SPELLER Family and Friends Template cover letter/email to send with handout, 9.2024

Dear <Insert name Friend/family HCP>:

First of all, thank you for all of your support over the years. You are always willing to hear my voice, and I can't express to you how much it is appreciated. <insert whatever you want to say here to personalize the email and/or say something about your spelling journey, if you choose to do so>.

My second purpose in contacting you is to give you some information about myself and other nonspeakers. I hope that it will be useful to you both in my care and in the care of your other nonspeaking patients. Enclosed is a handout created by my nonspeaking peers at the Spellers and Allies Advocacy Network to educate healthcare professionals. It includes information about our communication needs, and what you can do to foster a collaborative relationship with us as patients.

Here's some background information about nonspeakers. We cannot use our mouths, lips, and tongues to produce the sounds containing information that is speech. Our minds are full of ideas, but we cannot execute the motor (muscle) actions to vocalize them. Scientists call this apraxia. We nonspeakers call it the brain-body disconnect. In order to communicate, I use a [letterboard/keyboard] to spell out my thoughts and ideas by pointing to letters, one at a time. As you have seen, with this method I can say anything I want.

There are over 500,000 nonspeaking children and 1.8 million nonspeaking adults in the United States. This includes 1/3 of all autistics, 50% of all people with Down syndrome, and many more people with other motor-sensory conditions.

There are many myths about us, among them:

- Our inability to speak is the result of low intelligence
- We are not interested in other people and do not understand human emotions

- We cannot learn to communicate using methods other than vocalized speech

These incorrect ideas about us prevent us from getting an academic education, receiving healthcare that includes our input, having good jobs, and exercising agency and autonomy in our lives.

Finally, I am requesting that you help me and my group of nonspeaking self-advocates educate other healthcare professionals by doing the following:

- Train your staff about us
- Pass this information on to your colleagues
- Connect us to organizers of professional education for others in your field so that we can give a presentation to them
- Connect us to thought leaders who might be interested in learning more about us!

Please use this link/QR code to complete a very brief 5-item questionnaire that will give us feedback about the handout and let us know if you can help connect us with organizers of conferences and other thought leaders.

Thank you for wanting to learn more about nonspeakers. We need the support of people like you to educate others and accomplish our goals. We thank you from the bottom of our hearts.

Sincerely, <Your Name>