

Crowdsourcing a solution to eczema and atopy

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Project Summary

Elevator Pitch

Concise Summary: Help us pitch this solution! Provide an explanation within 3-4 short sentences.

SolveEczema.org is about helping families problem solve and eliminate their children's eczema, asthma and other atopic manifestations, without drugs or treatment of any kind, through identifying and addressing the underlying environmental cause.

For the past 9 years, I have run a website, SolveEczema.org, that helps families ameliorate or eliminate their children's (and often their own) eczema and atopic manifestations like asthma, without medications or any chronic treatment or reliance on interventions at all. Given the rapid rise of eczema and atopic manifestations in the last 50 or 60 years, many researchers acknowledge that the problem must be primarily environmental, although there is a genetic susceptibility. The accepted working theory is the Hygiene Hypothesis, which does not lead to a solution for individuals.

Eczema and atopy have risen dramatically in the industrialized world, every decade since WWII. Children are especially affected. In many nations today, fully fifteen to thirty percent of all children develop eczema, often going on to develop atopic manifestations like asthma or allergies, and many do not "outgrow" it. Eczema has a dramatic effect on quality of life, as even mild eczema can cause unrelenting itching and poor sleep. Quality of life studies show eczema having an equal or more dire impact on family quality of life than having a child with diabetes. Billions are being spent on research and treatment annually, with no acknowledged comprehensive solution in sight.

Yet my website has helped families all over the world eliminate their children's eczema and restore normal skin, including doctors who refer the site to patients or have thanked me after the site helped them more for their own children than did anything else. The site is noncommercial, I have never search-optimized nor advertised, yet in just the space of the 11 months since January of this year, it has had nearly 33,000 unique visitors, with over 50,000 visits and 109,000 pages viewed in that time (and many tens of thousands of visitors worldwide in the years prior). A Georgia mom recently posted a blog in which she details the eczema journey, the unsatisfactory nature of existing treatments, and the results of fully implementing the environmental changes detailed on my website: <http://www.sammyskin.blogspot.com>

When I first wrote the SolveEczema site, I wasn't prepared to come out fully with my theories about eczema and atopic manifestations, but I am now, and I can better support them. I am writing a book for the site, and although I have discussed some of my ideas on my blog, I will detail them (with citations) in the book. I have read extensively in the dermatological medical literature, and can propose a revision of the Hygiene Hypothesis — a "Detergent Hypothesis" — that is more consistent with the research underlying the proposal of the Hygiene Hypothesis, explains in a very simple way seemingly contradictory results on the topic since, and happens to lead, in the way the basis suggests, to families eliminating their children's eczema and atopic manifestations. Not just eliminating them, but doing so without drugs or reliance on ANY treatment. In the process, people realize their children are not the problem, are not ill, are not fragile — and are not irreversibly damaged — but that specific environmental influences that did not exist 100 years ago are the problem. I believe the genetic conditions that lead to susceptibility to this environmental cause would have been an advantage 100 years ago and prior, and I believe I can also show good support for that idea as well, with a different view of the purpose of allergies and why humans experience them.

However, in order to bring these ideas to the broader medical community and fundamentally change the way this problem is addressed in practice, scientific publication and peer review are key. I've spent a lot of time trying to figure out how to get a study done, even to convince a researcher to just take on a case study, but getting a study done is expensive for one, plus complicated if you aren't a researcher and don't have medical credentials or affiliations. Did I say complicated? I'm never willing to say "impossible", but let's just say I've come to a place where I'm willing to say it's not worth the effort to do the traditional way.

But I've also come to realize that trying to shoehorn this into the traditional research paradigm is wrong anyway. I'm not suggesting it doesn't need traditional peer review and publication, I'm suggesting the traditional route is all wrong for this problem, and is why it isn't being solved that way despite there being such overwhelming (albeit indirect) support for what I am saying in the existing literature. If you can accept for a moment, as I feel, that this seemingly complex problem has a simple (though not easily seen) solution, it's not beside the point that I solved this problem this way, as a "Citizen Scientist" — let's face it, as a mom (with a technical background), I had unique motivation, and access for the prolonged periods of time necessary to make empirical observations in the way they needed to be made — and I truly believe that kind of detailed problem solving could make the difference in solving other seemingly complex systemic diseases like multiple sclerosis, so I don't want to negate it by trying to shoehorn this stage of the work onto a paradigm that I believe is so ill-suited to solve a problem like this. I think it's as important to validate the problem-solving approach as the eczema solution.

