

SEPTEMBER 2014

E-Council offers you a voice

The Patient Family-Centered Care (FCC) Program offers many opportunities for parents to partner with staff to improve patient quality, safety and satisfaction at St. Jude Children's Research Hospital.

One of the ways staff and parents partner is through the St. Jude Family-Centered Care E-Council. This online advisory council consists of St. Jude patient families, caregivers and former patients who are interested in sharing their perspectives about the hospital.

Topics of interest and discussion questions are posted, and E-Council members respond by email, sharing their unique perspectives and suggestions with staff and other E-Council

members. The online setting is especially helpful for patient family members who would like to be a part of a St. Jude advisory council but have time constraints or live outside the Memphis area.

St. Jude welcomes applications from current and former St. Jude patients (18 years of age and older, please), as well as family members and caregivers of patients. Applicants must be either a St. Jude patient or the caregiver of a current or former St. Jude patient.

The FCC E-Council is hosted on a protected site called www.groupsie.com. Only members can take part, and they must complete membership requests and be approved to be

included in the online conversations. Once membership is approved, you will be sent a Web link to the E-Council.

Frequently a topic or a question may be posted, and E-Council members can respond with opinions, suggestions and other information to be considered by St. Jude staff.

Embracing family-centered care at St. Jude means the staff wants to hear from you about topics such as campus design and construction, the safest and best ways to provide quality patient care, family support during treatment, food and nutrition services, and other aspects of patient care. The St. Jude staff values your partnership in planning and delivering the best care possible.

To apply online, go to www.stjude.org/fcc-ecouncil. For more information about applying for the FCC E-Council, email or call Natassha Works at natassha.works@stjude.org, 901-595-6041.

Outpatient Room Service offered

When patients are in the Outpatient Clinics and Medicine Room, they can get hungry during extended visits. At these times, parents are able to call St. Jude Room Service to order food for their children. Ask the Clinic and Medicine Room staff for a copy of the menu.

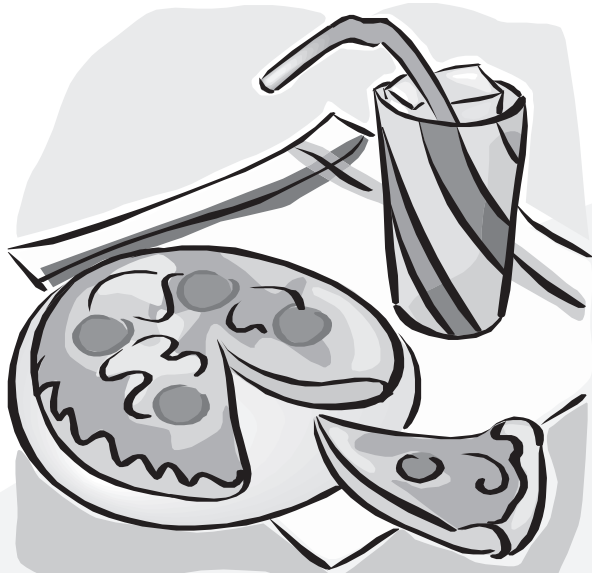
For the staff to better serve all Kay Kafe customers, parents can no longer place outpatient Room Service orders in the Kay Kafe; they must place these orders before arriving.

Below are some guidelines for ordering Room Service for outpatients.

- All orders must be placed in advance by calling extension 3000.
- When you call, please have the following information ready: **Patient's last name, medical record number, a call-back phone number and what you would like to order.**
- Family members and other visitors cannot place food orders for themselves using Room Service.
- Orders are cooked in the order they are received.
- **Orders may take up to 45 minutes to complete.**
- You will be called when your order is ready for pick-up.
- Orders not picked up within one hour will be discarded.
- You will pay for your orders at the Kay Kafe cash register.

If you prefer cafeteria items, you can purchase them in the Kay Kafe, but they are not offered on the Room Service menu. If your child is on the Low Bacteria Diet, all allowed food items are safe as served in the Kay Kafe.

If your child has a special diet and you have questions about what you should order, talk to the registered dietitian on your child's care team or call Clinical Nutrition at 901-595-3318.



What's new with My St. Jude

Last month St. Jude made changes to the online patient portal called *My St. Jude*.

Here are some changes that you will see when you first open the portal:

- New colors
- Menu items moved to the top instead of on the left

You can now use the portal on your mobile phone or other devices.

The rest of the portal has not changed. You can still message your health care team, review lab results and appointments, view parts of your Medical Record, and change your personal information.

If you have questions, please call Cerner Customer Support at 1-877-621-8014. Support is available 24 hours a day, 7 days a week.

If you would like to sign up for the portal, pick up a brochure from Patient Registration or download it at www.stjude.org/mystjude.



Talking about Medicines

Precautions for using fentanyl patches

By Shane Cross, PharmD, Pharmaceutical Services

At some point in your child's treatment, pain medicine might be needed. Fentanyl patches are one way to give pain medicine through the skin over time. Each patch helps relieve pain for three days.

The US Food and Drug Administration is stressing special precautions for fentanyl patches. Being exposed to fentanyl by accident can be harmful and even lead to death. Young children are at greatest risk because they are mobile and curious. Be sure to follow these guidelines to protect everyone from fentanyl patch dangers:

- Keep used and unused patches out of the reach of children.
- As soon as your child no longer needs fentanyl patches, throw away any patches that are left over. Remove the leftover patches from their protective pouches. Remove the protective liners and fold the patches in half, so the sticky sides stick to themselves. Flush them down the toilet. Do not flush the pouch and liner; throw them away in the trash.
- If anyone touches the gel on a loose patch, wash the skin right away with running water. Replace any loose patch using the guidelines in "Do You Know... About Fentanyl Patches."
- When it is time to replace a patch, remove the old patch and try not to touch the gel. Fold the used patch in half so the sticky side sticks to itself, and then flush it down the toilet. Wash hands well after handling the patch.
- The patch will release more medicine if it gets too warm, which could lead to an overdose. Your child may take a bath or shower while wearing a fentanyl patch, but avoid very warm or hot water. Your child should avoid hot tubs while wearing a fentanyl patch.

If you have questions about fentanyl patches or any of your child's medicines, talk to the doctor, nurse or pharmacist.

Teen Art Show: Submit your artwork or just enjoy viewing the masterpieces

Child Life will host the annual St. Jude Teen Art Show Wednesday, September 17, from 2–4 p.m. in the Danny Thomas/ALSAC Pavilion.

This year's theme is "The Fate in Our Stars," which will celebrate artwork about teens' experiences before,

during and since St. Jude.

You will have the chance to enjoy great art pieces as well as light snacks provided by the St. Jude chefs.

If you have teens interested in submitting artwork, please have them talk to their Child Life specialist.



St. Jude Children's Research Hospital

ALSAC • Danny Thomas, Founder

Finding cures. Saving children.

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St. Jude Parents is published on the first of each month by Patient Education and Bio-medical Communications. Your questions and comments are important to us. **We want to print advice and tips from St. Jude parents to other St. Jude parents.**

To share your ideas or to receive this newsletter by email, please call or email Alicia Huettel, RN, MSN, at 901-595-5453 (parents_newsletter@stjude.org) or Lois Young (lois.young@stjude.org). To subscribe to an online version of this newsletter, visit www.stjude.org/parents-newsletter.

If you have a smart phone, learn more about *St. Jude Parents* with this QR code.

St. Jude is an Equal Opportunity Employer.



For the latest details on upcoming events, see the bulletin board in the Patient Care Center lobby near Patient Registration.