

A Survey of Self-Treatment with Helminths: Practices and Outcomes

- **Description of Study:** This study consists of a survey designed to collect information regarding the practice and efficacy of self-treatment with therapeutic worms (helminths). The basic questions we are asking are, does self-treatment with helminths work, and if so, what is the best approach? The survey consists of a mail-in form which is to be completed by individuals wishing to provide information about their experience with self-treatment using helminths.

The study is designed to collect an initial set of data at the time of its release in 2013. Following that initial data collection, we hope to collect yearly updates from individuals who are interested in keeping us up-to-date regarding their self-treatment with helminths. In the future (after 2013), we also hope to continue collecting information from individuals who are self-treating with helminths for the first time. We think that practices regarding self-treatment with helminths might change over time, possibly becoming more efficient and effective. This survey will help us test this idea.

This study will not collect information that could be used to identify participants. With that in mind, we ask that participants do NOT include their name, address, specific dates, or the names of any doctors or medical centers. We also ask that participants do NOT include a return address label on their survey. We are not able to accept surveys returned by E-mail.

- **What is self-treatment?** In this case, “self-treatment” includes treatments that are obtained by individuals acting with the aid of other individuals, and it includes treatments obtained by individuals acting alone. Thus, the self-treating individual may receive help with obtaining and administering the helminths. However, “self-treatment” excludes individuals who are receiving treatments as part of a clinical study and treatments prescribed and administered by a patient’s doctor as part of standard medical practice.
- **Outline of the survey:** The survey consists of five parts. In the first section, consisting of 15 questions, information is requested that will provide general information about the people who are completing the survey, and about their general health. Most of these questions are not related directly to immune disease, but will help us understand health issues that may indirectly affect immune disease.

In the second section of the survey, consisting of 13 questions, we ask questions about your health and the standard medical health care you received for your immune condition or disease. In this section, we are particularly interested in the condition or disease that prompted you to seek helminth therapy.

In the third section, consisting of 30 questions, we ask about your experience with self-treatment using helminths.

The fourth section is optional and gives you an opportunity to comment on any aspects of your medical condition or on your self-treatment with helminths that you feel might be important.

The fifth section is designed for people providing updates after their initial survey and is not intended for people completing the survey for the first time.

The first three sections of the survey are very brief, taking about 20 minutes to complete. The time needed to complete the fourth, optional, section depends on what information you choose to provide.

Costs: Individuals are responsible for printing and mailing the survey.

Risks and benefits of the study: There may be a small risk of anxiety that may happen when completing the survey and reviewing issues that previously caused distress. However, some benefit is also possible, since the survey might provide a level of satisfaction in the knowledge that his or her experiences with helminth therapy might benefit others.

Withdrawal from the study: Because we will have no way to determine which survey belongs to a particular individual, once you send us the survey by mail, there is no way to for us to withdraw your survey from the study.

Contact for questions: The principal investigator on this study is William Parker, an Associate Professor at Duke University Medical Center. He may be contacted by E-mail with any questions or concerns about the survey. The E-mail address is William.Parker@Duke.edu.

Procedures: The survey consists of a single PDF file. It is available by E-mail through Professor Parker (William.Parker@Duke.edu) or it may be obtained from other individuals who have already received it from Professor Parker or from others. Any participant who requires assistance in completing the survey is encouraged to obtain such assistance from any individual they designate.

Please follow the following instructions.

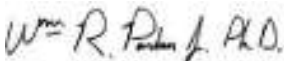
If you have questions about the survey, please contact Dr. Parker by E-mail (William.Parker@Duke.edu).

- Print out the survey and complete the survey. Please do NOT include any information such as your name, your address, specific dates, places or names of hospitals or doctors that could be used to identify you personally.
- Mail the survey, without a return address label, to the following address:

William Parker
Department of Surgery
Duke University Medical Center
DUMC Box 2605
Durham, NC 27710

Thank you very much for your participation in this survey.

