

COMMUNICATION TIPS

A guide for any **PARENT** navigating a rare diagnosis

Positive

Be optimistic

Communicate with a positive tone. Move the dialogue forward with compassion, intention, and clarity.

Check yourself:

Would you want your child to mirror your actions and attitude?

Are you setting a good example for your child?

Advocate

Keep your child's best interest in mind

Bring yourself back to the main goal of the conversation – your child's wellbeing. Listen, interpret, and respond with an "I" message, rather than "you".

Check yourself:

Is the conversation 2-way or 1-way?

Do you need to take a deep breath?

Relate

Help others understand

Use videos and photos to educate others about your family's journey. Realize the various perspectives and guide them to an empathetic understanding.

Check yourself:

Do you need to collect your thoughts?

Have you given them the tools to relate to your journey?

Educate

Speak with intention

Take advantage of opportunities to be proactive instead of reactive. Think before you speak and educate whenever possible.

Check yourself:

Did your emotions dictate the conversation rather than the facts?

Navigate

Be open to change

Prepare for the future, while living in the moment. Build community to offset isolation.

Check yourself:

Are you setting your family up for success?

Are your goals manageable and realistic?

Trust

Follow your instinct

Prioritize transparency when you communicate. Vulnerability strengthens trust, builds respect, and helps navigate difficult conversations.

Check yourself:

Is your communication leading with courage?

Are you open to trusting those who are willing to listen?