



Guidelines for Taking Part in the Family-Centered Care E-Council

Please follow these guidelines to help protect all St. Jude Children's Research Hospital patients.

What the FCC E-Council is not

- It is not a place to voice complaints about a specific patient's care but to share your experiences in a non-emotional, general discussion, and to offer suggestions for improvements that might apply to the experiences of other patient families.
- It is not a place to ask for or share medical advice.
- It is not a place to relay information about other patients' experiences or to violate others privacy by sharing experiences that are not your own.
- It is not an advocacy group but is advisory in nature.
- It is not a place for sharing medical information about yourself or others except that which is truly needed to make your recommendation. Remember that the patient's information is private and should be kept that way.

What is a patient complaint and how should it be shared appropriately?

The E-Council is not a place for raising specific patient care complaints. If you have a complaint specific to your treatment or the treatment of your child, please talk to your St. Jude doctor or the nursing coordinator.

Messaging on the E-Council

Please do not share your account log-in information with anyone.

Protected health information (PHI) is information about a person's health status, diagnosis, treatment, or payment for health services when combined with information that can be used to identify you or your child. Information that identifies the patient can include name, address, certain dates, phone and fax numbers, email address, social security number, medical record number, photos or anything that is unique to the patient. To take part in this group, you do not have to and should not disclose PHI to the overall group. However, you will have to disclose some information to the St. Jude staff so they can understand your St. Jude connection and what E-council issues relate to you.

You may not use the E-Council to do the following:

- Make any inappropriate or discriminatory statements based on race, gender, religion, national origin, sexual preference, disability or veteran status
- Harass, intimidate, put down, or speak ill of another person

- Interfere with another person's ability to perform their role
- Access, read, copy, store, or forward inappropriate or sexually explicit messages or materials
- Use, copy, or distribute documents in violation of U.S. copyright laws;
- Create and send an email so it appears to be from another person;
- Obtain access to the files or emails of others without proper permission;
- Breach any information security systems;
- Send non-requested communications such as "chain letters," "prayer wheels," solicitations for goods or services, or emails that ask the recipient to forward the message to others
- Broadcast or circulate personal information, such as items for sale, giveaways, promotional activities, personal announcements, etc.
- Do anything that may violate any laws or regulations

If you use email or messaging in the E-Council and violate any of the guidelines above, your E-Council membership will be suspended or ended.

Confidentiality

All information posted through the E-Council should be treated as strictly confidential and not shared outside of the E-Council. Do not share information posted by other E-Council members or share discussion topics with others outside of the E-Council. Do not discuss E-Council topics "off line" in private emails or other communications.

Computer and device screens should not be left open or unattended. E-Council members should exit the E-Council program or use the lock computer function before leaving the computer or device. The account password should be changed periodically for a greater level of security.

Privacy

Be aware that by posting information about yourself or your family, you are sharing personal health or private information. Only share personal information that you do not mind others knowing. You do not have to and should not disclose PHI to take part in this group.

- Only share information about your own experiences.
- Do not forward emails or postings.
- Do not attempt to contact other members individually.

Criteria for removal from the E-Council

Violating confidentiality and privacy rules, not following other E-Council messaging guidelines, or taking part in other inappropriate online behavior will lead to your removal from the E-council.