

PARENTAL CONSENT FORM

TITLE: A Multiple Sclerosis Patient-Powered Research Network,
iConquerMS™

PROTOCOL NO.: ACP-MS-PPRN-001
WCG IRB Protocol # 420140400

SPONSOR: Accelerated Cure Project for Multiple Sclerosis

INVESTIGATOR: Robert McBurney PhD
Accelerated Cure Project
460 Totten Pond Rd, # 420
Waltham, MA 02451

STUDY-RELATED

PHONE NUMBER(S): **Daytime Telephone Number(s):** 844-897-1211
 24-hour Contact Number(s): 844-897-1211

Taking part in this research is voluntary. You may decide not to participate, or you may leave the study at any time. Your decision will not result in any penalty or loss of benefits to which you are otherwise entitled.

If you have any questions, concerns, or complaints or think this research has hurt you, talk to the research team at the phone number(s) listed in this document.

RESEARCH CONSENT SUMMARY

You are being asked for your consent for your minor child to take part in a research study. This document provides a concise summary of this research. It describes the key information that we believe most people need to decide whether to consent to allow their child take part in this research. Later sections of this document will provide all relevant details.

What should I know about this research?

- Someone will explain this research to you.
- Taking part in this research is voluntary. Whether you allow your child to take part is up to you.
- If you don't allow your child to take part, it won't be held against you or them.
- You can allow your child to take part now and later request they drop out, and it won't be held against you or them.
- If you don't understand, ask questions.
- Ask all the questions you want before you decide.

How long will my child be in this research?

We expect that your child will take part in this research until they reach the age of majority.

Why is this research being done?

The purpose of this research is to enroll children and teens with pediatric multiple sclerosis (MS) into a multiple sclerosis people-powered research network (MS-PPRN), iConquerMS, to enable them to contribute their health and other data. Survey data will be made available to research scientists who are studying pediatric MS and similar diseases. Our goal is to use this data to answer questions that researchers, those with pediatric onset MS, and their family members have regarding the disease, including its causes, treatments, and other topics.

What happens to my child if I agree to let them take part in this research?

If you decide to allow your child to take part in this research study, the general procedures include allowing them access to a registered-member section of iConquerMS, with a username and password to keep their account private. They will be asked to provide information about their health and experiences of living with MS by completing online surveys, optionally providing their electronic health records, and optionally participating in activities (like focus groups) to share their experiences with researchers.

Could being in this research hurt my child?

The most important risks or discomforts that you may expect from your child taking part in this research include feeling uncomfortable upon reviewing some of the survey questions and a potential risk of loss of confidentiality.

Will being in this research benefit my child?

It is not expected that your child will personally benefit from this research.

Possible benefits to others include that the information your child provides may help current and future generations better understand pediatric onset MS and other diseases.

What other choices do I have besides allowing my child to take part in this research?

The only alternative is to not allow your child to participate in this research.

DETAILED RESEARCH CONSENT

You are being invited to consent for your minor child take part in a research study. A person who takes part in a research study is called a research subject, or research participant.

In this consent form “you” generally refers to the research subject. If you are being asked as the parent or guardian to permit the subject to take part in the research, “you” in the rest of this form generally means the research subject.

What should I know about this research?

- Someone will explain this research to you.
- This form sums up that explanation.
- Taking part in this research is voluntary. Whether you take part is up to you.

- You can choose not to take part. There will be no penalty or loss of benefits to which you are otherwise entitled.
- You can agree to take part and later change your mind. There will be no penalty or loss of benefits to which you are otherwise entitled.
- If you don't understand, ask questions.
- Ask all the questions you want before you decide.

Why is this research being done?

The purpose of this research is to enroll children and teens with pediatric multiple sclerosis (MS) into a multiple sclerosis people-powered research network (MS-PPRN), iConquerMS, to enable them to contribute their health and other data. Survey data will be made available to research scientists who are studying pediatric MS and similar diseases. Our goal is to use this data to answer questions that researchers, those with pediatric onset MS, and their family members have regarding the disease, including its causes, treatments, and other topics.

While the MS-PPRN is focused on enrolling people with MS, people without MS are also welcome to participate in this research study.

This study will be conducted online via the iConquerMS.org website. This is an ongoing study and will last for an indefinite period of time.

About 20,000 subjects will take part in this research.

How long will I be in this research?

We expect that your taking part in this research will last until you reach the age of majority at which point you may consent to join the adult version of iConquerMS.

What happens to me if I agree to take part in this research?

