

## HIPAA RELEASE FORM-MEDIA

Worldwide Syringomyelia & Chiari Task Force, ("WSCTF") is always pleased when members are willing to communicate stories, experiences, and information. WSCTF respects your privacy. As a 501c3 nonprofit organization, we are working to always ensure that your medical information is protected.

WSCTF seeks your permission to use your submitted information and your consent to allow us to take and use audio/video/written/photographic material of you in WSCTF' internal and external communications, including medical and general interest publications, medical and educational information, and distribute such materials online, in print, and in news media (such as TV, radio, newspapers, and magazines). You also understand that any medical information you release or share with WSCTF for these purposes may be utilized in our own marketing, publicity, social media, and other campaigns.

To ensure that WSCTF is acting in accordance with your wishes, and using you or your child's personal information with your authorization, we ask you to fill out and sign this form. WSCTF will keep a copy of your written permission on file.

I do give my permission for WSCTF to use my or my child's name and share details of my or his/her treatment and experience, and consent to take and make use of my and my child's audio/video/photographic images in publications produced by or on behalf of WSCTF. This permission extends both to electronic versions on the WSCTF website and other internet/electronic applications as well as to printed, filmed, and taped versions.

I do give my permission for WSCTF to release my or my child's name and details of his/her medical care to the news and electronic media including, but not limited to internet/online publications, TV, radio, newspapers and/or magazines, and allow the news media to make images (digital, video, or otherwise) of me or my child for purposes of illustrating my treatment and experience as a patient.

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If I decide to sign this form, I have the right to request that audio/video recording, filming, publishing of articles, or photographing cease at any time. I am aware that my protected health information will exist forever in either a recorded, printed, and/or electronic version or other version as may develop over time and that once it is published or disclosed pursuant to this authorization may be subject to re-disclosure by the recipient and will no longer be protected by the federal regulations protecting privacy of an individual's health information under the Health Insurance Portability and Accountability Act of 1996 ("HIPAA") and other applicable federal and state laws.

I understand that I may revoke or withdraw this permission at any time to prohibit future use of my information. To do so, I must send written notice to Worldwide Syringomyelia & Chiari Task Force. You may send correspondence to:

Worldwide Syringomyelia & Chiari Task Force Attention: Authorized Media Rep Lisa Johnson RN, JD PO Box 491975 Lawrenceville, GA 30049

I understand that WSCTF, as well as other persons or entities, will retain copies of any such electronic or printed versions and shall retain these versions forever and that any revocation of this authorization will only extend to the versions of information within WSCTF' control that have not been previously published. If not revoked/withdrawn by me, this authorization expires 50 years from the date that I sign it.

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