It turns out there are web platforms now for "citizen scientists" — tens of thousands of people sign up in hopes of being able to volunteer for cataloguing bird behavior in their area, or watching a part of the sky for comets or stars. Mainly, these groups allow ordinary people to become free lab assistants, not really scientists, in order to collect large amounts of data for a traditional researcher. However, at least one of these societies eschews the idea of turning people into "research pawns" for others, and is promoting real science by the average joe. So I thought — why not do a medical study that way? Use a citizen scientist platform to solicit volunteers as part of a uniquely modern medical study: enroll as many people as possible to either try the site or continue to follow their doctors' recommendations, and ask people to bring a questionnaire to

their doctors to verify the diagnosis and be sure they have a doctor on board, and have people fill out a questionnaire to help characterize their home environment, how they change it (or not), and how the eczema changes. The costs of the study would be distributed, as would the responsibilities and reporting. I could publish about it before and after. I'll even be looking into whether it's possible for some people to even make cheap DIY kits for measuring TEWL (trans-epidermal water loss) and other measures of skin barrier function, but that remains to be seen.

In the coming weeks, I'll be trying to hash out the details with some other parents who used the site successfully, though I probably will not load the project until the book is ready (to self publish) and other groundwork is laid. I have been bearing the costs of this endeavor on my own for the past 9 years — unlike medical professionals and researchers, I have no institutional affiliations or salary; the site will continue to be available for free, but the book will hopefully provide some financial support for the me as the principal investigator. In this way, I hope to conduct the first major crowdsourced medical study, with essentially no traditional funding. If I have gathered correctly the purpose of this contest, mentorship and guidance from RWJF experts would be most welcome.

About Project

Problem: What problem is this project trying to address?

Pediatric eczema and allergies are a rising global epidemic. In some parts of the world, every 3rd or 4th child suffers from this problem, often with attendant asthma. Many researchers acknowledge the problem is primarily environmental, yet research efforts focus on treatment. For nearly 9 years, SolveEczema.org has been helping parents from all over the world to end their children's eczema and allergies, without medications or treatment at all; if parents are given the information to understand the environmental cause, they can give their children normal lives simply by eliminating the cause from their home environment. The greatest barrier is demonstrating this through medical research and publication, in order to change the paradigm of thinking about allergies and eczema. Parents in rural and third-world countries can protect their families without dependence on interventions.

Solution: What is the proposed solution? Please be specific!

The SolveEczema.org solution gets to the cause of skin barrier disruption at the root of eczema, shows parents how to identify and understand it to give their children normal skin and lives without treatment. The problem comes down to how modern detergents - ubiquitous in homes across the world today in cleaning and personal care - impact the skin barrier and increase membrane permeability and allergic sensitization. Eliminating this influence is not as simple as changing cleaning products. The SolveEczema solution gives families the detailed information to identify how they may be affected and what they can do to solve the problem. A medical study is needed to put the information in the hands of medical practitioners.

Impact: How does it Work

Example: Walk us through a specific example(s) of how this solution makes a difference; include its primary activities.

I receive email from families all over the world whose children suffer immensely. Many of these children haven't slept a single night through in their lives from the itching, or have been in the hospital because of infections, or ostracized because of their broken, oozing skin. I met a 7-year-old boy recently whose mom used the site to solve his eczema when he was about 18 months old. Eczema doesn't usually scar, but this boy's eczema had been so bad, he has a scarred area along the side of his face and neck. I realized, if his mom hadn't stumbled across my website one late night, this child would have been disfigured for the rest of his life. Instead, he's a beautiful, bright, sweet child with normal skin. For a detailed example of how the solution made a difference for another family, see <http://www.sammysskin.blogspot.com> Everyone thinks eczema is something wrong about the children. Imagine what that does to a child, for the family to believe the child is weak or "defective". This problem has a genetic component, but it is fundamentally an environmental one, and unnecessary for most of these children to ever suffer. This solution allows these kids to lead normal lives and see themselves as healthy. Enlightening and demonstrating this would have a profound global impact. Demonstrating this solution with eczema would also highlight the benefits of the problem-solving approach used to come to this solution, potentially leading to further simple solutions for other diseases currently deemed intractable.

Sustainability

Marketplace: Who else is addressing the problem outlined here? How does the proposed project differ from these approaches?

I only wish there were competitors to solve the problem. There are many expensive treatments that fall short. I read the medical literature and see a lot of sincere effort and billions spent on research. I see study after study of eczema quality of life, quality of life in infants, adults, families, proposed measurement instruments for measuring quality of life, comparing measurement instruments, measurement instruments for eczema severity and prevalence, comparing and reviewing measurement instruments for severity and prevalence, etc. But I don't see empirical problem-solving. The biggest challenge is old myths and beliefs about what causes eczema and allergy. It's difficult for anyone to accept that the answer is simple (although not obvious). I'm not associated with an academic institution, so I do have to publish to be taken as a peer.

About You

Organization:

SolveEczema.org

About You

First Name

A.J.

Last Name

Lumsdaine

Twitter URL

Facebook URL

About Your Organization

Organization Name

SolveEczema.org

Country where this project is creating social impact

Source URL: <https://www.changemakers.com/rwjfopen/ideas/entries/crowdsourcing-solution-eczema-and-atopy#comment-0>