Sincerely,



William Parker, PhD

Section 1: General information

1.1. Height _____ feet, _____ inches **OR** _____ cm

1.2. Weight _____ pounds **OR** _____ kilograms

1.3. Number of children _____ Age of children (years) _____

1.4. Ethnic background (please circle one)

Asian Black Hispanic White Mixed Other

If mixed or other, please specify _____

1.5. Date that survey was completed _____

1.6. Age (in years only) at the time survey was completed

1.7. Gender (please check appropriate box): Male Female

1.8. Highest level of education (If applicable, please provide degree and subject. For example, B.A. in Sociology) If you have medical education or training, please specify your specialty. _____

1.9. Current occupation

1.10. Employment status (please check all appropriate boxes)

employed full time earning wages student

employed full time in family care (e.g., homemaker) retired

unemployed due to disability

unemployed due to layoff or other difficulty in finding employment

other (please explain) _____

1.11. Have you previously filled out this survey and mailed it to William Parker at Duke?

Yes No If yes, please skip to question 5.1 and provide any updates you would like to provide. Please note that at least one year should elapse between updates.

Section 2: Immune disorders and treatment BEFORE helminth therapy

Please limit your answers to all questions in this section only to your experience with the condition or conditions that prompted you to self-treat with helminths, and with medical treatment you received for that condition or conditions. **The next section (Section 3) will deal with your self-treatment with helminths. This section (Section 2) only deals with the conditions that prompted you to self-treat with helminths. Please do not include any information such as your name, your address, specific dates, places or names of hospitals or doctors that could be used to identify you personally.**

2.1. At what age did you first experience symptoms that were immune-related? (Please provide a single number that represents your best estimate, in years.) ___

2.2. Did you discuss your immune-related symptoms with at least one medical doctor prior to considering helminth therapy?

(please check appropriate box) Yes No (If no, please skip to question 2.8.)

2.3. Approximately how many doctors did you see for your immune condition **BEFORE** your self-treatment with helminths? (Please provide a single number that represents your best estimate.) _____

If possible, can you provide the specialties of your doctors? Please do not include the doctor's names. (Examples of specialties include Allergy and Immunology, Family Medicine, Dermatology, Emergency Medicine, and Internal Medicine.)

Reminder: all questions in this section pertain **only to your experience with the condition or conditions that prompted you to self-treat with helminths, and with medical treatment you received for that condition or conditions BEFORE you self-treated with helminths.**

2.4. In your opinion, how was your condition diagnosed by your physician? (please check the appropriate box)

U Adequately: at least one doctor understood the symptoms and was able to identify the disease

U Not at all: no doctor was able to provide an accurate or meaningful diagnosis which explained the symptoms.

U In part, but not entirely: at least one doctor could explain some aspects of the symptoms, but others were unexplained by the diagnosis.

U Other: please explain. _____

2.5. Please rate your **overall level of frustration** with the standard medical establishment (professional medical personnel and prescribed medical treatments) before you self-treated with helminths. Use a scale of 0 to 10, with 0 being absolutely no frustration, and 10 being the most profound and emotionally draining frustration imaginable. (Please circle one)

no frustration 0 1 2 3 4 5 6 7 8 9 10 most frustration

2.6. Please rate your **overall experience** with the medical establishment before you self-treated with helminths. This rating should reflect a general average of all experiences involved in your immune-related condition or conditions, not the best or the worst experience. Use a scale of 0 to 10, with 0 being a wonderful and positive experience, and 10 being the most negative experience imaginable (and 5 being a neutral experience). (Please circle one)

wonderful 0 1 2 3 4 5 6 7 8 9 10 horrible

2.7. Please rate any **regret** you may have regarding your experience with standard medical practice prior to receiving helminths. Use a scale of 0 to 10, with 0 being the most regret imaginable, and 10 being absolutely no regret. (Please circle one)

most regret 0 1 2 3 4 5 6 7 8 9 10 no regret

2.8. Please rate the impact of your immune-related condition or conditions on your life before you self-treated with helminths. Use a scale of 0 to 10, with 0 being absolutely no effect, and 10 being the most profound negative effect, with a complete loss of everything meaningful to you in life. (Please circle one)

no effect 0 1 2 3 4 5 6 7 8 9 10 horrible effect

2.9. Diagnosis: Please indicate the diagnosis you were given (the disease or condition that was identified) by a medical doctor or that you self-identified prior to self-treating with helminths. Please indicate whether the diagnosis was a self diagnosis or if it was made by a medical professional. If there was disagreement between doctors or between you and doctors, please indicate. If no diagnosis was ever made, please indicate that.

