



The International
22q11.2 Foundation Inc.

Monthly News & Updates

International 22q11.2 Foundation, Inc.

April 3, 2020 Issue 1

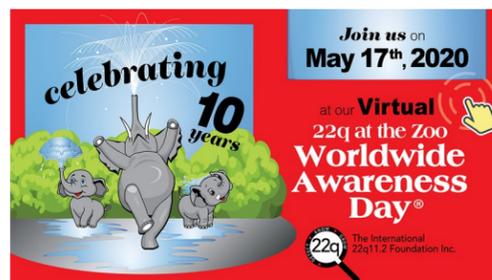
22q FAMILIES AND FRIENDS: On behalf of the International 22q11.2 Foundation, we hope everyone is in good health and practicing social distancing. These are unprecedented times for all of us, and together we are learning to deal with new challenges on a day to day basis. The foundation has reached out to professionals and asked them for suggestions on how **WE** can assist **OUR** families. We wanted to share some educational, interventional, and resourceful links that we hope can help with everyday therapies while at home. We have gathered resources to provide additional supports in speech therapy, occupational therapy and physical therapy. **Remember to always consult first with your direct therapists.**

We have and will continue to provide information to our community, through our website and social media platforms as we receive updates from the medical and professional community.

Please join us for our

Virtual 22q at the Zoo - Worldwide Awareness Day!

Celebrating 10 years of sharing and caring!
Happening across the globe on Sunday May 17, 2020!



We hope you will join us and we wish you all continued good health.

Speech and Language Stimulation Activities for Children with 22q11.2 Deletion Syndrome

Contributed by:

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PRESCHOOL

LANGUAGE FACILITATION STRATEGIES

Get face to face with your child first.

- **Observe:** body language-actions, gestures and facial expressions to see what your child is noticing/pointing.
- **Wait:** stop talking, lean forward, and look at your child (wait to see if they send you any message – via sounds, words, or gestures)

Listen: pay close attention to words and sounds.

- Sometimes, you may have to guess if you cannot understand the message.
- Try to respond to what they are trying to say e.g., Child: "Mu" Adult: "Milk? You want milk?"
- Try to respond to any attempts to communicate, acknowledging, and expanding what he/she says if it's a comment, and answering if it's a question. (OWL, Hanen Program, 2004)

Receptive Language Strategies

- Gain attention before giving directions
- Encourage the child to repeat the direction prior to completion of a task
- Provide emphatic stress
- Reduce length of utterances
- Break down directions into individual steps
- Use a multi-sensory approach (e.g., pointing to pictures; using gestural support)

Early Language Facilitation Strategies for Toddlers and Preschoolers

- Repeat sounds the child makes
- Use exclamations and environmental sounds
- Model social-communicative gestures (e.g., waving, pointing, head

- shaking/nodding, lifting arms up)
- Encourage slot-filling during songs and familiar phrases (e.g., ready, set, _____; socks and _____)
- Provide appropriate models commensurate with child's linguistic need
- Self talk:** communication partners should describe their own activity (e.g., talk out loud about what you are seeing, hearing, doing or feeling)
- Follow your child's lead in play and use **parallel talk** (e.g., use words that describe what the child is doing, seeing and hearing)
- Echo-expansion modeling:** Adding one or more words to what your child says (e.g., "up" -> "come up")
- Focus early on requesting so that the child discovers that using language gets results

Strategies to Promote Vocabulary Expansion/Word Retrieval

- Teach a word in its most natural context initially (e.g., learning "kick" while kicking a ball)
- Use real objects initially to teach words rather than pictures (e.g., use animal props while you are singing Old MacDonald)
- Develop a core vocabulary book
- You can organize it by category and include: people, foods/drinks, toys, clothing, household objects, favorite places, outside objects, and animals
- Review the words on a daily basis.
- The book can be used for both receptive and expressive vocabulary development
- Develop experience stories to reinforce vocabulary (e.g., Pictures from a trip to the beach)
- Provide phonemic cues (e.g., /b/ for bubbles) to facilitate word retrieval
- After use phonemic cues and before sentence completion cues:
- Use rhyming cues to aid word retrieval, (e.g. rhymes with _____)
- Use sentence completion cues (e.g., Pop the _____)
- Encourage comprehension/use of action words using toy props (e.g., Make Elmo jump, Make Elmo go to sleep, What's Elmo doing?) and playing Simon Says
- Cultivate categorization skills (e.g., What fruits do we like to eat?)
- Sort and label objects at home (e.g., give me all the animals, books, vehicles)
- You can also discuss the objects, (e.g. where they come from, where they live)
- Encourage choice making give choices, for example when making requests: ("do you want a cookie or a pretzel?")

