

## SAMPLE MEDIA PITCH FOR ZTTK SYNDROME

Dear (name of reporter/editor),

Would you be interested in a story about ZTTK Syndrome and a local family affected by this very rare disease? (Optional: Specify any relevant occasion such as Rare Disease Day in February, ZTTK Awareness Month in September etc.)

I live in (name of town/city) and my (daughter/son) has ZTTK Syndrome. This is an ultrarare genetic disease that leads to severe developmental delays, seizures and other medical complexities. ZTTK was recently discovered in 2016, has only 60 known patients, and has no known cures or treatments.

[Short paragraph about your child]

ZTTK is grossly underdiagnosed with no current treatments or cures, but with greater awareness, increased access to genetic testing, and more support of the research, we can change the lives of individuals like my (daughter/son).

I am hoping to share my family's story so we can raise awareness of ZTTK Syndrome. If that story would be of interest, please contact me at (phone/email).

Sincerely,

(Your name)

(Your preferred phone number and email address)