If you consent to take part in the study, we give you access to the registered-member section of the iConquerMS website. You create your username and password to keep your account private. Through iConquerMS, we give you access to a series of online surveys. Each survey focuses on a specific topic, such as medical history, diet and exercise, and other areas of health and well-being. We repeat some questions over time to track changes. We will add new surveys in the future. The answers you provide are your "research data."

The iConquerMS website also has the capability to allow you to optionally submit your electronic medical records as part of the information you are providing. Data obtained from your electronic medical records will also become your "research data."

In iConquerMS, you may also elect to provide input on ideas for MS research, post comments in a web-based forum with other participants, or monitor your own health history in comparison to the aggregate iConquerMS membership. Data obtained through these activities will also become your "research data."

ACP provides the information you and others enter to investigators conducting research on MS and other diseases. Researchers who want access to this information will be asked to submit a written request. Before providing the data to researchers, a Pediatric Steering Committee reviews the request. We assess requests based on many factors, including the scientific merit of the research, the ability of the researcher to increase the knowledge of pediatric MS and similar diseases, and its adherence to this consent. Before releasing data, we remove information that identifies you directly.

We may contact you periodically to complete additional surveys, to update your contact information, or for other reasons associated with the research study.

What are my responsibilities if I take part in this research?

If you take part in this research, you will be responsible to:

- Complete questionnaires on the iConquerMS website
- Let us know if your contact information changes

Could being in this research hurt me?

You may not feel comfortable answering some of the survey questions. You may decide to not complete a survey if it contains questions that you do not wish to answer.

There is a risk of loss of confidentiality in research studies. Reasonable efforts will be made to protect you and your health information to the extent possible. Absolute confidentiality cannot be guaranteed. Your identity may become known in conjunction with your medical or research data. ACP and the company developing the iConquerMS website and computer systems will take reasonable technical precautions to keep your data secure.

The iConquerMS.org website will allow for participants to communicate with each other through forum functionality. Information you choose to share about yourself in this optional forum might enable another participant to identify you. Information shared by other participants in the forum may make you uncomfortable.

Will it cost me money to take part in this research?

There will be no costs associated with your participation in this research.

Will being in this research benefit me?

You will not likely receive direct benefits in this study, but the information you provide may help current and future generations better understand MS and other diseases.

What other choices do I have besides taking part in this research?

This research is not designed to diagnose, treat or prevent any disease. Your alternative is to not take part in the research.

What happens to the information collected for this research?

Your private information and your medical record will be shared with individuals and organizations that conduct or watch over this research, including:

- The research Sponsor, Accelerated Cure Project, and its research collaborators.
- People who work with the research Sponsor including clinical advisors and researchers.
- Government agencies, such as the Food and Drug Administration.
- WCG IRB, the Institutional Review Board (IRB) that reviewed this research.

We may publish the results of this research. However, we will keep your name and other identifying information confidential.

We protect your information from disclosure to others to the extent required by law. We cannot promise complete secrecy.

Who can answer my questions about this research?

If you have questions, concerns, or complaints, or think this research has hurt you or made you sick, talk to the research team at the phone number listed above on the first page.

This research is being overseen by WCG IRB. An IRB is a group of people who perform independent review of research studies. You may talk to them at 855-818-2289 or researchquestions@wcgirb.com if:

- You have questions, concerns, or complaints that are not being answered by the research team.
- You are not getting answers from the research team.
- You cannot reach the research team.
- You want to talk to someone else about the research.
- You have questions about your rights as a research subject.

Can I be removed from this research without my approval?

The person in charge of this research can remove you from this research without your approval. Possible reasons for removal include:

- It is in your best interest
- The research is cancelled by the Sponsor
- You are unable to respond to the online questionnaires

We will tell you about any new information that may affect your health, welfare, or choice to stay in this research.

What happens if I agree to be in this research, but I change my mind later?

To withdraw from participation, you must access your iConquerMS account online and follow the instructions for withdrawal. Withdrawing from the study means that you will no longer

receive correspondence about this study and will no longer be asked to complete surveys. Any data you had submitted prior to withdrawal will be kept by ACP, but will no longer be distributed to researchers. Any data that had previously been shared for research purposes cannot be retrieved from the researcher.

If you have any questions or concerns related to withdrawal from the study, please contact the investigator for this study at 844-897-1211.

Will I be paid for taking part in this research?

You will not be paid for taking part in this research.

Statement of Consent:

- All children are required to assent.
- For children younger than 7 years old, the parent/guardian documents assent on the parental consent form.
- For children 7 years of age and older, the child will document assent on a separate form.

Checking the box below documents your permission for you or your minor child to take part in this research. For children younger than 7 years old, checking the box also documents their assent.

I consent for my child to take part in this research study.