Question Processing/Formulation

- Introduce questions using a developmentally appropriate hierarchy (e.g., what, who, where, what...do, why, when)
- Encourage children to ask questions (e.g., Where's the bread?)
- Use games such as Guess Who, Go Fish, I Spy, and Hide and Seek to encourage language formulation
- Hide objects (play Treasure Hunt) in different places and encourage questions to find them.

Follow your child's lead and interests

- Provide quiet "wait time" after you model something for your child to give him/her a chance to try to imitate or say something
- Children learn language through play. Build activities with toys of their choice
- Use simple toys and everyday objects. Model a variety of different play actions and actions appropriate to the toy, such as drinking from a cup, mixing in a bowl, or pretending to feed/bathe/dress yourself, animals, or dolls. Pretend to go shopping or to cook
- Encourage development of social communication, symbolic, imaginative and pretend play
- Model a variety of different actions with each toy in order to encourage play in a novel and flexible manner

Fill-in-the-blank activities

- Use exaggerated pauses (e.g. Ready, set...Go!). You can also incorporate many exclamatory phrases into play (e.g. "uh-oh!", "Boom!" and "Whee!")
- It is helpful to use rich intonation, sing-song tones and rhythms.** Use routinized sing-song inputs for daily phrases, such as "it's time for your bath now" or "it's time to eat" etc. Musical inputs can aid learning and your child may imitate the sound and/or the rhythm, with or without the words
- You can also use nursery rhymes and songs to see if your child will fill in the blank with a gesture or word. Provide hand-over-hand assistance for gestures in the song, if needed
- It is also very helpful to encourage choice making: for example - "do you want a cookie or a pretzel?" to encourage word use for requesting

To encourage back-and-forth/reciprocal interactions and shared enjoyment

- Engage your child in social routines, such as "Peek-a-boo" and "I'm gonna get you." Model waving 'Hi" and "bye" to encourage greeting
- Roll/throw a ball back and forth and name the person to receive the ball. You can also add in saying "my turn," etc.
- Taking turns, reading and turning pages in a book, racing cars, dressing a doll
- Vocalize with sounds/songs, back and forth imitation

PROMOTING LANGUAGE IN DAILY ROUTINES

- Use daily routines** - *To build vocabulary and give opportunities to request*
- Use simple language with your child** - *to ensure comprehension and to model at their level*
- Use language naturally** - *In the course of your activities*
- Try to avoid asking too many questions** - *Or asking him/her to label things too*

Mealtime Concepts

- **Nouns:** (e.g., food items, food categories, dishes, utensils, furniture, associated items, breakfast, lunch, dinner, snack)
- **Verbs:** (e.g., eat, drink, slurp, chew, cut, pour, wash, cook, bake, wipe)
- **Opposite terms:** (e.g., hot/cold, sweet/sour, empty/full, clean/dirty, a little/a lot, liquid/solid)
- **Adjectives/Descriptive terms:** (e.g., colors, shapes, crunchy, chewy, messy, thirsty, hungry, whole)
- **Pronouns:** (e.g., my spoon/your spoon, give the cup to me)

Bath Time Concepts

- **Nouns:** (e.g., towel, washcloth, soap, water, drain, faucet, bath toys, bathroom, tub, body parts)
- **Verbs:** (e.g., wash, rub, clean, splash, play, pour, drip, dry)
- **Opposites:** (e.g., wet/dry, clean/dirty, cold/hot, empty/full, hard/soft, front/back)
- **Location terms:** (e.g., up, down, in, out, behind)
- **Temporal concepts:** (e.g., before, after, next, first, then, last)