2.10. Did you receive medical treatment of any kind for the immune related symptoms prior to your treatment with helminths?

(please check appropriate box) Yes No (If no, please skip ahead to question 3.1.)

2.11. Please rate the **effectiveness** of the standard medical treatments you received prior to receiving helminth therapy. This rating should reflect the best result you were able to obtain. For example, if the first two treatments were completely unsuccessful, and a third treatment was partially successful, please rate the third treatment. Use a scale of 0 to 10, with 0 being completely ineffective and the symptoms remained unchanged (or even worsened), 5 being that the symptoms were decreased by about half, and 10 being a complete cure. (Please circle one)

ineffective 0 1 2 3 4 5 6 7 8 9 10 effective

2.12. Please rate the **side effects** of the standard medical treatments you received prior to receiving helminth therapy. This rating should reflect a general average of the side effects of all treatments, not the best or the worst treatment. Use a scale of 0 to 10, with 0 being absolutely no side effects, and 10 being the most debilitating or damaging (either psychologically or physically) side effects imaginable short of death. (Please circle one)

no side effects 0 1 2 3 4 5 6 7 8 9 10 horrible side effects

2.13. What items listed below limited your satisfaction with standard medical treatment before you self-treated with helminths? Please rank EACH item listed below, with 1 being not at all important, and 5 being a very important factor that decreased your satisfaction with your medical treatment to a very large degree. Please circle the appropriate number beside each item listed below. This is not a question regarding which factor has more impact than another. All items or none of the items listed may have a strong impact on your satisfaction with your medical treatment:

	Not important				Very important
	1	2	3	4	5
Negative side effects:					
Negative experience with professional medical personnel:					
Limited effectiveness (does not effectively cure disease):					
Temporary effectiveness only (disease returned):					
High financial burden (high costs):					
Other (please identify) _____					
Other (please identify) _____					

Section 3: Self-treatment with helminths

REMINDER: Please do not include any information such as your name, your address, specific dates, places or names of hospitals or doctors that could be used to identify you personally.

3.1. How did you **first** learn about helminth therapy? (please check appropriate

box) From a friend or acquaintance

From a scientific article

From a book (please specify _____)

From a news article in a paper, a website, or on the radio

From a website (please specify _____)

From a social network group interested in my condition/disease

Other: please identify. _____

3.2. What sources of information or knowledge about helminths influenced your decision to self-treat with helminth therapy? Please rank EACH item below, with 1 being not an important source of information, and 5 being a very important source of information (one that heavily influenced your decision making process). Please circle the appropriate number beside each source of information. This is not a question regarding which source of information was more important than another. All or none of the sources of information listed may have been very important to you:

	Not important				Very important
	1	2	3	4	5
Experience of friends:	1	2	3	4	5
Information from websites about helminth therapy:	1	2	3	4	5
Experience from others:	1	2	3	4	5
Interactions with those providing helminths:	1	2	3	4	5
Scientific articles:	1	2	3	4	5
Other (please identify) _____	1	2	3	4	5
Other (please identify) _____	1	2	3	4	5

3.3. What initially led you to decide to treat yourself with helminth therapy? Please rank EACH item, with 1 being not at all important, and 5 being very important (this influenced your initial decision to try helminth therapy to a very large degree). Please circle the appropriate number beside each item. This is not a question regarding which item has more impact than another. All items or none of the items listed may have a strong impact on your decision to treat with helminth therapy:

	Not important				Very important
Desperation after standard medical approaches failed:	1	2	3	4	5
Fear of the side effects of standard medical approaches:	1	2	3	4	5
Curiosity:	1	2	3	4	5
To evaluate the potential for helminths to help others:	1	2	3	4	5
Evidence indicated that helminths are effective:	1	2	3	4	5
Financial costs were within budget:	1	2	3	4	5
In support of a friend:	1	2	3	4	5
Other (please identify) _____	1	2	3	4	5
Other (please identify) _____	1	2	3	4	5

3.4. Do you have concerns regarding “legal issues” about your self-treatment with helminths? Concerns about legal issues include the idea that you or the company that supplies your helminths will encounter trouble or problems with legal authorities, including local law enforcement or government agencies.

