



Great job! Now that you have your list, share it with a few patients, caregivers and loved ones impacted by this disease. Can they think of others? If so, please list them here. Teamwork makes the dream work!



2. Time to gather the community! Pull out your Rolodex! (That’s an old-fashioned version of a contact list, if you don’t know what a Rolodex is.) Who do you know that fits into those categories? Write in 5–10 names per category.

Don’t worry if people can fit into multiple categories. Life is complicated and so is your list. Just put them in the category that best fits them.

Here’s an area for you to start making your lists! We prepopulated this space, but feel free to delete them and/or add more.

- People living with the disease
- Loved ones of people living with the disease
- Caregivers
- Former caregivers
- Asymptomatic gene carriers
- Potential gene carriers
- Health care professionals treating and/or supporting individuals with the disease
- Advocates with no connection to the disease
- Can’t think of five people? Don’t fret! Ask people within your network to help you out.

