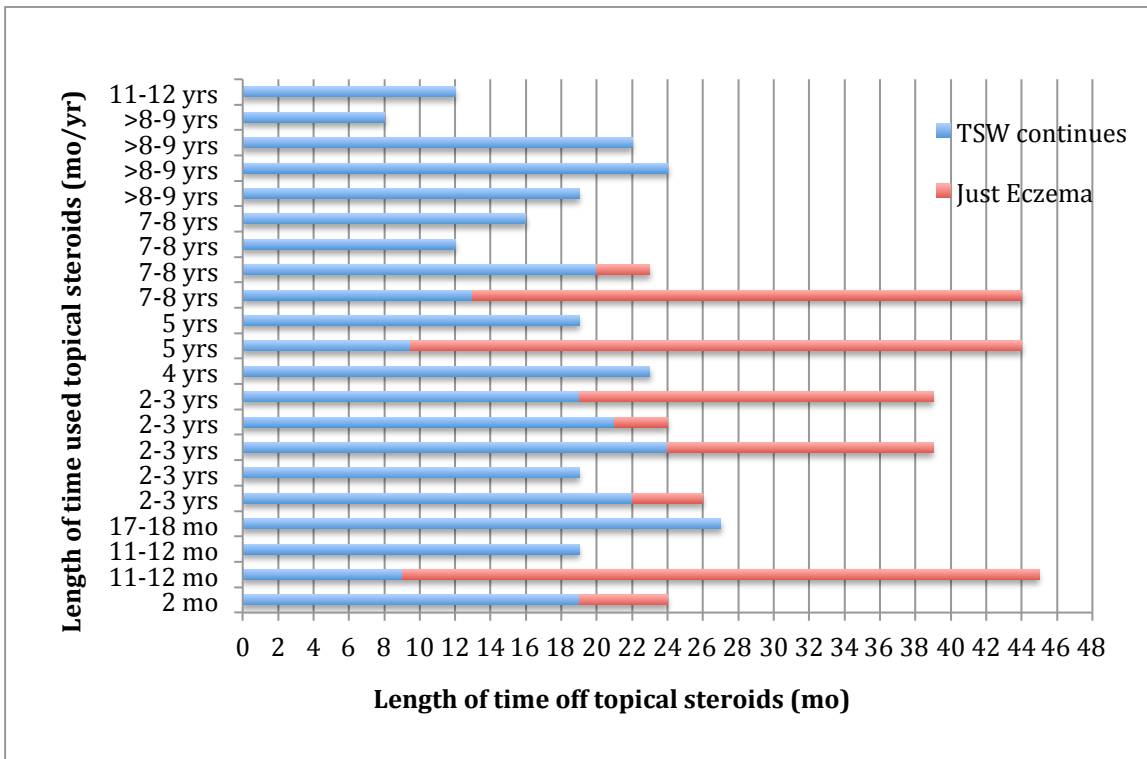
<sup>d</sup> Awake at night and sleeping during day or unable to sleep

<sup>e</sup> Other reported issues: impetigo, skin infections, increased anxiety, decreased concentration, aching joints, severe dandruff, impaired vision, emotional lability, infected heel/bone

<sup>f</sup> Ranged from a few days, weeks, or months to a whole year



**Figure 4.** Common signs of Topical Steroid Withdrawal. **Red sleeves**<sup>17</sup> (A, B) 1 mo. TSW. **Full body shedding**<sup>17</sup> C) 2-7 mo. D) 11 mo. restart daily shedding 1/2 tsp E) 15 mo. almost 1 tsp F) 18 mo. ½ tsp G) 19.5 mo. 1/8 tsp. **Elephant skin**<sup>23</sup> (H, I) 15 and 19 month TSW. (Reproduced with permission.)



**Figure 5.** Length of time used topical steroids vs. length of time off TS and transition to just eczema as of review (n=21 subjects). 6 subjects not included due to insufficient information available to determine length of time used TS.

Out of 21 subjects whose TSW duration could be determined, 2 subjects reported being free of all TSW signs and symptoms at 9 and 9.5 months (Figure 5). Both reported continued mild, intermittent eczema but manageable without TS (follow-up correspondence).<sup>29</sup> Another 7 of 21 appear to have recovered from TSW, with no reported return of full-body signs and symptoms (Figure 5).