(please check appropriate box) Yes No

Optional: If you have such concerns, can you specify the nature of your concern?

3.5. Please rate the degree of concern you had regarding legal issues associated with helminth therapy **BEFORE** you obtained your first helminths. Please use a scale of 0 to 10, with 0 being absolutely no concern, and 10 being great concern that almost prevented you from obtaining helminths. .

(Please circle one)

no concern 0 1 2 3 4 5 6 7 8 9 10 great concern

3.6. Please rate the degree of concern you have regarding legal issues associated with helminth therapy **AT THE PRESENT TIME**, after your experience with helminth therapy. Please use a scale of 0 to 10, with 0 being absolutely no concern, and 10 being great concern that almost prevents you from continuing your helminth therapy. (Please circle one)

no concern 0 1 2 3 4 5 6 7 8 9 10 great concern

3.7. Please rate the degree of concern you had regarding your supply of helminths **BEFORE** you obtained your first helminths. Concerns might include but are not limited to contamination of your helminths with dangerous organisms, the wrong species of helminth, or simply being a victim of a scam. Please use a scale of 0 to 10, with 0 being absolutely no concern, and 10 being great concern that almost prevented you from obtaining helminths. (Please circle one)

no concern 0 1 2 3 4 5 6 7 8 9 10 great concern

3.8. Please rate the degree of concern you have regarding your supply of helminths **AT THE PRESENT TIME**, after your experience with helminth therapy. Concerns might include but are not limited to contamination of your helminths with dangerous organisms, the wrong species of helminth, or simply being a victim of a scam. Please use a scale of 0 to 10, with 0 being absolutely no concern, and 10 being great concern that almost prevents you from continuing your helminth therapy. (Please circle one)

no concern 0 1 2 3 4 5 6 7 8 9 10 great concern

3.9. Please let us know how you felt about the available supply of helminths **BEFORE** you obtained your first helminths. Please rank EACH statement, with 1 being strongly disagree, 3 being neutral, and 5 being strongly agree. Please circle the appropriate number beside each statement.

	strongly disagree	2	neutral	4	strongly agree
The supplier was highly reliable:	1	2	3	4	5
The treatment was very safe:	1	2	3	4	5
There is no danger of legal ramifications:	1	2	3	4	5
I was confident that the helminths would help me:	1	2	3	4	5

3.10. Please let us know how you feel about the available supply of helminths **AT THE PRESENT TIME**, after your experience with helminth therapy. Please rank EACH statement, with 1 being strongly disagree, 3 being neutral, and 5 being strongly agree. Please circle the appropriate number beside each statement.

	strongly disagree	2	neutral	4	strongly agree
The supplier is/was highly reliable:	1	2	3	4	5
The treatment is/was very safe:	1	2	3	4	5
There is no danger of legal ramifications:	1	2	3	4	5
I am confident that the helminths will continue to help me:	1	2	3	4	5
I am confident that the helminths do/did NOT help me:	1	2	3	4	5

3.11. Where did you initially get your helminths from? (please check appropriate box or boxes)

- From a friend
- From a vendor of helminth therapy (a company that sells helminths for human use)
- Acquisition by natural means in an area where the helminth is endemic
- Raising or farming helminths using other species as hosts (farming them outside of my body)
- Other: please explain but provide no information regarding a specific person or company.

3.12. Have you ever used sources of helminths other than your initial source?

(please check appropriate box) Yes No

If yes, where did you get those from? (Please check all appropriate boxes.)

- From a friend
- From a vendor of helminth therapy (a company that sells helminths for human use)
- Acquisition by natural means in an area where the helminth is endemic
- By self inoculation using my own helminths as a source
- Raising or farming helminths using other species as hosts (farming them outside of my body)
- Other: please explain but provide no information regarding a specific person or company.

3.13. Please identify all of the helminths you currently use or have ever used in the past for your self-treatment.

(Please check all appropriate boxes.)

- Human hookworm
- Human whipworm
- Rat tapeworm
- Bovine tapeworm
- Other (please identify)

3.14. Please identify **only those helminths that you currently use** for your self-treatment. (Please check all appropriate boxes.)

