A response to The Sensitive One Podcast: Ep#7

"Could Worms Cure Coeliac Disease? With Immunology Researcher Dr Paul Giacomin"

Dear Dr Giacomin

I'm writing in response to comments you made recently in the interview you gave to Gina Susan Long for The Sensitive One, published on YouTube on 9 Sept 2021.
https://www.youtube.com/watch?v=gv-2v7DzWCE&t=29s

Firstly, I would like to draw your attention to the following paper by Venkatakrishnan, et al, which was published late last year.
https://www.preprints.org/manuscript/202012.0340/v1

Secondly, I would like to point out some of the insights gained by the helminthic therapy self-treatment community which have significant implications for the design of clinical trials involving helminths, as well as for interpreting their results.

Unlike the very small sample sizes that you and other academic researchers have worked with, the Helminthic Therapy wiki presents data gathered from many *hundreds* of self-treaters over the past decade.
https://helminthictherapywiki.org

Here are a few of our discoveries that have particular implications for hookworm studies.

1. For helminthic therapy to be effective, it is essential to maintain *continuing* exposure to the selected organism. Unfortunately, the period of survival of a helminth varies considerably between individual hosts, and the experience of self-treaters has shown that, in the case of N. americanus, survival of the organism ranges from several years to as little as two months.
https://helminthictherapywiki.org/wiki/index.php/Self-treating_with_NA#Hookworm_lifespan

2. There is a 10-fold difference in the level of helminth dosing required to achieve disease remission in different hosts. In the absence of any tests capable of providing guidance about the extent of dosing that might be required by each individual, determination of the optimum dosing regimen (the number of larvae in, and the intervals between, doses) currently requires the employment by each self-treater of a individualised dose-finding protocol, which can be a lengthy process in the case of the human-adapted species, N. americanus and T. trichiura.

3. The benefits derived from hosting N. americanus can take a long time to develop in some cases. While some benefits may appear within weeks, these do not become consistent until at least 12 weeks, and, in a few cases, can take up to two years before making their first appearance. There have even been a few cases where clear benefits only appeared during the third year.

These three factors are explained in much more detail in the wiki, with how they relate to N. americanus being featured on the following page.
https://helminthictherapywiki.org/wiki/index.php/Hookworm_dosing_and_response

4. A further factor that can limit the extent of any therapeutic benefit produced by helminths is the potential for certain substances to adversely affect, or even kill, these organisms in some individuals. N. americanus is the most susceptible of the currently available probiotic helminths, and exactly how this organism is affected in this way is explained in the Human Helminth Care Manual.
https://helminthictherapywiki.org/wiki/index.php/Human_helminth_care_manual

To take the example of oregano, some hookworm hosts who ingest this herb may experience reduced benefit from their helminths, possibly even losing their entire colony if they eat a sufficiently large quantity of the plant, consume a concentrated extract or tincture of oregano, or take an oregano oil supplement.

A more complex situation pertains with coconut products, some of which are harmless to N. americanus, while others have been reported to have exerted varying levels of harm up to, and including, the total eradication of entire colonies.

Beyond being dependent on the form in which the substance is encountered, and the dose level, the adverse effect of such substances differs widely between hosts. Users of N. americanus are therefore advised to avoid these, and a few other substances, where possible, until the self-treater is seeing clear and consistent benefits from the therapy, and then to begin to gradually reintroduce them to assess any effects. This way, the hookworm self-treater is able to learn which, if any, of the potentially risky foods, drugs and other substances they might need to avoid in the long term.

Since you commented in the podcast on the results of a number of studies investigating the therapeutic potential of Trichuris suis ova (TSO), I would like to draw your attention to the rarely acknowledged, but very serious, design issues with many of the most recent TSO trials, flaws of such significance that they render the stated results of these trials unreliable, as is explained in the entry for 2008 at the following link.
https://helminthictherapywiki.org/wiki/index.php/The_history_of_helminthic_therapy#2008

If you read the whole of the History of Helminthic Therapy at this last link, you will see how this therapy has undergone continual development within the self-treatment community since 2003, in parallel with insights provided by formal science, and how the therapy is now ready, given an appropriate up-scaling of production by the nine helminth providers, for population-wide application.

Further clinical trials would obviously be required before regulatory authorities would approve the clinical use of helminthic therapy, but it must be stressed that this is not exclusively a medical treatment. What we have come to refer to as “helminthic *therapy*” is actually a simple probiotic practice closely akin to the well established inclusion of bacterial probiotics in the diet to enhance health. As anyone who reads the Helminthic Therapy wiki will come to realise, the value of helminth probiotics for immune enhancement is now without question, and requires no further validation by researchers before being used by members of the public.

Unfortunately, due to poor trial design, the majority of work in this area by academic researchers is generating a stream of negative feedback that fosters doubt in the minds of the public about the value of replenishing their biomes with probiotic worms. In order to provide encouragement to members of the public, as well as to pave the way for eventual acceptance of this modality by mainstream medicine, we urgently need researchers to improve the design of their clinical trials by utilising the insights that have been gained within the self-treatment community. In particular, it is critical that researchers cease treating living helminths as if they were pharmaceutical products.

Until the unique nature of each individual helminth/host relationship is acknowledged and taken into account when designing formal studies, science will continue to fail millions of patients who have life-changing immune-related disorders, condemning many of them to continue suffering the limitations and long-term side effects of existing pharmaceutical treatments. It will also perpetuate the misrepresentation of the effects of helminth replacement to currently healthy members of the public who could live longer, healthier lives if their biomes were enriched by probiotic worms.
https://helminthictherapywiki.org/wiki/index.php/Helminthic_therapy_for_well_people

Yours sincerely

John Scott

Founder, the Helminthic Therapy wiki - an independent, volunteer-led, non-profit information resource.