**Duration of TSW signs and symptoms.** 18 of 20 subjects (90%) who are 12 months TS-free are still experiencing TSW symptoms at 12 months; 15 of 18 (83%) subjects who are 16 months TS-free are still experiencing TSW (82%) at 16 months; 7 of 13 (54%) subjects who are 20 months TS-free and 5 of 13 (38%) at 22 months TS-free are still presenting with TSW symptoms at 20 and 22 months, respectively (Table XV and Figure 5).

**Secondary Outcomes**

**Treatment.** 100% of the caregivers used various nonsteroidal pharmaceutical and nonpharmaceutical treatments to address the worsening eczema and the signs and symptoms of TSW (Table XVI).

**Table XVI.** Treatments used after cessation of topical steroids

<b>Nonpharmaceutical treatments</b>	<b>no. reported<sup>a</sup></b>
Cessation of topical steroids	27
Apple cider vinegar baths	11
Ace/gauze wrapping, cotton mitts/gloves	10
Ice packs, cool compresses	9
Psychological support	5
Hot packs/moist or dry heat	4
Narrow band UVB light (later stages of TSW)	3
<b>Pharmaceutical treatments</b>	
Antibiotics (oral)	9
Antibiotics (topical)	4
Antihistamines (oral)	8
Atarax	4
Analgesics (motrin, advil, Tylenol)	3
Systemic steroids during hospitalization	1
Tapering topical steroids	0
<b>Moisturizers (for those who can tolerate it)</b>	
Petroleum jelly	
Coconut and olive oils	
Essential oils (primrose, neem, tea tree, lavender)	
Other: aloe vera, Cereve, ceramides, sudocream, organic unrefined shea butter, zinc manuka honey, lemongrass balm, Dr. Fukaya's skin repair lotion (Tanaka Science Laboratory, Japan)	
<b>Other interventions</b>	
Apple cider vinegar and Dead Sea salt baths, epsom salt baths, topical vitamin D	
Probiotics, cod liver oil, active B vitamins, various vitamins and supplements as prescribed by healthcare provider	
Face massage machine, handheld fan, massager, soft tactile stimulation brushes	
Sunlight, exercise and activity as tolerated, deep breathing and relaxation techniques, visualization, acupuncture	
Video games, movies, other distractions and activities requiring two hands	
Diet: GAPS, anti-inflammatory, elimination diets, organic/non-GMO, others	

*ACV-apple cider vinegar*

<sup>a</sup> Reflects how many blogs mentioned doing the intervention; does not indicate that other caregivers withheld intervention.

<sup>b</sup> In-hospital allergist ordered 4 rounds IV, resulting in partial clearance, but subject "began pouring fluid from every pore in his body"<sup>18</sup> within 48 hours of discharge.

**Sources of caregiver support and information on TSW.** Caregivers utilized the internet and social media, particularly adult and child TSW blogs, and Facebook support groups, for help, support, and treatment information on TSW (Table XVII). Some caregivers were able to find healthcare providers who supported cessation of TS, or the original provider became supportive of TS cessation after seeing improvements in the child. 5 parents consulted with dermatologist Marvin Rapaport, MD in Los Angeles to confirm TSA/TSW diagnosis when no support was found in their hometown (Table XVIII).

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**Table XVII.** Source of caregiver support and information during topical steroid withdrawal (n=26 blogs)<sup>a</sup>

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no. (%)

- 9 (35) Internet search: Blog 8<sup>27</sup>, JB,<sup>b</sup> and JY<sup>c</sup> blogs led to ITSAN.org<sup>d</sup>; out-of-control eczema, Red Skin Syndrome, and Topical Steroid Withdrawal Facebook support groups
  - 7 (27) Internet search; searched “ITSAN”
  - 6 (23) Internet; Dr. Google; “searching for pictures of children with eczema that looked like mine and came across ITSAN.org”
  - 1 (4) Research university library files for medical facts; Internet: came across caregiver blog then ITSAN.org
  - 3 (12) Unspecified
- 

<sup>a</sup> There are 26 blogs and 27 children because one blog was about 2 siblings with TSW.

