



PHACE Photovoice Project

Thank you for signing up for the PHACE Photovoice Project!

Now that I'm signed up, what should I do?

1. Take photos that represent what it is like to live with PHACE Syndrome.

How many photos should I take? As many as you'd like! We just ask that each photo is meaningful and represents what it is like to live with PHACE Syndrome.

What should I take pictures of? Anything you want! Take pictures of anything that represents what it is like to have or care for someone with PHACE Syndrome. The pictures can be of everyday life, relationships, places, events, and objects or they can be of particularly extraordinary or unique circumstances that you want to highlight. Here are some questions that might help you decide what to photograph:

- What is it like to live with PHACE?
- What do I want to tell other people about living with PHACE?
- What do I wish my doctors knew about living with PHACE?
- How does PHACE affect me at places like home, school, or work?
- What in my life or community is the most rewarding or challenging?
- What makes me feel happy/excited/joyful?
- What makes me feel sad/scared/angry?
- What are my hopes for the future?

Can I take pictures of other people? Sure! Just be sure that you have them (or their parent) sign the attached photo release form and that you upload it with the picture.

Can my parent/guardian help me take photos? Absolutely! We encourage you to work with your parent or guardian to take photos that are meaningful to you.

The only rule is that you take **NEW pictures for this project.**

Please do not submit old pictures that you or someone else took before this project started.

My child is too young to take a photo, can they draw a picture? Of course! Your child can draw a picture. Just take a photo of that drawing to upload for the project.

2. Upload the photos and a short description by clicking on the URL in your e-mail. Please do not share this link with anyone.

How often can I upload photos? As often as you'd like! You can upload them one-by-one, a few at a time, or all at once. We will send you a weekly e-mail just to remind you to upload your photos.