

## FROM ONE PATIENT AND FAMILY TO ANOTHER:

### CHAT ROOM AND INTERNET BULLETIN BOARD RESOURCES

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*With the exception of the Inspire/ALS Association website, these internet resources and their content are not specifically endorsed by the ALS Association. These sites have been passed along by other patients and families who found them helpful in coping with ALS.*

*Websites often change: these were confirmed as of January 5<sup>th</sup>, 2015. Please let us know if any of these links are no longer working, or if you discover any other legitimate and helpful ALS chat room sites!*

*With **\*any\*** internet sites, your privacy and safety is paramount- be sure you are sharing only information you feel safe sharing with anyone, and adequately mask your real identity with a made-up one, if you choose to post your contact information or profile.*

- 1) <http://www.patientslikeme.com>

The "Patients Like Me" website has an ALS-specific area with search criteria- you can find what other people are doing for any number of specific ALS issues (from communication to constipation), and you can even narrow it down by gender or age or geographic area. Some people post personal profiles. *With **\*any\*** internet sites, privacy and safety is paramount- be sure you are sharing only information you feel safe sharing with anyone, if you post your contact information or profile, or make up a name and use an anonymous email to be safe!*

- 2) <http://www.alsforums.com/>

This forum connects both PALS and CALS with multiple "threads" of conversation and subsets of group forums, from "newly diagnosed," "stories of hope," "gadgets and gadgets" to "general discussion." This site also hosts blogs and extensive chat room opportunities.

- 3) <http://www.inspire.com/groups/als-association/>

A forum of the ALS Association, a Support Community connecting patients, families, friends and caregivers for support and inspiration.

- 4) <https://health.groups.yahoo.com/group/living-with-als/>

This is a public forum with over 3000 members. You need to join Yahoo groups to participate. An avenue for persons living with ALS and their caregivers to communicate with the ALS community immediately, to share information, ideas, support and fellowship. You cannot hide your email address, so I suggest for safety's sake, prudent use of the public domain would include: making up or using a separate, "dummy" email without your real/full name or other identifying information like date of birth or street address, and not connected to your everyday use or any financial transactions. Sites like this are safe with just a few common sense precautions!

- 5) <https://groups.yahoo.com/neo/groups/ALS-discuss/info>  
A forum to post messages discussing Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease). If you have this disease or are a relative or friend of someone who does, this is a place to come to visit and share information. This site has about 300 members. Same precautions as the above Yahoo group site.
- 6) [www.alsindependence.com](http://www.alsindependence.com)  
People helping people. An individual's site, based in Canada, but which posts ALS news, key links, and the submitted personal stories of PALS and CALS from around the world.
- 7) <http://neurotalk.psychcentral.com/forumdisplay.php?s=89f0d67c5b334b8c4b139e52a46f7fe3&f=6>  
This site within "NeuroTalk" has an ALS News and Research discussion forum for posting messages.
- 8) <http://client1.sigmachat.com/sc.php?id=144320>  
According to one of our PALS and a key source for on-line chat rooms, this is one of the most active ALS chat rooms right now. Just type in a name you would like to be called in the Chat room and click the "log in" link.
- 9) <http://www.magimedia.co.uk/buildforum/index.php?sid=66a0b29ea0c3994f7d06e69a25723d06>  
This is a British forum. It describes itself as a "place to have serious discussions about a variety of issues surrounding MND /ALS."
- 10) <http://www.mda.org/chat/chatroomlogin.aspx>  
This a chatroom at MDA: currently the "Living with ALS" chat is from 12:00-1:00 pm on Wednesdays. You will need to register. Click the "Join Chat" or "calendar" to see the chats for the month.