

MAY 2016

Working together for better family care

The Family-Centered Care (FCC) Program offers many opportunities for parents to partner with staff to improve patient care quality, safety and satisfaction. In 2015, more than 40 dedicated parent advisers gave a total of 2,696 volunteer hours on programs related to the Family Advisory Council (FAC), Parent Mentor Program and Quality of Life (QoL) Steering Council.

To learn more about how you might get involved in these efforts, call or email Family-Centered Care Director Alicia Huettel at 901-595-5453, alicia.huettel@stjude.org.

FAC accomplishments for 2015:

The 18 parent advisers and five staff members on the FAC work to strengthen care, services and communications between staff and families. In 2015, members of the FAC focused on the following areas. These are just a few examples of the progress made in these areas. For a full listing, go to

www.stjude.org/

FAC accomplishments.

Improved clinical care experience

- Offered input into many policies, processes, services and research opportunities, some of which include: Reducing the use of anesthesia for scans, the Early Childhood Clinic, use of banked bio-specimens for genetic studies, Genomes for Kids (G4K) study, and the patient-family housing focus group.
- Shared in Magnet appraisal, resulting in the Magnet appraisers commending the institution for outstanding parental involvement.
- Worked collaboratively with the School Program and Volunteer Services to fully implement the Volunteer Tutor Program for patients.
- Served as members of many hospital committees, councils and workgroups.

Pressure ulcers, also called bed sores, can be dangerous for your child

Pressure ulcers, also called bed sores, can be harmful because the skin is the body's first line of defense against infection. If a pressure ulcer causes the skin to open, then your child is at risk for infection. Many St. Jude patients have weakened immune systems and can get infections more easily. An infection can make your child feel sicker and can become serious or even life threatening.

What is a pressure ulcer? A pressure ulcer is a place where the skin is damaged from pressing against a bed, chair or other surface. These sores are caused by a lack of blood flow because of the pressure placed on that area. Pressure ulcers can also look like blisters or bruises. They can be caused by lying in bed or sitting in a chair or wheelchair without changing positions often.

Here at St. Jude the staff wants to work with parents as a team to prevent pressure ulcers before they occur. When patients need to stay in bed, the staff will turn them every

two hours and use cushions to keep pressure off the bony parts of their bodies.

The staff will also check your child's skin from head to toe every shift and more often if they think your child is at greater risk of getting a pressure ulcer.

The staff will check your child's skin especially over bony areas like the back of the head, the back, elbows, heels, collarbone, tailbone, hands, feet and hips. They will look for red or dark areas or anything that looks like a blister or sore. When checking for pressure ulcers, the nurse will look under your child's clothing to be able to see every area of your child's skin.

You can help by sharing concerns with the nurse if you see areas on your child's skin that are red or dark or look like a blister or sore. Together, you and the staff can prevent pressure ulcers and help lower your child's risk of infection.

Education and information sharing

- Provided input for developing educational resources such as central line care video, unit welcome videos, proton therapy video, Do You Know...handouts and the *St. Jude Parents* newsletter.
- Shared perspectives for Childhood Cancer Awareness Month.

Spreading FCC culture at St. Jude

- Broadened the reach of the FCC E-Council (an online advisory group for St. Jude patient families), increasing membership to more than 195 members.
- Hosted FCC awareness month activities to educate and honor patient families and staff.
- Hosted "Coffee Talk," informal parent-to-parent social meetings that connect FAC parents to active patient families in all areas – inpatient, outpatient and housing.

Campus planning

The facilities subcommittee meets regularly with the Design and Construction staff for ongoing input into developing construction projects. Specific projects for 2015 included: Kay Research Care Center (inpatient room design, function and décor); adding digital charging stations in key waiting areas; and the Parent (caregiver) Exercise Room equipment and design.