<sup>b</sup> Brown J. Steroid Red Skin Syndrome. Available at: <http://steroidredskinsyndrome.blogspot.com/> Accessed on 5/26/15.

<sup>c</sup> YJ. Juliana’s Topical Steroid Withdrawal Journey. Available at: <https://antisteroid.wordpress.com/> Accessed on 5/26/15.

<sup>d</sup> International Topical Steroid Awareness Network. Available at: <http://itsan.org/> Updated 5/24/15. Accessed on 5/26/15.

**Table XVIII.** Supportive healthcare providers after stopping topical steroids.<sup>a</sup>

Pediatrician or General Practitioner	7
Naturopath	5
Chiropractor	3
Homeopath	3
Holistic pediatrician	2
Acupuncturist	2
Endocrinologist	1
Nutritionist	1
Dermatologist	0 <sup>b</sup>

<sup>a</sup> The subject can have more than one supportive healthcare provider. That provider did not necessarily believe in TSA or TSW but was supportive in finding alternative treatments.

<sup>b</sup> 5 parents later consulted with dermatologist Marvin Rapaport, MD in Los Angeles to confirm topical steroid addiction/topical steroid withdrawal diagnosis when no TSW-knowledgeable provider was found in their hometown.

**TSW Diagnosis.** TSA was not officially diagnosed in 15 (56%) cases. In 6 (22%) cases, Rapaport (4) or other provider (2) confirmed the diagnosis suspected by the parent (Table XIX).

**Table XIX.** TSW diagnosis after subjects had already stopped using TS  
no. (%) (n=27)

15 (56)	TSW was not officially diagnosed by healthcare provider but it was assumed due to the signs and symptoms that resulted after stopping TS that were consistent with adult TSW symptoms reported in the forums, blogs, and research by Rapaport <sup>6</sup> and Fukaya. <sup>13</sup>
6 (22)	TSW was suspected by parent, then officially diagnosed by a doctor or other healthcare provider (4 diagnosed by MJ Rapaport, MD; 1 by holistic pediatrician; 1 by pediatrician, who later consulted with Rapaport)
6 (22)	Unspecified

*TSW, Topical Steroid Withdrawal; TS, topical steroids*

## Discussion

“Case reports are part of the evidence hierarchy in evidence-based practice and guide an important part of dermatologic practice...Frequently they are the first and sometimes major source for detecting rare adverse events.”<sup>43</sup>

TSA/TSW has been labeled “rare” and warrants further attention and investigation because of the devastating impact it has on the child and family that equals or exceeds that of eczema alone. In the absence of formal research evidence and literature on TSW in children, the caregiver blogs reviewed in this paper serve as a series of informal case reports that provide evidence suggesting that TSA/TSW can occur in some children who stop using TS for eczema. Despite their limitations, they describe the TSW sequelae in detail and photographic progression not generally documented in the lab or clinic.

Despite living in different states and countries, the children in the blogs have almost identical TS/eczema stories which are similar to the TS/TSW experience reported in adults.<sup>3,6,11,13</sup> The infant or child was diagnosed with eczema and prescribed a low or mid-to high-potency TS which was initially effective in managing the eczema. When the TS stopped working to control the eczema, the parents consulted various health care providers, continuing to use increasing potencies and frequencies of application as prescribed to treat the worsening eczema. TS use ranged from 2 months to 12 years, and neither the parent nor the provider suspected the TS until parents discovered the blogs of adults and a child<sup>27</sup> experiencing the same signs and symptoms they observed in their children. Having tried all other avenues--except for cessation of the TS--the caregiver chose to stop TS because the child’s condition had continued to deteriorate despite TS use, and the TS was no longer effective in managing worsening eczema. Cessation of TS resulted in the signs and symptoms of TSW in the child.

