





Approved by the Nemours IRB  
Valid From: July 31, 2019  
to January 2, 2020  
[456569]

- 0 copy of informed consent with original signature
- 0 copy of medical release form with original signature
- & medical records and medical images ;x)ray and/or & ! I=

'y agreeing to be in the registry, you allow study team members to review your child's medical records and collect information about their condition.

19. W ! " ! R# POSSI2\$# RIS : S O% 2#IN , IN " IS S"& ' ( )

The risks involved in this study are the same as the risks your child would ordinarily encounter in daily life or during a routine physical examination. This research is observational which means that there is no change to any treatment that your child may be receiving. The possible risks are described below.

The most common risk of participation in a registry is the chance that your child's private information ;ex? status of health, treatments prescribed= may be used for purposes other than those described in this permission form. A loss of privacy may affect your child's insurability, employability or may result in labeling



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2emours expects these companies and organization to protect the privacy and confidentiality of research participants, but it is not possible for 2emours researchers to assure that this happens.

\*overnment agencies that may look at records for this research study, including the above health information, include?

- The K.3. Bood and ( rug \$dministration
- The K.3. ( epartment of %ealth and %uman 3ervices
- 9ther agencies of 3tate and local government as required by law

The research results may be presented at scientific meetings or in print. Participants' identities will not be disclosed in these presentations.

16. SIGNATURE

I am making a decision whether or not 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 read this form, or have had it read to me in a language that I understand. 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 give permission for my child to participate in this study. My signing this form, I am not giving up

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+hec> Relation to Participant? #arent Aegally \$uthorized !epresentative

;Aegally \$uthorized !epresentatives must have documented authority to give permission for a child's



OPTIONAL: We may need to contact you in the future by phone, mail or email to request additional information, ask about any new medical problems, or ask you to complete questionnaires about your child's health and daily activities. Please indicate whether or not you would want to be recontacted by checking the box below?

- Yes, I do wish to be recontacted.
- No, I do not wish to be recontacted.

If you permit researchers to contact you again, please give your current contact information in the space below. Please notify the study coordinator, Dr. Assonora, if your contact information changes.

Address: \_\_\_\_\_

Home phone: \_\_\_\_\_, email: \_\_\_\_\_

\_\_\_\_\_