Dressing Concepts

- **Nouns:** (e.g., clothing items, parts of clothing, body parts)
- **Verbs:** (e.g., pull, push, zip, button, snap, tie, stand up, sit down, lift, take off, put on, get, find)
- **Adjectives/opposite terms:** (e.g., dirty/clean, new/old, same/different, warm/cool, long/short, right/left, in/out, on/off, pretty, handsome, colors, patterns)
- **Temporal concepts:** (e.g., first, next, last, before, after, night, day)

Pivot Phrases/Functional Phrases

To develop word combinations, you can use one word around which other words are used, such as:

- my ____
- I see ____
- I hear ____
- I want ____
- ____ me
- help me
- pick up
- put on
- vake off
- go home
- my turn

Phrase Structures

Additional phrase structures to use might include:

- action + object (e.g. eat cookie)
- agent + action (e.g. mommy hug)
- attribute + entity (e.g. big bubble)
- possessor + entity (e.g. mommy shoe)
- recurrence + entity (e.g. more swing)
- rejection + entity (e.g. all done song)
- object + disappearance (e.g. ball gone)
- action + location (e.g. jump up)
- entity + location (e.g. block down)
- action-attribute-object (e.g., roll blue ball; push big car)
- object-locative-object (e.g., car under table)
- agent-action-locative (e.g., Daddy go down)
- demonstrative-object-action (e.g., That ball bounce)

Communication Temptations

(expanded from Wetherby & Prizant, 1989)

Create "communication temptations," or Motivating scenarios that encourage your child to communicate/make requests/comment

Italics are offered as examples of means for your child to communicate. However, any response your child makes during a pause and wait time should be considered and explored as a possible communication attempt.

Eat a desired food item in front of the child without offering any to the child

- *Wait and see what the child will do to request some of the food*
- *He/she might grunt, reach, point or make eye contact with you*
- *Any of these can be considered the child's attempt to request and communicate*

Activate a wind-up toy, let it deactivate, and hand it to the child

- *Wait and see how the child will ask you to wind the toy again.*
- *Provide hand over hand assistance for him/her to hand the toy to you as a means to request and communicate.*

Give the child four blocks to drop in a box, one at a time

- *Or use some other action that the child will repeat, such as stacking blocks or dropping the blocks on the floor*
- *Then immediately give the child a small animal figure to drop in the box.*
- *Wait and see if the child looks at you, as if to indicate you gave him/her the wrong item*

Open a jar of bubbles, blow bubbles, and then close the jar tightly and give the closed jar to the child

- *Wait and see how the child will ask you to open or blow bubbles again*
- *Provide hand over hand assistance for him/her to hand the jar to you as a means to request and communicate*

Imitate a familiar and an unfamiliar social game with the child until the child expresses pleasure (i.e., peek a boo)

- *Then stop the game and wait*
- *See how your child will continue the sequence, for example, will he put your hands over your eyes again?*
- *Will he put his own hands on his eyes?*
- *If you are using a sheet, will he pull the sheet off of your face as a means to initiate the game?*

Blow up a balloon and slowly deflate it, then hold the deflated balloon up to your mouth and wait

- *See if your child will put the balloon to your mouth*
- *Point to the balloon*
- *imitate blowing or imitate signing or saying, "balloon," as a means to continue the sequence*

Place a desired food item or toy in a clear container that the child cannot open while the child is watching

- *Then put the container in front of the child and wait*
- *Wait and see how your child will ask you to open the container again*
- *Provide hand over hand assistance for him to hand the jar to you as a means to request and communicate*

Wave and say, "bye bye," to an object/toy upon removing it from the play area

- *Repeat this several times, and then repeat it but do nothing upon removing the object*
- *Prompt your child or provide hand over hand assistance if he doesn't imitate the word or gesture, "bye bye."*

Hide a stuffed animal under the table

- *Knock and then bring out the animal*
- *Have the child greet the animal (saying hi, waving etc..)*
- *After several trials, knock and bring out the animal*
- *Wait and see how your child greets the animal.*

Bounce your child on your lap or on a large stability ball

- *Before beginning the bouncing, seat your child facing you and say with animation, "ready...set...go!"*
- *After doing this several times, pause before saying, "go."*
- *Wait and see how your child will initiate the "go."*
- *He might make eye contact with you, start bouncing while looking at you or imitate the word, "go."*
- *Wind-up toys or any other activity with things that go can be done in the same fashion.*

Sign Language

Your young child will benefit from introduction to some basic signs to promote vocabulary and communication skills.

