NEMOURS

Parental Permission and Informed Consent for Participation in the Asthma Research Study
(revision date 10/08/2013)

Title of Study:
Use of Mobile Devices and the Internet to Streamline an Asthma Clinical Trial

I am making a decision whether or not to consent to participate and to permit my child to participate in this study. I understand that my child may also have to agree to participate in the study before he/she will be allowed to be in this study. I have watched the Asthma Research Study video and reviewed the other information on the website. I have been given enough time to make this decision. I have asked questions and received answers about things I did not understand. I willingly consent to participate and give permission for my child to participate in this study. By electronically signing this form, I am not giving up any rights to which I am entitled under law.

I understand that:

• I can withdraw permission for participation in this study and for the use and/or disclosure of (Protected Health Information) PHI by contacting the persons in charge of the study.
• The use and/or disclosure of my/ my child’s PHI will stop after Nemours receives the withdrawal notice. Information that is used or disclosed before the withdrawal may still be used.
• Unless I withdraw permission, the use and/or disclosure of PHI, that is described in the section of the Video called “Protecting your Privacy” and the sidebar material, will not have an expiration date.
• My/ my child’s PHI may be disclosed again by the person or organization (other than Nemours) that receives it. If this happens, Federal or state law may not protect the information.
• I have the right to refuse to sign this permission form.
• If I refuse to sign this permission form, I/my child will not be allowed to be in this research study.
• I have the right to ask Nemours to tell me who has received my/ my child’s protected health information.
• I have the right to revoke my permission for the use and disclosure of my/ my child’s health information at any time, which would end my/ my child’s participation in this study.
• I can download or print an electronically signed and dated copy of this form for my records from my child’s MyNemours account.

My electronic signature indicates that:

• I give the researchers and Nemours permission to use and/or disclose my/ my child’s individually identifiable health information, for this research study, as described in the section of the Video called “Protecting your Privacy” and the sidebar material.
• As his or her parent or guardian, I give my permission for the minor child named below to participate and give consent for my participation in the research study described in the Asthma Research Study video and the other information on the website.
What is the first name of the minor child (the participant) who will be in this study?

Please type your child’s first name in the box:

What is the last name of the minor child (the participant) who will be in this study?

Please type your child’s last name in the box:

Please enter your child’s birth date
for example, for May 3, 2000, please type 5/3/2000:

What is your relationship to the participant?
Guardians must have documented authority to give permission for participation in a research study according to the laws of the State in which the treatment occurs.

- I am the parent of the participant.
- I am the legal guardian of the participant.

What is your decision about participating in this study and having your child participate in this study called “Use of Mobile Devices and the Internet to Streamline an Asthma Clinical Trial”?
Hold your cursor over the answer to read the entire sentence.

- Yes, I agree to participate and I give permission for my child to participate in this study.
- No, I do NOT agree to participate and I do NOT give permission for my child to participate in this study. I understand by checking this box, my child will NOT be able to participate in this study.

What is your decision about having your and your child’s conversation with the study staff audio recorded and downloaded and stored for later analysis at Visit 1 and Visit 6?
Hold your cursor over the answer to read the entire sentence.

- Yes, I agree to have my and my child’s conversations with the study staff audio recorded at Visit 1 and Visit 6.
- No, I do NOT agree to have my and my child’s conversations with the study staff audio recorded at Visit 1 and Visit 6. By checking this box, my child will NOT be able to participate in this study.
What is your decision about sharing your child’s lung function test (spirometry) results with your child’s primary asthma care doctor?

- Yes, please send my child’s results to the doctor.
- No, do NOT send my child’s results to the doctor.

What is your decision about collection and storage of your child’s blood for DNA and possible future genetic analysis?

Hold your cursor over the answer to read the entire sentence.

- Yes, I agree to allow my child to provide blood for DNA for use in this study and to be stored for possible future genetic analysis.
- No, I do NOT agree to allow my child to provide blood for DNA for use in this study and to be stored for possible future genetic analysis.

Please type your first name in this box: 
This is your electronic signature.

Please type your last name in this box:

You may print a copy of this document with your choices after submitting it by going to your Sent Messages in MyNemours. Once it is submitted a copy will be entered into your child’s Nemours medical record. A copy of this document can be found in your MyNemours Sent Messages unless it is deleted. A copy can also be obtained from your child’s medical record at Nemours.