- I currently use no helminths
- Human hookworm
- Human whipworm
- Rat tapeworm
- Bovine tapeworm
- Other (please identify)_

3.15. Please rate the **effectiveness** of your self-treatment with helminth therapy. This rating should reflect the method that gives you the best and most reliable results. For example, if the first two attempts at helminth therapy were completely unsuccessful, and a third attempt was partially successful, please rate the third attempt. Use a scale of 0 to 10, with 0 being completely ineffective and the symptoms remained unchanged (or even worsened), 5 being that the symptoms were decreased in severity or in duration by about half, and 10 being a complete cure. (Please circle one)

ineffective 0 1 2 3 4 5 6 7 8 9 10 effective

3.16. Please rate the **side effects** of your self-treatment with helminth therapy. This rating should reflect a general average of the side effects of all treatments, not the best or the worst treatment. Use a scale of 0 to 10, with 0 being absolutely no side effects, and 10 being the most debilitating or damaging (either psychologically or physically) side effects imaginable short of death. (Please circle one)

no side effects 0 1 2 3 4 5 6 7 8 9 10 horrible side effects

3.17. Please rate your **overall level of frustration** with your self-treatment with helminth therapy. Use a scale of 0 to 10, with 0 being absolutely no frustration, and 10 being the most profound and emotionally draining frustration imaginable.

(Please circle one)

no frustration 0 1 2 3 4 5 6 7 8 9 10 most frustration

3.18. Please rate the impact of your immune-related condition or conditions on your life after your self-treatment with helminth therapy. Use a scale of 0 to 10, with 0 being absolutely no effect, and 10 being the most profound negative effect, with a complete loss of everything meaningful to you in life. (Please circle one)

no effect 0 1 2 3 4 5 6 7 8 9 10 horrible effect

3.19. Please rate your overall experience with the individuals who provided you with helminths for therapy or helped you gain access to helminths. This rating should reflect a general average of all experiences involved in your helminth therapy, not the best or the worst experience. Use a scale of 0 to 10, with 0 being a wonderful and positive experience, and 10 being the most negative experience imaginable. (Please circle one)

wonderful 0 1 2 3 4 5 6 7 8 9 10 horrible

3.20. Please rate any **regret** you may have regarding your self-treatment with helminths. Use a scale of 0 to 10, with 0 being the most regret imaginable, and 10 being absolutely no regret. (Please circle one)

most regret 0 1 2 3 4 5 6 7 8 9 10 no regret

3.24. Please rate the difficulty you had in initially obtaining helminths. Use a scale of 0 to 10, with 0 being very easy, and 10 being extremely difficult. (Please circle one)

very easy 0 1 2 3 4 5 6 7 8 9 10 extremely difficult

3.25. Please rate the difficulty in maintaining your helminths (or exposure to your helminths) at an effective level, if applicable. Use a scale of 0 to 10, with 0 being very easy, and 10 being extremely difficult. (Please circle one)

very easy 0 1 2 3 4 5 6 7 8 9 10 extremely difficult

3.26. Have you, at any point, unintentionally lost your helminths or the effectiveness of your helminths?

(please check appropriate box) Yes No

If yes, can you identify any particular reason or potential cause? For example, did the life span of the organism run out, or was some particular drug administered or food ingested which you feel may have damaged or killed your helminths? _____

3.27. Please rate the level of your support or enthusiasm for efforts to make reliable, safe and effective helminth therapy part of the services offered by your local health care provider. Use a scale of 0 to 10, with 0 being very negative and unsupportive, 5 being neutral, and 10 being extremely enthusiastic. (Please circle one)

opposed 0 1 2 3 4 5 6 7 8 9 10 very supportive

3.28. Which of the following statements reflects your opinion of helminth therapy? (Please check all appropriate boxes that apply.)

Helminth therapy will continue to develop and improve as new information becomes available.

Helminth therapy will eventually be replaced by drugs that are based on molecules produced by helminths.

Helminth therapy will remain an alternative to modern medicine, and will never be a main-stream treatment.

Helminth therapy will eventually become standard medical practice.

None of the above reflect my opinion about helminth therapy.