**Signs and symptoms.** TSW is a 24-hour per day ordeal, which consists of constant cycling of skin through phases of almost full-body redness, swelling, tightness, oozing, crusting, dryness, flaking, cracking, and shedding. Early months appear to be the worst, characterized by burning, stinging, pain, intensified itching, temperature dysregulation, altered sleep-wake cycle or insomnia, hyperesthesia, and hair loss. A classic sign of TSW is the “red sleeve” in arms and/or legs: a clear demarcation between white palms and soles and the erythematous limbs proximally<sup>13</sup> (Figure 4A and 4B). Children in 7 blogs reported growth delays prior to stopping TS. Of the 7 reporting growth delays: 2 had oral; 2 had inhaled; 1 had intravenous; 1 had oral and inhaled; and 1 had oral, inhaled, and injected corticosteroids in addition to TS used for their eczema. It is unclear to what extent each route of corticosteroid administration contributed to the growth delays. It is uncertain if growth delays occurred in the other children or if they were just not reported. Unlike the adults in the NEA study,<sup>11</sup> TSW symptoms in these children were not confined to the face.



By 6 to 8 months of TSW, the full-body symptoms seem to become less intense and swelling, redness, and oozing diminish, though the itching remains. The skin continues to cycle as outlined above. TSW is characterized by many flares during its entire course. The flares consist of an exacerbation of the full-body symptoms and may see a return of oozing or other symptoms that were believed to have improved, or the skin presents as it did in early months of TSW. Many flares of varying lengths occur during the course of TSW. The underlying eczema may also reveal itself in the later months, but distinguishing it from TSW symptoms is difficult and is another subject that warrants further study.

Written narrative and dated progression photos in 19 blogs show the children in different stages of healing and severity of TSW signs and symptoms. Those in the early months of TSW have more severe physical and system-wide issues (Table XV) than those in later months of TSW, where the body systems (eg, temperature regulation, sleep-wake cycle, energy level) have almost returned to normal while the skin and itch continue to flare and cycle for an unpredictable number of weeks or months.

**Duration.** TSW appears to have a protracted, non-linear course described as a “living hell” by parents and Kligman.<sup>3</sup> It is a horrific rollercoaster ride on the background of constant skin cycling which can take from 8-16+ months to end. Unlike the adult TSW cases in the NEA study, the 8 to 9 “healed-from-TSW” children in this review manifested full-body TSW symptoms for 8 to 18+ months before fully resolving.

The duration of TSW is a point of contention among clinicians and individuals suffering from TSW. Personal correspondence with physicians regarding TSW duration has brought up two points worth addressing. Some have suggested that the children in the blog photos after 6+ months of TSW look like the cases of chronic AD in the clinic and that the parents are mistaking the underlying chronic AD for TSW. However, if the children in the clinic are using TS for their chronic AD, then is it not possible that those clinic children may actually have TSA, also, and are exhibiting signs of TSW, thereby presenting like the children going through TSW?

Another correspondent stated that the pictures reveal a bad case of months of untreated erythroderma. Again, if the clinic patient with erythroderma has developed it as a consequence of AD, and if that patient has been taking TS for treatment of the AD and erythroderma, is it not possible that the erythroderma is actually the manifestation of TSA/TSW due to the continued TS use? (Idiopathic erythroderma is different from TSW and will not be discussed here.) There is no scientific data to support that TSW can not last 12+ months. In their experience and research treating thousands of adult patients with TSA, Kligman, Rapaport, and Fukaya find it can take months to years for TSW resolution.<sup>3,6,13,44</sup>

As of this review, 9 of 21 subjects appear to have recovered from TSW, with no reported return of full-body signs and symptoms (Figure 5). Follow-up with authors of these blogs reveal: 7 children experience occasional mild eczema in classic

locations; 1 child has no eczema, allergy issues, or itching;<sup>18</sup> and 1 child continues to have strong eczematous flares in classic eczema locations.<sup>27</sup> All continue to watch what they eat due to allergies, avoid triggers, moisturize if tolerated, prevent infection, and manage itching or dry patches of eczema as needed without TS.<sup>20,29,31,33,37,38,42</sup> In 6 of the 9 cases, TSW lasted 16 or more months.