All children learn gestures

- *Waving, reaching, pointing*
- *Before they begin to speak*
- *Many can learn signs before they can use words*

Pairing words with signs can provide a bridge into expressive language development

The following core signs may be introduced initially:

- *more, all done, help, open, eat, drink, again, and mine*

Baby Signs:

How to Talk with Your Baby Before Your Baby Can Talk by Linda Acredolo, Susan Goodwyn, and Doug Abrams

- *Provides a nice glossary with pictures of common early words and signs for children.*

Other resources are available on

- www.signingtimes.com
- www.babysignlanguage.com

Use play and routines as opportunities to talk about language concepts

The best way for children to learn these ideas is within real, functional experiences

You can encourage learning of spatial, temporal, quantitative and qualitative concepts. For example:

- **Position:** "Let's put the dog *next to* the house," "The cat is *on top of* the barn."
"The ball is *under* the chair."
- **Time:** "Before we put the toothpaste on the toothbrush, we have to turn on the cold water," "Get your cup *after* we set the table."
- **Size:** "My shoe is *bigger* than yours," "Find the *little* car."
- **Equality:** "Can you find the socks that *match*?" "These cups are the *same*."
- **Quantity:** "You have *more/the most* crackers," "Give me *one* block."

Read with your Child every day

Let your child choose stories they want to hear

After they have heard the story, re-tell it and leave a word out at the end for them to fill in

- Or, make a mistake on purpose – just for fun
- Let them correct you!
- For example: “and the cow jumped over the....pizza?”
- Have your child re-tell the story
- Act out the story too
- Make up your own stories using pictures

Ask questions about why things happen

- About how a character feels
- You can ask about things that are not specifically in the story
- Such as what would happen if something in the story didn’t happen
- Or happened differently
- Or make predictions about what might happen after the story ends

As you read, exaggerate the rhythm and intonation of your speech and model pointing to and labeling the pictures

- It’s okay if your child cannot pay attention to the entire story
- You can use this as an opportunity to talk about the pictures
- Read books that are repetitive and predictable,
- such as *Goodnight Moon* or *The Very Hungry Caterpillar*

After you have introduced the book and read it a number of times

- You can change the way the story is told
- Vary your language, intonation, and words used
- Encourage your child to retell the story in his/her own way

Take turns telling parts of the story

- You can start the story and then have the child continue, then you go again, and so on

Speech

Accept approximations

- These may be the best way your child can say something
- You may model the correct target for them
- It is important that the child feel they are successful communicators with you

Listen to *what* your child is saying

- Allow your child to tell you what they are thinking/feeling/needing with acceptance, and without interruption for the child to correct a sound
- At the moment they are communicating their experience, what they need to tell you is the most important thing, not as much *how* they tell it

If you cannot understand what your child says, you can ask to repeat and say:

- “Mommy/daddy didn’t hear you, can you say that again?”
- This strategy will facilitate self-confidence about speaking
- If you understand part of what is said, then repeat back that piece of his message and ask about the remaining portion(s)
 - For example, “I heard you want a drink
 - What drink do you want?”
- Suggestions to “Show me,” or offering choices may also help to reduce frustration

It is often best to practice the sounds your child is already working on in speech therapy

- If you know your child’s speech sound targets in speech therapy, you can practice those in the context in which your child has success
- For example, is he/she working on production in syllables, words, phrases, sentences, connected speech, conversation?
- Your child may not be able to produce the target sound in longer contexts than those they are practicing in therapy, such as sentences, if they are just learning the sound at the word level

It is beneficial to have structured speech practice

- Short, frequent practice sessions are preferable

Have your child say the word 5 (to 10) times in a row – only count the times the sound is produced accurately

- Repeat 10x/day at various times of the day and in different parts of the house
- This helps build accuracy and automaticity
- You can open with “give me 5!”

