



CHROMOSOME 22 CENTRAL MEMBERSHIP FORM

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www.c22c.org

Your Name: _____

Address: _____

E-Mail: _____

I HAVE READ THE NOTICE OF PRIVACY RIGHTS AND UNDERSTAND THE POLICIES OF C22C INC. REGARDING HOW MY CONFIDENTIAL INFORMATION WILL BE HANDLED:

Yes No

Phone Number (optional, but helpful if wanting family contacts): _____

Child's Name: _____

Child's Date of Birth: (mm/dd/yy) _____ Male Female

Child's diagnosis/Karyotype: _____

I would like to have contact with other members of the group and allow my name to be shared with others by adding it to the family database. This listing is only provided to other registered members for the purpose of networking: Yes ___ No ___

I allow my name and contact information to be listed in the newsletter: Yes ___ No ___

There are currently studies underway for many chromosome 22 disorders. Would you like to be contacted by a research facility if a study is underway for your child's disorder? **Your name may be forwarded to researchers studying your/your child's specific disorder.** You will then have the option to participate or not. Yes ___ No ___

I am interested in becoming a family contact person to be listed on C22C's website.
Please tell me more! Yes ___ No ___

Membership is FREE but we are grateful for voluntary fees – which we count on to keep operating. Can you contribute at this time? If so, our suggested membership fees are:

US/CANADIAN FAMILIES: () 1 year/\$15, () 2 years/\$27, () 3 years/\$35

PROFESSIONALS and INTERNATIONAL FAMILIES: () 1 year/\$18, () 2 years/\$34, () 3 years/\$45

Please find my cheque enclosed _____ OR

Further donations are gratefully accepted. Please feel free to submit a narrative and/or photo of your child on a separate piece of paper to be featured in a future newsletter.

CHROMOSOME 22 CENTRAL NOTICE OF PRIVACY RIGHTS

THIS NOTICE DESCRIBES HOW INFORMATION ABOUT YOU MAY BE USED AND
DISCLOSED.

PLEASE REVIEW IT CAREFULLY.

- C22C Inc. is a voluntary organization which shares information provided by members, with other registered members, for the purpose of supportive networking. Members of C22C include families and interested professionals.
- Only members who select to be added to our network database or be published in our newsletter will have their confidential information shared between registered members.
- Members who choose to have their personal information published in the newsletter or family networking lists accept that the newsletter is distributed through print and mailed out to registered members, and sent via email to other members. Only first names and geographical locations are indicated in the newsletter, unless otherwise requested.
- If members indicate a desire to accept contact for research purposes on the membership form, their confidential information **may be** shared with professional research institutes. Members if contacted are under no obligation to participate in any proposed studies.
- C22C Inc. will not provide confidential information to requests made by outside parties without the direct signed consent of the individual, or in most cases, the consent of BOTH parents of the individual.
- Registered members have the right to change their personal information at any time by contacting the head office of C22C Inc., Fuquay-Varina, NCA USA or by emailing steph.stpierre@c22c.org.
- C22C Inc. does NOT sell or provide confidential information for benefit or gain. No information is exchanged about registered members except in the above noted manner.
- Registered members have the right to revoke their registration at anytime, and have all confidential information on them destroyed in an acceptable manner.
- C22C Inc. has the right to revise the terms of this policy and members have the right to be notified in the event of any such change.