**TSW vs. chronic AD.** Based on years of closely inspecting, observing, and treating their children's skin, the caregivers in the blogs say they know it is still TSW because the symptoms are still full-body manifestations, and the lesions do not look or act like the eczema they had treated for years prior to TSA. Also, other TSW symptoms are still present such as full-body shedding, sweat stinging, hypersensitivity to water or moisturizers, and elephant skin (Figure 4C-4I). Rapaport recommends checking the serum nitric oxide levels, which are elevated in patients with TSW (and in other medical conditions) but not in healed TSW patients and patients with eczema.<sup>44</sup> He suggests nitric oxide levels may help to gauge healing time since the levels decrease as the TSW resolves.<sup>44</sup> More studies are needed to ascertain the differences between the signs and symptoms of TSA/TSW and the natural course of eczema so that clinicians can implement treatment strategies specific to and appropriate for each condition. Objective severity scoring measures for TSA/TSW may assist in following its progression, marking the end of TSW, and differentiating it from true eczema and other dermatoses.

**Treatment.** "No TS treatment" does not mean "no treatment." Treatment for TSA involves cessation of TS. Treatment for the signs and symptoms of TSW are highly variable, depending on the caregiver, but they all attempt to employ non-pharmaceutical and pharmaceutical measures to provide comfort, facilitate healing, prevent infection, and relieve symptoms that include but are not limited to: itching, pain, burning, stinging, edema, oozing, infection, fatigue, and anxiety. These measures are consistent with TSW management recommended by Rapaport.<sup>6</sup> Parents also consulted with healthcare providers regarding swollen lymph nodes, growth delays, HPA axis suppression or adrenal issues, and infections or other physical ailments that were unresponsive to home care.

**Healthcare providers.** Parents who stop using TS for their children (because it no longer controlled the eczema) have been labeled steroid-phobic and distrustful of the medical community. However, this does not appear to be true in these cases. Before stopping TS, 21 children in the blogs saw a minimum of 93 doctors, all of whom recommended continuing TS despite worsening of the eczema, and the parents trusted and followed the doctors' orders in an effort to get it under control. It is unclear what the clinicians told the parents to do if the eczema did not resolve after the prescribed time frame, but a post-marketing safety review submitted to the FDA in 2001 recommended that labeling of TS products should include information on how quickly improvement should occur after TS treatment starts and that practitioners "should be advised to discontinue the product if improvement does not occur within this timeframe."<sup>45</sup> Closer monitoring is needed for early detection of TSA/TSW in children who are prescribed TS, and appropriate labeling as recommended in the FDA safety review should be implemented to ensure proper use.

**TS dosing, frequency, and duration.** In the 2014 AAD guidelines on AD treatment, Eichenfield et al state that a lack of studies has resulted in the great variability in TS dosing and that no universal standard for quantity of TS application exists.<sup>1</sup> This was evident in the reported dosage, frequency, and duration of TS prescriptions in the blogs, which ranged from “a few times per month” to 2 to multiple times daily for 3, 5, 7, or 30 days or “until it clears the skin” (Table IX). It is unclear at what point the TS applications increased to regular daily use. It is reasonable to assume that as the eczema spread from the original lesion sites, the amount of TS also increased. More research is needed to determine safe, child-specific dosing, frequency, and duration of TS use to help prevent TSA/TSW from developing in susceptible individuals.

The AAD guidelines for the safety of wet wrap therapy (WWT) with TS<sup>1</sup> used for 14 days (diluted TS) are based on 24 studies with evidence level 4.<sup>46</sup> Of the studies, 13 were based on expert opinion (study design level 5), and the authors gave WWT with TS a grade C recommendation. In 2 blogs reporting use of WWT with TS, the treatment prescribed was allowed to continue for 3 months to 2 years, and the worsening skin conditions were blamed on undertreatment--despite 1-3 times per day applications as directed--and on the parents for not applying the treatment correctly.

High quality research is needed to determine a safe dosage and time frame for WWT with TS use on children, and the subjects should be followed for at least 2 years to note the long-term effects of this method. Since ethical and other constraints make randomized controlled trials and other formal studies difficult to conduct, clinicians who employ WWT with TS on children should closely monitor and carefully document their patients' responses to treatment—positive and negative—so that safer protocols can be devised and adverse effects such as TSA and subsequent TSW can be prevented.

