

FOCUS ON RHABDO

Physician Information Program and HIPAA Release Form

The Many Faces of Rhabdomyosarcoma: 50 Stories

Thank you for participating in Focus On Rhabdo's educational initiative: "The Many Faces of Rhabdomyosarcoma: 50 Stories."

While Rhabdomyosarcoma is the most common soft tissue sarcoma of childhood, most physicians will never have the opportunity to see or diagnose a case. It is a disease that has the propensity to metastasize early, meaning that any delay in diagnosis could further complicate the patient's treatment and chances for long-term survival.

The aim of this project is to compile a set of patient stories into an e-book that can be distributed to pediatricians and primary care physicians around the globe, showing the many ways and locations that Rhabdomyosarcoma can present itself. It is not meant to be a primer on the disease, but rather a source of information derived from the experiences of patients and their families who have had to deal with the complications of this disease.

Since you will be revealing personal medical information, a HIPAA release form is required. Please know that no last names will be used in the publication of the material. Our aim is to use our experiences - good and bad - to highlight the insidiousness of this disease so that those who are stricken in the future will be diagnosed quicker - leading to a better outcome.

We are asking that you provide a written account - a story - of how you or your family member was initially diagnosed. Was there any delay - and what was the cause of the delay? What was the location of the disease (head, neck, genitals, extremities, etc.) and what stage was it. Each story will be unique. The more information you provide the better the educational experience will be for those who read it. We will edit out any information that we feel to be inappropriate but you will have the opportunity to approve the final copy prior to publication.

In addition, we would like a photograph of the patient alone or with their family that can be used with your story. The photograph is totally optional - we fully understand if the patient's family does not wish to provide one.

Please fill out and sign the release below, attach your story and photograph (if desired) and email it to stories@focusonrhabdo.org or by 'snail mail' to Alan Ehrlich, 100 Middlesex Blvd, Apt 212, Plainsboro, NJ 08536.

HIPAA Release for Publication

Patient's Name: _____

As of this ____, day of _____, 20__, I authorize the use or disclosure of the above-named individual's health information **as provided** in conjunction with educational programs offered by Focus On Rhabdo - an online advocacy group bringing patients, families, researchers and clinicians together to find the means to make Rhabdomyosarcoma universally survivable.

By providing a story of the events surrounding the diagnosis and start of treatment of the named patient's Rhabdomyosarcoma, I/we consent to having it published in "The Many Faces of Rhabdomyosarcoma: 50 Stories." (Working Title), an educational publication to be distributed to pediatricians and primary care physicians around the globe.

I/we understand that these materials will be developed and distributed by Focus On Rhabdo at no cost to me, my family, or the reader. I/we acknowledge that neither Focus On Rhabdo nor any other entity including the patient's physicians have conditioned any treatment or have proffered any other benefits or consequences for signing or not signing this waiver.

By signing this document, I/we hereby understand that Focus On Rhabdo is required to protect the patient's certain protected health information. I/we agree to the release of this information pursuant to the terms of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). **This information may include any and all of the following: First name of child/patient, age, diagnosis, treatment status, cancer location, state or province of residence, country of residence, photographs as provided, and other potentially identifiable data that has been provided. No information provided will be otherwise shared or published in any other matter without prior notification and consent. Since this authorization is for publication of the above protected information, it does not have an expiration date.**

Consistent with law, I/we hereby waive any privilege or right of privacy that I/we may have under Federal Law regarding this information as to Focus On Rhabdo, and understand that if I/we agree to allow Focus On Rhabdo and its agents to utilize our story, my/our image or likeness, or the image or likeness of my child(ren), including any provided and requested information, I/we waive any privilege to the information utilized in any public forum. The release for the story may be rescinded prior to publication by the patient or legal guardian upon timely written notice to Focus On Rhabdo. The release for a provided photograph may be rescinded by anyone whose image appears in the photograph by timely written notice to Focus On Rhabdo.

I/we understand that the information that I/we authorize to be disclosed includes personal, confidential health information that is protected by federal privacy law, and that once released to Focus On Rhabdo may no longer be so protected. **This release is limited to the specific information provided by you within the story.**

Additionally, I/we hereby agree to release and hold harmless Focus On Rhabdo, including their respective officers, directors, employees, agents and contractors from and against any claims, damages or liability arising from or related to the use of the story (as provided and/or approved), images and/or recordings, including but not limited to any re-use, distortion, blurring, alteration, optical illusion or use in composite form, either intentionally or otherwise, that may occur or be produced in production of the finished product. I/we agree to release Focus On Rhabdo, its agents and any others acting pursuant to their respective authority from liability for any violation of any personal or proprietary right I/we may have in connection with any use of my/our likeness or image for any use described above.

I/we have read and understood this release and consent to the terms herein.

Child's age: _____ Diagnosis: _____

Treatment Status: _____

Location of Cancer: _____

Any Additional Information You'd Like to Provide:

Signature of individuals in the picture:

1. _____ Date _____
2. _____ Date _____
3. _____ Date _____
4. _____ Date _____
5. _____ Date _____

Patient, Parent or Legal Guardian (please print) _____

Patient, Parent or Legal Guardian (signature) _____

Date _____

For FOCUS ON RHABDO Use:

File Name(s) of Digital Image(s): _____

File Name(s)/Location of Physical Images: _____