It is sometimes beneficial to practice and model sounds and/or words without asking your child to imitate

- If he/she attempts to imitate or produce a sound or word that you model, praise him even if the production is not perfect
- e.g., “Great job trying”
- “You worked really hard to say that”

Create a list of the most used (+/-10) words and short phrases your child attempts to use throughout the day

- Model these words frequently during daily routines to provide opportunities for imitation
- Increasing the intelligibility of frequently used words and phrases can help make the day more fun and less frustrating

Be patient

- Once a child correctly produces a sound in therapy on their own it will take time for it to be used consistently

Establish a Vocabulary/Speech Book to organize vocabulary with your child’s target sound(s)

- You can remove and add words as the words are mastered
- You can play games with pairs of pictures with their target sounds, such as Match Game

For older children, you can also work on sound-symbol associations to enhance early reading skills

Older children might enjoy looking for their sound in a magazine or newspaper

article

- Have them highlight their sound with a highlighter, and then read aloud to you while practicing the sound

SCHOOL AGE RECEPTIVE LANGUAGE

Build vocabulary and word skills

- Highlight new words in text and see if your child can determine its meaning from context
- Look up the word together and use it in a new sentence

Form antonyms and synonyms of words

Define multiple meanings of words and use them in different sentences with their different semantic values

- e.g. bat = sports equipment or an animal

Build word lists needed for their favorite activities and subjects in school

Practice following directions with multiple steps

- Try to use/teach concepts they are working on, such as spatial, temporal, comparative and sequential concepts, For example, "Before you get the chips, can you put the large white bowl on the table".
- Art projects, household chores and cooking together are great activities for natural instructions

Teach the meanings of idiomatic and metaphorical language

- Such as: "It's raining cats and dogs" or "Hold your horses"
- Children often interpret these literally and become confused

Tell jokes and try to discuss why something is funny

- The humor often lies in a different use or meaning of a word than what is on the surface of the joke
- There are many joke lists on line to choose from for the age of your child
- Have fun!

Practice memory games, such as Match Game and cards

Speak slowly

- Repeat as needed
- Break instructions and input into parts

Help your child to visualize instructions as they come in to aid recall

Practice Mindfulness Meditation

- This will help your child in many ways including focus and cognition

Language Expression

Give instructions to your child on how to:

- Make a drawing, or build a construction with blocks. For example with different sizes and colors. Give direction to follow such as "put the little green block on top of the red one", and so on

Then have your child tell you what to do

- Do exactly what they say so they see the direct result of what they say
- This helps to build their sense of the listener's needs, using details and explanations. And, it's really fun!

Have your child explain the rules of a game

- Step by step
- And follow them
- So they can see the direct result of what they say

Or have them explain how to cook, build, draw something with you

- Take some photos and make a sequence for them to follow
- You say it first while doing it, then have them relate what was done
- Then, the next day have them tell you what to do with the photos as their guide
- Encourage use of words to connect their ideas, such as first, next, last, and then, because

Re-tell a story just heard

- Provide visual cues and icons, written words to guide them
- Then provide wordless pictures and have them create their own stories

Practice grammar targets your child may be working on

- Forming multiple sentences using the particular grammar structure

Define words

- Aim for the most critical features
- Then use the word in a sentence

Play "Guess what I'm thinking of"

- For example, taking turns saying, "I'm thinking of something that is yellow, you peel it, and you eat it"

PRAGMATIC LANGUAGE

Encourage your child to "be a detective" (observer) and use "clues"

- Clues can include: nonverbal information including facial expressions, body language, tone of voice, etc.
- To identify how others are feeling and what they may be thinking
- As well as to predict what may occur next
- This activity can be done while reading novel picture books, watching video clips, television or movies, or while in a social setting

Provide verbal cues

- Which are concrete
- And are relevant to the situation to broaden conversational turn-taking
- Provide scaffolding as necessary and remove /fade as possible
- Using phrases such as "Do you want to know more?" and "How could you find out?" may be helpful

Ask about cause and effect

- What and how events happened

Ask about the perspective of different characters in a story

- Try to tell the story from each character's unique perspective.

