

Consent form for Case report

Case report title: First Report of Variant Late Infantile Ceroid Lipofuscinosis in Jordan

Principal Investigator: Omar Nafi, MD, Pediatric Department, Mutah University, Karak, Jordan

You are being asked to consider allowing Dr. Omar Nafi to use information about your children's clinical records and available ancillary exams to write what is called a case report.

Case reports are typically used to share new unique information experienced by a patient during his/her clinical care that may be useful for other physicians and members of a health care team. A case report may be published for others to read, and/or presented at a conference. This form explains the purpose of this case report. Please read this form carefully and take your time to make your decision and ask any questions that you may have. The purpose of this case report is to inform other physicians about the possibility of variant late infantile lipofuscinosis in children presenting with physical and neurological symptoms, as well as pointing out the importance of whole exome sequencing in making the diagnosis. Your children's information being used for this case report includes the details of their clinical condition and medical treatment. Dr. Omar Nafi is obligated to protect your privacy and not disclose any personal information (information about you, your children, and their health that can be identifying e.g. name, date of birth, medical record number). When the case report is published or presented, your identity will not be disclosed. Although your personal information collected or obtained will be kept confidential and protected to the fullest extent of the law, there is a limited risk associated with this case report that could result in a loss of confidentiality by virtue of your unique experience. You will not directly benefit from participating in this case report. The information that can be shared with other health care professionals, however, may improve the care that is received by others in the future. Allowing your information to be used in this case report will not involve any additional costs to you. You will not receive any compensation. Taking part in this case report is your choice (voluntary). You may choose not to take part or you may change your mind at any time. However, once the case report is written and published, it will not be possible for you to withdraw it. Your decision will not result in any penalty or loss of benefits to which you are entitled including the quality of care you receive. You will be told about any new information relating to this case report that may affect you. Your signature below means that you have read the above information about this Case Report and have had a chance to ask questions to help you understand how your information will be used and that you give permission to allow your information to be used in this case report.

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Name of participant/parent: [REDACTED]

By signing this form I confirm that:

- The case report has been fully explained to me and all my questions have been answered to my satisfaction
- I have been informed of the risks and benefits, if any, of allowing my/my children's information to be used in this case report
- I have been informed that I do not have to participate in this case report
- I have read each page of this form
- I authorize access to my personal health information (medical record) as explained in this form
- I have agreed to participate in this case report

[REDACTED]
Name of participant/parent

[REDACTED]
Signature

6/17/19
Date