



Support Specialist REGISTRATION FORM

Thank you for your interest in being a volunteer Support Specialist with AVM Alliance. Our one-on-one support program is designed to match individuals and families with others who are experiencing the same or similar challenges. It can be a rewarding experience to help someone who is just starting out on this journey. We cannot thank you enough for your time, your willingness to share your experiences, and commitment to offer support.

Your name: _____

Address: _____ City/St/Zip: _____

Best contact email: _____ Best contact phone: _____

Languages spoken other than English: _____

Check all categories in which you have personal experience:

- ☐ Parent of a child who had a stroke. Age at time of stroke _____ Age now _____
- ☐ Young adult who had a stroke as a baby/child/teen (current age 18 – 35)
- ☐ Lost a child from complications from stroke

Indicate areas where you have experience and are comfortable in addressing with others – check all that apply:

- | | | |
|--------------------------------------------------------|------------------------------------------|-----------------------------------------------------|
| <input type="checkbox"/> Aphasia/Apraxia | <input type="checkbox"/> Feeding issues | <input type="checkbox"/> IEP/504 |
| <input type="checkbox"/> Complex issues | <input type="checkbox"/> General Support | <input type="checkbox"/> Learning/Memory Challenges |
| <input type="checkbox"/> Emotional/Behavioral | <input type="checkbox"/> Grief/Loss | <input type="checkbox"/> Social challenges |
| <input type="checkbox"/> Epilepsy | <input type="checkbox"/> Hemiplegia | <input type="checkbox"/> Vision |
| <input type="checkbox"/> Other (please specify): _____ | | |

Once a family contacts us, we will reach out to you via email with their registration form. Connections will be made based on the needs of the family and your experience. We will not share your information with the family. You will then choose the best method (email or phone) to connect with the family. We will send you an intake form which you can use to record any further assistance this family may need and give us a short evaluation about the phone call or email exchange. Again, we appreciate your willingness to participate!

Consent: I, _____ agree to be a Support Specialist for AVM Alliance. In signing below, I give my permission for AVM Alliance to connect me with families who have submitted their registration form. I have read the AVM Alliance Guidelines and agree to those terms. I can ask to be removed from this list at any time, by notifying Raylene Lewis at avmalliancegroup@gmail.com.

Signature: _____ Date: _____

By typing my name here, I am stating I read the guidelines below. I understand that this form of electronic signature has the same legal force & effect as a manual signature.



SUPPORT NETWORK GUIDELINES

Thank you for volunteering to be a Support Specialist for families with a child who has had a stroke. You probably remember when you first heard the word “stroke” in relationship to your child and how alone you felt. You wondered where to turn and were unclear about what the future might be for your child. If you survived a stroke as a child, you have the firsthand experience of learning to navigate through the school system, social interactions and learning daily skills that work for you. If you endured the tragedy of losing a child, you understand the pain that envelops you. Each of you now has the opportunity to share your experiences and may be the support and comfort that gives hope to another family.

Families will be contacting us through Facebook. I will match up the request with one of you based on geographic location and/or your experiences. We are starting with a core group and will be adding more as we go along. If for any reason, you are not available at the time of the request, you can decline, and I will pass the family to someone else. We don’t know what volume we will have, so if it becomes overwhelming, you can drop out at any time. We want this to be a positive experience for you as well as the families.

You will be interacting via email and phone, so I wanted to provide some guidelines, techniques, and dos and don’ts. The information you are given is confidential and should not be shared with anyone else. **The main key point to remember is not to give recommendations for medical care and treatment.** You can, however, provide the most current medical information available and current treatment options. You can also share the names of doctors and treatment you have used.

There may be a need to connect a family with a neurologist/medical specialist or with resources in their area. We will be using Dina Chon (dina@taafonline.org), Executive Director of The Aneurysm and AVM Foundation (TAAF).

The KISS Facebook group and The International Alliance for Pediatric Stroke website (<https://iapediatricstroke.org>) are good resources to give to families.

TECHNIQUES FOR PHONE CONVERSATIONS

1. Active Listening
 - Be prepared to listen. Give the other person your full attention. If you can’t, try to arrange a time with the caller when you can give full attention.
 - Listen to understand rather than to refute. Postpone your judgement of what the individual is saying and try to ascertain what the person means.
 - Control your own emotions. If you find yourself reacting strongly to what is being said to you, try to put your own feelings aside for the time being.
2. Responding and Clarifying
 - Encourage the individual to express themselves completely, by saying something like “How did that make you feel?”
 - Help the individual to identify the essence of the problem or issue they are trying to discuss.
 - Paraphrasing or restating what the individual said can contribute to open communication. For example, the individual states, “I’m angry with the doctor and he was incompetent”. Your response, “It sounds like you are angry with the doctor and he was not a competent doctor?”
3. Summarizing
 - This is an attempt to condense and crystalize what the person has stated.
 - If done at the close of the call, it will let the person know you heard what was said. You can state what the next step is and who is going to do what.

CONTINUED...

PHRASES TO HELP LISTENERS BE ON TARGET

For active listening, here are some suggested responses.

1. Give Support:

- "I sense that..."
- "So, you think that..."
- "You feel that..."
- "So, your main concern at this time is..."

2. Seek Information:

- "What happened when...?"
- "Let me see if I understand what happened..."
- "What did you think..."
- "How did you feel..."

3. Explore Alternatives:

- "What else happened?"
- "Any other thoughts?"
- "Any other possible avenues?"

4. WORDS TO AVOID:

- **"Should, Shouldn't"** - implies that the person has options that may not exist. e.g. "You should put your child in a private school", when the family may not be financially capable of doing that.
- **"If I were you..."** - you are not that person.
- **"Don't worry" or "Don't feel angry/guilty/etc."** - implies that you are capable of judging the situation.
- **"Be realistic"** - each person has the right to view their situation the way they perceive it.
- **"I know how you feel"** - you don't know how they feel; you only know how you felt. You can use your experience by stating how you felt at a similar point in the process.
- **"Oh, you don't mean that"** - They probably do mean it. It is their thoughts, their feelings, their situation, and their life.

DO THESE...

- ⇒ Just listen
- ⇒ Ask questions that encourage the person to share
- ⇒ Control your emotions
- ⇒ Support – "You are not alone", "We are here for you"
- ⇒ Validate -- whatever they are feeling right now is OK
- ⇒ Reflect back what you have heard, paraphrase. It lets them know they have been heard
- ⇒ Keep the conversation to yourself. Confidentiality is imperative!

DON'T DO THESE...

- ⇒ Judge
- ⇒ Argue or refute an opinion or statement
- ⇒ Use words like "should", "must", "don't"
- ⇒ Tell them what you would do. "If I were you, I would get a new doctor."
- ⇒ Give medical advice (EVER)
- ⇒ Monopolize the conversation
- ⇒ Trash talk doctors, medical specialists, teachers, etc.
- ⇒ Share your problems

