iPERSiST
Motivated and Thriving

Alpha-1 Patient and Caregiver Support



You are not alone in the fight against Alpha-1

Living with Alpha-1 is a challenging experience both physically and emotionally. A diagnosis of Alpha-1 can have a significant impact on the mental health of patients and caregivers. A recent survey conducted by the Alpha-1 Foundation discovered that more than 70% of patients with Alpha-1 and their caregivers reported that they had anxiety and/or depression.

If you have Alpha-1 and are struggling with your mental health, there is plenty of support available from support groups, relatives, and even your doctor or healthcare professional.



What is a support network?

Whether you've been diagnosed with Alpha-1 or you're caring for someone who is undergoing treatment, it's important to have a support network that can help you along the way. A support network may offer you comfort, encouragement, and a sense of belonging as you navigate your treatment journey. It can consist of friends, family members, your healthcare team, and even fellow patients and/or caregivers who are living through the same experience.

Some patients find support networks through the people closest to them. But there are also organized support networks available through groups like the Alpha-1 Foundation.

iPERSiST
Motivated and Thriving

What should you ask your support network?

Having honest conversations with your support network can help you better understand your condition and feel less nervous about your diagnosis.

Questions for fellow patients:

1. What kept you motivated and hopeful when you were first diagnosed?
2. Which lifestyle changes did you find to be the most helpful in treating Alpha-1?
3. How can I keep a positive mindset as I navigate my treatment journey?
4. What resources will be the most helpful/educational for me?

Questions for friends and family:

1. Will you be able to drive me to my doctor and infusion appointments?
2. If needed, can you help me with daily tasks, like grocery shopping, cleaning, etc?
3. Would you be open to joining a support group with me?
4. Are you willing to make certain changes to our home to reduce environmental triggers that might harm my lungs?

Support programs and resources

Organizations like the Alpha-1 Foundation and AlphaNet run programs for patients and caregivers battling Alpha-1. There are also chat groups and support groups online, such as "Alpha-1 Antitrypsin Deficiency Support" on Facebook.

Alpha-1 Foundation Peer Guide Program

ALPHA-1 FOUNDATION

This program connects a "peer" (a newly diagnosed patient or caregiver whose life has been affected by Alpha-1) with a "guide" (a patient and/or caregiver who has gone through a similar experience). The peer guide connections are tailored to the individual's experience and allow the peer to discuss difficult issues and make informed choices with someone who understands their situation.

For more information on the Alpha-1 Foundation Peer Guide Program, visit **www.alpha1.org/peer-guide-program/**. For caregivers who would like to learn more about the Peer Guide Program, please visit **www.alpha1.org/caregivers**. To request a Peer Guide or to learn more about becoming a Peer Guide, contact the Director of Patient Services at **1-877-228-7321, ext. 315**.

Alpha-1 Foundation Support Group Network

This nationwide program offers virtual and in-person education, support, and information to patients and caregivers affected by Alpha-1.

Visit **www.alpha1.org/find-a-support-group** to find a support group near you.

AlphaNet

AlphaNet

AlphaNet will connect patients and caregivers with specially trained coordinators who provide individualized, comprehensive help. All coordinators are patients or caregivers living with Alpha-1, and they understand the unique experiences of their clients. Coordinators will provide educational resources, answer questions, and keep patients and caregivers informed to help them lead the best lives possible.

To learn more about AlphaNet's services, **visit www.alphanet.org/about/coordinators/**.