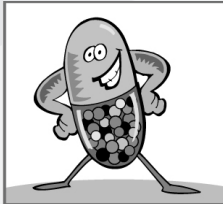
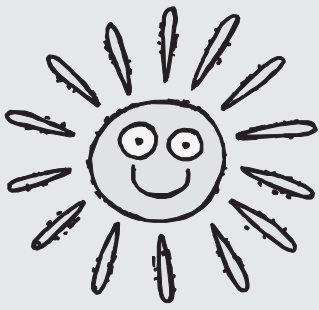
The QoL Steering Council accomplishments for 2015:

- Served on a parent panel at Schwartz Center Rounds and Day of Remembrance (DOR) and as presenters at two QoL education courses for St. Jude staff.
- Helped finalize and implement *Seasons of Change* booklet for 2015 Day of Remembrance.
- Co-led Day of Remembrance planning and implementation.

Parent Mentor Program accomplishments for 2015:

- The Parent Mentor Program connected 22 parent mentors and 125 parent mentees for a total of 862 encounters.
- The QoL Mentor program connected 15 parent mentors and 28 parent mentees for a total of 150 encounters.





Talking about Medicines

Folic acid and methotrexate therapy

By Hope Swanson, PharmD, Pharmaceutical Sciences

Cancer cells replicate (copy themselves) and spread in many ways. One way is through the folate pathway. Cells need folate, also called folic acid or vitamin B9, to copy themselves. Methotrexate (MTX) is an anticancer medicine that kills cancer cells by blocking folic acid metabolism. This results in less folate in the body.

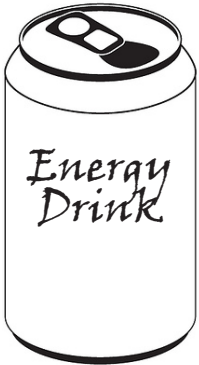
Both cancer cells and non-cancer cells need folate for survival. However, during treatment with methotrexate it is important that you **not** add extra folic acid to your child's diet.

Folic acid cannot be made by the body but can be absorbed when eating some foods, taking herbal and dietary supplements and even drinking energy drinks. A normal daily intake averages around 400 micrograms per day. While energy drinks are mostly known for their caffeine, they also contain other ingredients, including high levels of folic acid. **Taking in large amounts of folic acid can decrease the cancer fighting effects of methotrexate.**

Generally, your child should not take extra folic acid and should avoid food and drinks that contain large amounts of folic acid, such as energy drinks and some breakfast cereals.

To learn more about how vitamins, minerals and supplements can affect your child's medicines, ask for a copy of the handout called "Do You Know... Vitamins, Minerals and Supplements."

Please talk to the St. Jude care team before allowing your child to take any dietary and herbal supplements or to drink energy drinks.



Family Fun Day planned for patient families in May

Child Life will host St. Jude Family Fun Day Thursday, May 11, from 3:30–7 p.m. at the Danny Thomas/ALSAC Pavilion.

The event includes many fun activities to encourage family togetherness. Families can experience mini-vacations to Colorado, New York, Montana, and Florida. Activities include a photo booth, caricature artist, arts and crafts, and food to match the vacation destinations.

To help your family relax, the evening will conclude with a movie.

For more details, look for signs around the hospital about St. Jude Family Fun Day.

Electronic digital signs offer up-to-date announcements for patient families

For current information about upcoming events for patient families and other hospital announcements, look for the electronic digital signs located throughout the patient care areas and housing.

There are eight digital signs specifically for patient families. They are

located in the Patient Care Center, ALSAC Tower, Kay Research and Care Center, Kmart St. Jude Life Center, Target House I and II and Tri Delta Place.

You might see other electronic signs that are used for directions and to promote staff events, but they will not include patient family events.



St. Jude Children's Research Hospital

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St. Jude Parents is published on the first of each month by Family-Centered Care Services and Biomedical 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 or to learn more about *St. Jude Parents*, visit www.stjude.org/parents-newsletter.

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