Ask and assist the child to identify the main, and then side problems in the story

- Then discuss different ways the problem can be solved

Relate events of a story out of sequence

- Have the child explain re-order events
- Explain why/how the sequence affects the outcome
- Try to imagine what might happen if the sequence was followed out of order
- It's fun to make up silly scenarios

Discuss the meaning and impact of non-verbal cues

- Such as facial expression and body language; in picture stories, or in videos/movies

Keep a journal to log some of the day's events

- And how he/she felt about them
- Use these events/feelings to teach how to discuss their emotions
- Later this skill can be developed to understand others' thoughts and feelings

Helpful Books and Websites (Hover over reference links to open)

- [Baby Signs, Linda Accredolo and Susan Goodwyn, McGraw-Hill, 2002](#)
- [The Child With Special Needs: Encouraging Intellectual and Emotional Growth \(A Merloyd Lawrence Book\) by Stanley I. Greenspan, Serena Wieder, and Robin Simons \(Hardcover - Jan. 6, 1998\)](#)
- [The Hanen Program](#)
- [How to Talk So Kids Will Listen & Listen So Kids Will Talk by Adele Faber and Elaine Mazlish \(Paperback - Oct. 1, 1999\)](#)
- [Pepper, J. and Weitzman, E \(2004\). It Takes Two to Talk. Toronto: Hanen Early Language Program.](#)
- [The Clinician's Guide to Treating Cleft Palate Speech by Sally Peterson-Falzone, Judith Trost-Cardamone, Michael Karnell, and Mary Hardin-Jones \(2017\)](#)
- [Kaufman, N. \(1997\). Kaufman Speech Praxis Treatment Kit for Children: Basic and Advanced Levels](#)
- [Northern Speech Services, Inc.](#)
- [Materials for addressing social thinking deficits](#)
- [McAfee, J. \(1992\). Navigating the Social World. Arlington: Future Horizons, Inc.](#)
- [Wetherby, A. and Prizant, B. \(1993\). Communication and Symbolic Behavior Scales-Normed Edition. Chicago: Applied Symbolix.](#)
- [Speech-Language Disorders in 22q11.2 Deletion Syndrome: Best Practices for Diagnosis and Management](#)

Resources for sign language:

- [Baby Hands Productions](#)
- [Baby Sign Language](#)

Activities to Encourage Speech and Language Development:

- [American Speech-Language Association](#)

Reading to/with Your Children:

- [Study: Reading books to your children every day is worth a million, literally](#)
- [Children's Library Lady](#)
- [Readingrockets.org](#)
- [Scholastic Publishing has created free Learn at Home programs for use during school closures](#)

Learning and Literacy

- [The Literacy Shed](#)
- [Games and activities to promote literacy](#)

Speech therapy at home

Speech sound pictures:

- [Mommy Speech Therapy](#)
- [Little Bee Speech App Store](#)

Web based language learning activities

- [Where learning takes you](#)
- [Super Duper Publications app store](#)

OCCUPATIONAL THERAPY RESOURCES

Contributed by:

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Occupational Therapy is important, flexible and fun! It can be practiced at home at any time. The goal is to promote the highest level of functioning in daily life. Depending on

your child's needs, OT at home can consist of practicing hand strengthening exercises, pencil grasp development, scissor cutting, and additional fine and gross motor skilled activities.

A few examples are shaving cream, hair gel, play dough, slime, or putty. Have your child exercise their muscles and create different shapes and letters using these materials.

Create your own rice/sand bin, garden or have your child help assist you while cooking or baking.

I have listed a bundle of resourceful websites to help create fun engaging OT lessons in the comfort of your home. **Have fun learning!**

- [Therapeutic Crafts & Activities](#)
- [OT Mom Learning Activities](#)
- [Creative & Fun Ways To Help Kids Cut With Scissors](#)
- [Sensory Processing Disorder: Occupational Therapy Demonstration](#)

SCHOOL-BASED PHYSICAL THERAPY

Contributed by:

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School-based physical therapists (PT) are part of a team of related service providers who support a student's ability to access his/her educational environment. As specialists in movement, they assist a student's physical participation in a variety of settings throughout the school day. The primary role of the school PT is to help students benefit from their educational program within the educational environment.

Physical therapy helps improve an individual's ability to move and function. Based on your child's needs you can incorporate daily activities to assist in hand eye coordination, motor planning, and body/spatial awareness. Some activities include yoga and playing ball.

Below are sites that offer free resources to guide you in physical therapy activities:

- [Providing Physical Activities and Motor Planning Activities](#)
- [Tools to Grow](#)
- [Cosmic Kids Yoga](#)
- [Teachers pay Teachers](#)

Sincerely,

The Executive Board

International 22q11.2 Foundation, Inc.

Here for You Since 2003!

www.22q.org

Phone: (877) 739-1849
