

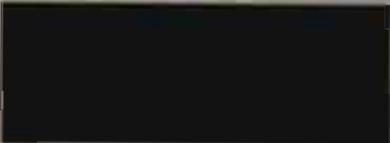
Consent and Authorization to Release Information for a Case Report

What Is This Form About?: You are being asked to allow your healthcare team to use protected health information about you in the writing of what researchers call a "case report". Case reports are typically stories that are published about one or a few patients that have a rare condition and/or an unusual response to treatment. Case reports, while shared among other providers within the same healthcare institution, are generally written to be published in print/online journals as well as presented at medical conferences. Publishing and presenting your case report is intended to help other patients and providers outside of our Institution, just as you or your providers here may have benefited from the case reports published about others. Publishing and presenting case reports also facilitates collaboration and more formal research to help patients like you. With that said, there are things you should consider prior to your allowing a case report about you to be published. Please read this consent and authorization form carefully. Take your time to make your decision and ask any questions that you may have.

Do I Have To Allow This? No. Allowing a case report to be written and published about you is voluntary on your part. Your alternative to giving consent to have a case report to be written about you is to simply to not give your consent. *Refusal to sign this consent form or withdrawing your permission later will not result in any penalty or loss of benefits to which you are entitled to. It will only stop all future progress toward publishing the case report about you.* If you do give your permission and decide to withdraw that permission later, note that while efforts to publish the case report will stop, some actions done prior to your withdrawal cannot reasonably be undone (such as if abstracts were already submitted). Also any clinically relevant information gathered that was not originally in your medical records may be placed in your medical records.

What Can You Expect? Case reports usually involve a two-step process. The first step is the research and writing of the case report itself and the second step is the publishing of the case report. You should not have any extra responsibilities as part of either step in this process other than responding to the occasional contact from those researching and writing the case report. There is nothing "experimental" about writing a case report. Also, no medical procedures will be done just because of this case report. Finally, while it is the intention to write a case report for publication, there is no guarantee that the report will be finalized, published or presented so this process may terminate without your knowledge. Finally, as the publishers usually copyright their material, you (as well as the Institution) may not have any (or limited) rights to a copy of the final publication or the ability to redistribute it without paying for it.

Are There Any Risks, Discomforts or Costs? There are generally no discomforts or risk of physical harm to you resulting from the writing and publishing of a case report. With that said, risks can be unforeseeable. Typically the only risks that case reports



have is that somebody can re-identify you when you hoped they would not. Despite privacy laws and our efforts to protect your confidentiality (such as not publishing your name or full facial photograph without your express consent), complete anonymity in today's world is difficult to achieve. Case reports often deal with a rare disease or unique situations and, therefore, a person could be re-identified by skilled or knowledgeable people even if no direct identifiers are published. Like any other information about you, *once this information is disclosed, it may further be re-disclosed and not be protected by patient privacy laws.* There are no funds set aside to compensate you if you are harmed (or re-identified) because of the writing and publishing of the case report, however you do not waive any legal rights you are entitled to if you are harmed.

You do not have to pay anything extra to have this case report written. There should also be no other costs to you as the researchers will try to gather all information during your routine visits or over the phone but if they cannot, they may contact you to make arrangements to come in person and if you choose to, you may have to bear those costs.

Are There Any Benefits To You Others? There will not likely be any immediate or direct benefit to you. The benefit of publishing case reports is that they may improve medical care received by others like you or inspire research that leads to new treatment products or protocols that may help you or others in the future. You will not be paid for the privilege of drafting this case study about you and you should not expect to receive any profit, royalties or any other compensation in connection with the case report's publication; such as from the publishing entities that charge subscription/attendance fees or from those whom it inspires to develop treatment products or services for which they charge.

Who Can I Contact If I Have Questions Or To Withdraw This Authorization? You are free to ask the person reviewing this form with you any question you like. You may have questions about (i) the process of researching, writing and publishing a case report; (ii) your rights in this process and (iii) what happens if you believe you have suffered some harm because of the case report. You may also contact the facility's privacy officer or patient advocate at any time prior to or after signing this form. *This authorization for research and publication does not automatically expire. If you change your mind after signing this form, instructions on how to revoke these kinds of authorizations to release protected health information are published in our Notice of Privacy Practices.*

Will I be contacted again in the future about further research or for other reasons? The writing of a case report in no way affects the usual contacts you receive from this Institution regarding your general healthcare here.

You may receive extra contacts during the research and writing of this case report if the researchers and authors need additional information, photographs or consents from you should the information needed not be in your records. The researchers may also contact you if they learn something that may reasonably affect your willingness to continue to have the case report about you written and published.

With that said, it is not uncommon for case reports to generate interest in future research projects. Data and biospecimens used for this case report may have identifiers removed in accordance with privacy laws to be further used or distributed to other researchers for future research studies (which may include genetic sequencing to find the genes that contribute to your condition or affect its treatment). This may be done without contacting you however you may be contacted especially if the researchers desire to use or disclose identifiable information. Note that you may not be contacted if such research leads to clinically relevant results, especially if your information and biospecimens were de-identified.

By signing this form, you are authorizing this Institution to release (i) information about you (which will contain potentially identifying information about your medical history and efforts related to your diagnoses and treatments) to other collaborators for purposes of researching and writing the case report as well as (ii) the final case report itself to organizations that publish journals, organize medical or research conferences or provide other educational content for publication purposes.

You are entitled to receive a copy of this signed form.

Print Name of Patient:

[REDACTED]

____ (Optional) Initial here if you consent that the released information to be published in the case report may contain information about alcohol use, substance use, psychiatric conditions, HIV testing, HIV results or AIDS information. I understand that certain federal substance use disorder confidentiality laws may allow me to obtain a list of entities receiving certain identifiable information protected by those laws.

____ (Optional) Initial here if you allow your name or facial photograph to be published in the text of the final case report. Note that you have the right to review the draft case report prior to submittal for publication when your name or face is in it.

Signature of Patient/Patient's Representative:

[REDACTED]

Date:

6/19/19

Print Name of Patient's Representative:

[REDACTED]

Relationship to Patient:

[REDACTED]