



Online Networking Opportunities for Heart Clinic Families

[en français](#)

Social networking web sites, such as Facebook and Twitter, and various on-line forums have made it easier to connect with people and families who are alike and share similar stories, thoughts, challenges and triumphs. Check out some of these web sites and forums you can find on-line that can connect you with credible organizations and other families to share ideas and experiences!



Facebook

As of January 21 2013, there were 6 Facebook groups related to “congenital heart defects”, each with between 19 and 1326 members (the largest being the CHD-UK group). The groups have varying levels of activity, but at least 2 or 3 of them were active when we last checked, having recent comments and responses. The CHD-UK group is a closed group, meaning potential members must make a request to be allowed to join the group, enhancing privacy. Active groups in Canada include: [Canadian Congenital Heart Alliance](#), [Tetralogy of Fallot](#), [CHD Support and Awareness in Canada](#). If you come across other groups that are of interest please let us know at communications@cchaforlife.org.



Ability Online

Ability Online is a free, monitored & supportive online community that welcomes kids, teens & young adults of all abilities. The site offers separate sections for different age groups & specialized tools to help address transitional needs and challenges. Parents and professionals are welcome. The forum and tools are broad, and the site itself is not geared specifically to those with complex heart problems. Once registered, members can see:

- Age and topic specific forums for ongoing discussions
- Homework Help
- Bully Bouncers
- Friendship Builder - including social skills videos
- Games
- Fun stuff- introduction to sports and recreation
- Tumblereadables - online library of books for all ages
- Resources and links

Applicants are screened with a phone call for safety and confidentiality reasons.



PD Heart

PDHeart promotes itself as a very active online support group and discussion forum for parents, family members and adults with congenital heart defects. It is targeted towards all ages, and registration is required before accessing the forums.



Baby Center

Baby Center is a very general site for baby care questions. However, this link will take you to a specific sub forum for babies and children with heart problems. An initial look into the forum suggests it is very active, with many recent questions and responses from parents. The forum is publicly accessible, so confidentiality only goes as deep as one’s username and the details they include in their posts, but the constant activity and long list of historical comments could make it a valuable resource to many parents.



Yahoo Support Group

This Yahoo Support group, sponsored by Kids with Heart National Association for Children's Heart Disorders, is a traditional online support group, and offers posting and responding options to its members. The group requires moderator approval before members may join.



[Cardiac Kids \(in support of SickKids\)](#)

Cardiac Kids is primarily a fundraising group, though this link introduces you to cardiac patients (all youths) who are sharing their stories and experiences. This site enables children and parents to read about the experiences of others.