3.29. What items below limit your satisfaction with your self-treatment using helminth therapy? Please rank EACH item listed below, with 1 being not at all a factor, and 5 being a very important factor that decreases your satisfaction with helminth therapy to a very large degree. Please circle the appropriate number beside each factor. This is not a question regarding which factor has more impact than another. All items or none of the items listed may have a strong impact on your satisfaction with helminth therapy:

	Not important		very important		
	1	2	3	4	5
Difficulty in maintaining the helminths at effective levels:	1	2	3	4	5
Disgust or “ick factor”:	1	2	3	4	5
Negative side effects:	1	2	3	4	5
Concerns about legal issues:	1	2	3	4	5
Fear of overdosing yourself:	1	2	3	4	5
Negative experience with those assisting in helminth therapy:	1	2	3	4	5
Limited efficacy (does not effectively cure disease):	1	2	3	4	5
Unreliable (variable results, some days better than others)	1	2	3	4	5
High financial burden (high costs):	1	2	3	4	5
Other (please identify) _____	1	2	3	4	5
Other (please identify) _____	1	2	3	4	5

3.30. How has your opinion of helminth therapy changed since you first decided to self-treat with helminths. (Please check appropriate box.)

- my opinion has remained the same
- my opinion has improved (I have a **more** favorable opinion of helminth therapy now than I had initially.)
- my opinion has declined (I have a **less** favorable opinion of helminth therapy now than I had initially.)

4.6. Please provide a brief medical history that **DOES NOT include any of the immunological problems that prompted you to self-treat with helminths.** For example, if you were born prematurely, had a broken bone with an infection at the age of 14, had appendicitis at the age of 18, and then self-treated with helminths at the age of 45 in an effort to treat MS, please include here the premature birth, the appendicitis, the broken bone and the infection, but not the MS. Only a brief history is necessary, and “routine” diseases (e.g., chickenpox as a child, the flu) are not necessary to document. However, we would like some information about your use of antibiotics, if any. (Please feel free to use a separate sheet if more space is needed, and to type your answers if you prefer.)

4.7. Please provide a brief medical history of **your immediate family, including parents, siblings, biological (genetically related) children, and, if known, the other biological parent or parents of your children. Please do include any immune-related diseases as well as all potentially life-threatening illnesses.** Only a brief history is necessary, and “routine” diseases (e.g., chickenpox as a child, the common cold) are not necessary to document. In this section, please do not mention your name or the names of any family members. Identification of the family relation to you (for example, daughter or mother or son’s mother) is sufficient. (Please feel free to use a separate sheet if more space is needed, and to type your answers if you prefer.)

After the survey is complete, please mail the survey, without a return address label, to the following address:

William Parker
Department of Surgery
Duke University Medical Center
DUMC Box 2605
Durham, NC 27710

There is no need to mail in pages of the survey that you did not complete. For example, there is no need to mail in the optional section (Section 4) unless that portion of the form was completed.

Section 5: Update (ONLY for those individuals who have previously filled out this survey and mailed it to William Parker at Duke)

Reminder: Please note that at least one year should elapse between the original survey and the first update, and at least one year should elapse between updates.

REMINDER: Please do not include any information such as your name, your address, specific dates, places or names of hospitals or doctors that could be used to identify you personally.

5.1 How long has it been since you sent in the original survey? (in years)

5.2. How many updates have you submitted since your first survey? (Please check the appropriate box):

U 0 (never, this is my first update)

U 3

U 1

U 4

U 2

U other (please give number _____)

5.3 How long have you been self-treating with helminths? (in years)

5.4. Please include any information you think we might find helpful in this update. This may include any new observations you have made regarding the effects (either good or bad) of helminths, new ways to obtain helminths, or new approaches to treatment with helminths. If you have no new observations, please indicate the current state of your self-treatment with helminths. (For example, "My dose of 20 human hookworms every 6 months continues to control my multiple sclerosis symptoms.")

Please feel free to use a separate sheet if more space is needed, and to type your answers if you prefer.

After the survey is complete, please mail the survey, without a return address label, to the following address:

William Parker
Department of Surgery
Duke University Medical Center
DUMC Box 2605
Durham, NC 27710

There is no need to mail in pages of the survey that you did not complete. For example, people filling out the update section do not need to mail in Sections 2 and 3, and there is no need to mail in the optional section (Section 4) unless that portion of the form was completed.