**TSA/TSW diagnosis.** TSA was not officially diagnosed in 15 (56%) cases but assumed due to the signs and symptoms that resulted after stopping TS that were consistent with adult TSW symptoms reported in the forums, blogs, and research by Rapaport<sup>6</sup> and Fukaya.<sup>13</sup> In 6 cases, Dr. Rapaport (4) or other provider (2) confirmed the diagnosis suspected by the parent. Clinicians who understand TSA and TSW are needed to help provide accurate diagnosis and effective treatment and support to the children who develop this condition.

**Sources of caregiver support and information on TSW.** Caregivers utilized the Internet and social media, particularly adult and child TSW blogs and Facebook support groups, for help, support, and treatment information on TSW. TSW blogs helped parents find the solution for their children's worsening eczema. Some caregivers were eventually able to find healthcare providers who supported cessation of TS, or the original provider became supportive of TS cessation after seeing improvements in the child. Many healthcare providers who do not acknowledge TSA/TSW as a real entity continue to recommend TS for “worsening eczema” and provide little assistance to the patient.<sup>13</sup>

**Limitations.** Lack of studies on TSA/TSW in children and on the effects of long-term topical steroid use in children with eczema, blog author and reviewer bias, and the variability in quality and quantity of information reported in the blogs are limitations.

### **Conclusion**

Children who stop using TS for eczema can develop signs and symptoms of TSW seen in adults. It appears that these signs and symptoms can last >12 months, even for the relatively short duration of use compared to adult usage. Unlike documented adult TSW cases, children in this review manifested full-body symptoms for 8-16+ months during the withdrawal process. The prevalence of this phenomenon is yet unknown. Clinicians and parents should be aware of this potential adverse effect, carefully weigh the risk-benefit, and closely monitor the application and effects of TS. More research is needed to establish safe, effective child-specific dosage, frequency, and duration for TS use and withdrawal. Further investigation into the thousands of TSW reports found in social media and other blogs can provide important information to train clinicians, guide hypotheses, and spur research on and development of effective measures in the prevention, early detection, and treatment of TSA and TSW in children.

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**REFERENCES**

1. Eichenfield LF, Tom WL, Berger TG, et al. Guidelines of care for the management of atopic dermatitis: section 2. Management and treatment of atopic dermatitis with topical therapies. *J Am Acad Dermatol*. 2014;71(1):116-32.
2. Hengge UR, Ruzicka T, Schwartz RA, Cork MJ. Adverse effects of topical glucocorticosteroids. *J Am Acad Dermatol*. 2006;54:1-15.
3. Kligman AM, Frosch PJ. Steroid addiction. *Int J Dermatol*. 1979;18(1):23-31.
4. Rapaport MJ, Rapaport V. Eyelid dermatitis to red face syndrome to cure: clinical experience in 100 cases. *J Am Acad Dermatol*. 1999;41:435-442.
5. Rapaport MJ, Lebwohl M. Corticosteroid addiction and withdrawal in the atopic: the red burning skin syndrome. *Clin Dermatol*. 2003;21(3):201-214.
6. Rapaport MJ, Rapaport V. The red skin syndromes: corticosteroid addiction and withdrawal. *Expert Rev. Dermatol*. 2006;1(4):547-561.
7. Fukaya M. *Steroid Addiction 2010 - I'd like to request the Japanese Dermatological Association to remedy its guideline for management of atopic dermatitis*. 2010. [Japanese version only]. (ISBN978-4-901402-47-7 C3047)
8. Fukaya M. *Atopy steroid addiction in Japan*. [Website is English translation of the book published in Japan with original title: *Steroid Addiction 2010 - I'd like to request the Japanese Dermatological Association to remedy its guideline for management of atopic dermatitis*. (ISBN978-4-901402-47-7 C3047)]. Available at: <http://topicalsteroidaddiction.weebly.com/> Published January 1, 2010. Accessed April-May 2015.
9. Fukaya M. My personal story. *Dr. Fukaya's blog (Topical Steroid Addiction)*. Available at: <http://mototsugufukaya.blogspot.com/search/label/My%20personal%20story> Published June 4, 2013. Accessed May 22, 2015.
10. National Eczema Association. NEA forms scientific advisory committee task force to study topical steroid addiction. *National Eczema Association*. Available at: <http://nationaleczema.org/nea-forms-scientific-advisory-committee-task-force-study-topical-steroid-addiction/> Published December 11, 2013. Accessed on May 22, 2015.
11. Hajar T, Leshem YA, Hanifin JM, et al. A systematic review of topical corticosteroid withdrawal ("steroid addiction") in patients with atopic dermatitis and other dermatoses. *J Am Acad Dermatol*. 2015;72(3):541-549.e2. Published online January 13, 2015. doi: <http://dx.doi.org/10.1016/j.jaad.2014.11.024>

