

Dear John Doe,

I'm writing to share with you the story of my son/daughter\_\_\_\_\_, who has an ultra-rare genetic condition called SPATA5/SPATA5L1 Related Disorder. We'd like to ask for your support in improving his/her life.

Share 3-4 sentences about your child and their life with SPATA5/SPATA5L1 Related Disorder).

SPATA5/SPATA5L1 Related Disorder is an ultra-rare genetic condition that affects fewer than 150 worldwide. This condition results in hearing loss, epilepsy, developmental delay & disability, movement disorders, visual impairment, and more.

Unfortunately, rare diseases are often overlooked and the burden of advocacy and fundraising is left to the families.

Our small, rare community is grateful to have a foundation dedicated to driving research towards a cure. The SPATA Foundation is a non-profit founded in 2023 by family of an affected child who dreams of a cure for all those affected. The SPATA Foundation's mission is to advocate, educate, and drive research for SPATA5 and SPATA5L1 Related Disorders.

Thank you for taking the time to read about my incredibly strong child. We'd be so grateful if you can help change his/her life. If you would like to hear more, I'd love to speak with you. I can be reached at phone number and/or email address.

With gratitude,

Your Name Here