12. Fukaya M. Improvement of atopic dermatitis after discontinuation of topical corticosteroid treatment. *Arch Dermatol*. 2000;136(5):679-80.
13. Fukaya M, Sato K, Sato M, et al. Topical steroid addiction in atopic dermatitis. *Drug Healthc Patient Saf*. 2014;6:131-138. doi: <http://dx.doi.org/10.2147/DHPS.S69201>
14. Eichenfield LF, Tom WL, Chamlin SL, et al. Guidelines of care for the management of atopic dermatitis. Section 1. Diagnosis and assessment of atopic dermatitis. *J Am Acad Dermatol* 2014;70:338-51.
15. Morris BM. The importance of case reports. *CMAJ*. November 1, 1989;141(9):875-876. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1451465/?page=1>
16. Fukaya M. How long does the rebound period continue? Am I really suffering from TSA now? *Dr. Fukaya's blog about TSA (Topical Steroid Addiction)*. Available at: <http://mototsugufukaya.blogspot.com/search/label/How%20long%20does%20the%20rebound%20period%20continue%3F%20Am%20I%20really%20suffering%20from%20TSA%20now%3F> Published June 12, 2013. Accessed on May 22, 2015.
17. Blog 2. Beyond the Itch: Brian's journey through eczema and withdrawal from topical steroids. Available at: <http://beyondtheitch.wordpress.com> Published February 2014. Updated May 26, 2015. Accessed March-May 2015.
18. Blog 4. Isaiah Quinn. Available at: <http://isaiahquinn.blogspot.com> Published August 31, 2013. Updated April 27, 2015. Accessed March-May 2015.
19. Blog 3. The Story of Bo. Available at: <http://thetswstoryofbo.blogspot.co.nz> Published June 2, 2014. Updated April 19, 2015. Accessed March-May 2015.
20. Blog 15. My Little Red Warrior: our journey through topical steroid withdrawal. Available at: <http://mylittleredwarrior.wordpress.com> Published July 18, 2013. Updated March 2014. Accessed March-May 2015.
21. Blog 17. Amy's journey through topical steroid withdrawal. Available at: <http://amysitchyjourney.blogspot.com> Published October 29, 2013. Updated March 17, 2015. Accessed March-May 2015.
22. Blog 23. It's a mom life: topical steroid withdrawal. Available at: <http://itsamomlife.blogspot.com/2014/12/topical-steroid-withdrawal-one-year-in.html> Published January 2013. Updated December 10, 2014. Accessed March-May 2015.

23. Blog 13. Keegan's topical steroid addiction. Available at: <http://keeganstопicalsteroidaddiction.blogspot.com> Published May 10, 2013. Updated December 11, 2014. Accessed March-May 2015.
24. Blog 19. Topical steroid withdrawal. Available at: <http://www.topicalsteroidwithdrawal.com> Published October 17, 2013. Updated May 10, 2015. Accessed March-May 2015.
25. Blog 25. Steroids make eczema worse: Josh and his journey through topical steroid withdrawal. Available at: <http://steroidsmakeeczemaworse.blogspot.com/> Published March 7, 2014. Updated March 10, 2015. Accessed March-May 2015.
26. Blog 24. Little house mama. Available at: <http://littlehousemama.blogspot.com> Published November 23, 2011. Updated March 1, 2015. Accessed March-May 2015.
27. Blog 8. Kline's topical steroid hell. Available at: <http://klinestопicalsteroidhell.blogspot.com> Published: February 21, 2012. Updated April 16, 2015. Accessed March-May 2015.
28. Blog 18. Katiebug's quest. Available at: <http://katiebugsquest.blogspot.sg> Published May 25, 2014. Updated July 6, 2014. Accessed March-May 2015.
29. Blog 5. Scratchy monster. Available at: <http://scratchymonster.blogspot.com> Published April 27, 2012. Updated January 23, 2015. Accessed March-May 2015.
30. Blog 10. Willis snapshots. "TSW: one month down!" Available at: <http://willisnapshots.blogspot.com> Published July 23, 2010. Updated September 14, 2013. Accessed March-May 2015.
31. Blog 21. The boy the greek fire and me. [Original site: <http://theboythegreekfireandme.blogspot.com/?wref=bif> ] Available at: <http://itchylittleworld.com/tag/cortisone-withdrawl/> Published July 3, 2012. Accessed March-May 2015.
32. Blog 11. A teen with eczema. Available at: <http://ateenwitheczema.blogspot.com> Published August 11, 2013. Updated March 14, 2015. Accessed March-May 2015.
33. Blog 14. Life with eczema. Available at: <http://life-with-eczema.tumblr.com> Published April 24, 2013. Updated April 24, 2015. Accessed April-May 2015.
34. Blog 9. Edenskin. Available at: <http://edenskin.blogspot.com> Published May 10, 2013. Updated March 10, 2015. Accessed March-May 2015.



35. Blog 12. Shredsteroids. Available at: <https://shredsteroids.wordpress.com> Updated Published September 22, 2014. Updated May 10, 2015. Accessed March-May 2015.
36. Blog 1. Healing topical steroid withdrawal. Available at: <https://healingtopicalsteroidwithdrawal.wordpress.com> Published April 5, 2014. Updated May 19, 2015. Accessed March-May 2015.
37. Blog 16. Warrior girl beats topical steroid. Available at: <http://warringirlbeatstopicalsteroid.blogspot.com> Published October 2013. Updated May 5, 2014. Accessed March-May 2015.
38. Blog 6. Topical steroid addiction and cure. Available at: <http://topicalsteroidaddictionandcure.blogspot.com> Published April 2012. Updated October 22, 2013. Accessed March-May 2015.
39. Blog 22. Chelsea blogs. Available at: <http://www.chelseablogs.com/2014/05/topical-steroid-addiction-it-is-real.html> Published May 2014. Updated November 2014. Accessed March-May 2015.
40. Blog 26. Torrin TSW journey. Available at: <https://torrintswjourney.wordpress.com> Published March 12, 2015. Accessed April-May 2015.
41. Blog 7. I hate steroids. Available at: <http://ihatesteroids.blogspot.co.uk> Published April 1, 2013. Accessed March-May 2015.
42. Blog 20. My side is greener. Available at: <https://mysideisgreener.wordpress.com> Published April 23, 2011. Updated April 11, 2015. Accessed March-May 2015.
43. Albrecht J, Werth VP, Bigby M. The role of case reports in evidence-based practice, with suggestions for improving their reporting. *J Am Acad Dermatol*. 2009;(60(3)412-418. doi: 10.1016/j.jaad.2008.10.023
44. Rapaport MJ, Rapaport VH. Serum nitric oxide levels in “red” patients: separating corticosteroid-addicted patients from those with chronic eczema. *Arch Dermatol*. 2004;140(8):1013-1014.
45. Weaver J. Post-marketing safety review—PID D010141. Drugs: Topical corticosteroids. [FDA Memorandum]. Available at: [http://www.fda.gov/ohrms/dockets/ac/03/briefing/3999B1\\_21\\_Weaver-Memo%2007-09-01.pdf](http://www.fda.gov/ohrms/dockets/ac/03/briefing/3999B1_21_Weaver-Memo%2007-09-01.pdf) Published July 9, 2001. Accessed May 2015.

46. Devillers ACA, Oranje AP. Efficacy and safety of 'wet wrap' dressings as an intervention treatment in children with severe and/or refractory atopic dermatitis: a critical review of the literature. *BJD*. 2006; 154(4):579-585. doi: 10.1111/j.1365-2133.2006.07157.x