

JANUARY 2018

St. Jude Family, Guest and Volunteer Services

When you need a helping hand

St. Jude Family, Guest and Volunteer Services offers many programs that directly support patients and their families. During the next few months, the *Parents* newsletter will highlight some of these programs that might be helpful for you.

The St. Jude staff knows that you love your children and you want to be there to support and care for them all the time, but sometimes you might need a break. What do you do? You feel bad about leaving your child alone. Family, Guest and Volunteer Services has the answer.

Through the Helping Hands program, volunteers provide short-term sitter services for patients and siblings. Most Helping Hands requests involve a volunteer sitting with a patient while a parent takes a break from one of the inpatient units or outpatient clinics. St. Jude patient families gave these positive responses to the program:

“I love this program. When we need to step out but aren't comfortable leaving our child alone, it's so nice to be able to rely on this volunteer team for help.”

“This program has been a valuable resource.”

Request a Helping Hands volunteer

Helping Hands volunteers are here to help families during these hours:

- Monday through Friday, 9 a.m.–8 p.m.
- Saturday and Sunday, as volunteers are available

Reasons to use the service

- St. Jude staff need to speak to parents in private.
- Siblings need care while patients are being treated.
- Parents need a break for dinner, laundry or to run an errand to housing.
- Parents just need a brief “mental health” break.

Limits to the service

- If a volunteer is working with a sibling who is not toilet trained, the parent needs to stay nearby to help with diaper changes when needed.
- Each Helping Hands visit should be no longer than two hours.
- Each volunteer is allowed to stay with no more than one patient or two siblings.
- The Helping Hands service is offered only in the hospital, not housing.
- This service is not meant to be a babysitting service for parents to

take long outings.

How to request

- Talk to your child life specialist, social worker or nurse. They can call Volunteer Services to request a Helping Hands volunteer. (All requests should come through a staff member.)
- Please give as much advance notice as you can. Volunteers will do their best to help you if they are not already assigned to another family.

During the 2016–2017 fiscal year, Helping Hands volunteers served 1,890 patients and 253 siblings. They averaged about 215 placements each month, and the average stay for each volunteer was about an hour and a half.

New options for patient snack bags

A few months ago Food Service and Child Life staff members held a taste testing session with St. Jude teens. “We had some products that we thought might be an improved snack bag alternative for patients,” said Kevin Krueger, Food Service procurement and sustainability manager. The teens liked the new products, so Food Service began the ordering process.

Four flavors of these snack boxes are now available in the Kay Kafe. “We hope this will provide a more appealing option to patients and parents who want healthier snacks” Krueger said.

The new LunchBundle snack boxes are made by Revolution Foods, and they offer meat raised with no antibiotics, cheese from cows not treated with rBST, and food items that do not have artificial flavors or preservatives. These snack boxes come in vegetarian, vegan and gluten-free options.

Every day, each St. Jude outpatient can get a free snack bag or LunchBundle along with a piece of fruit and a bottle of water. Other Kay Kafe customers can also buy these LunchBundle boxes for \$3.99 each.

Reorganizing to improve patient services

St. Jude has reorganized some patient care areas to make your life simpler and to improve how these programs work. The Patient Family-Centered Care Program has moved under the direction of Kathryn Berry Carter and the newly named Family, Guest and Volunteer Services department.

At the heart of family-centered care is the belief that health care staff and the patient family are partners, working together to best meet the needs of the child. As part of this program, parents and former patients serve in roles such as:

- Members of the Family Advisory Council or the Quality of Life Steering Council,
- Parent-to-parent mentors,
- Educators in programs for staff, and
- A variety of other staff-to-parent partnerships.

You can find out more about these roles and how you might help by calling Patient Family-Centered Care Manager Brittany Barnett at 901-595-7560 or by visiting stjude.org/familycenteredcare.

Alicia Huettel Wright, director of Patient Education and Information, will now focus on patient family education and managing and expanding the Linda R. Hajar Family Resource Center. If you have questions about patient education materials or resources, call her at 901-595-5453 or stop by the Family Resource Center on the Patient Care Center second floor.



Talking about Medicines

At St. Jude, we take medicines personally

By St. Jude Pharmaceutical Staff

Why do certain medicines work for some people and not for others? Why do some people get side effects from a medicine and other people don't? The answers to these questions may be in our DNA.

DNA is like a set of instructions for your body. Each person has a slightly different version of DNA; that's why we are all different. Certain parts of our DNA, called genes, are responsible for how we respond to medicines—whether they work for us and whether we get side effects from them. “Pharmacogenetics” (FAR mah coh je NEH tiks) is the word used to describe how our DNA (our genetics) affects medicines.

Researchers at St. Jude and all over the world are finding out which genes affect which medicines. Pharmacists at St. Jude are using these kinds of research discoveries to select and dose medicines based on your child's unique DNA. These staff members are also looking for the best way to put your child's genetic information in the medical record so it is easy for doctors and other clinic staff to find. Knowing what certain parts of your child's DNA look like from a blood test helps doctors pick the medicines that will work best for your child and the ones that will have the fewest side effects. This is one of many ways the staff personalizes care for St. Jude patients.

The staff tries to talk to every eligible St. Jude patient and patient family about being a part of the PG4KDS (Pharmacogenetics for Kids) program. All enrolled patients have the option of receiving their DNA test results by mail. These letters explain what the DNA test results mean and how they might affect certain medicines. Please keep these letters and show them to your child's doctors or pharmacists outside of St. Jude so that others can personalize medicines for your child, too. These letters are also viewable online in the documents section of the My St. Jude patient portal (stjude.org/mystjude).

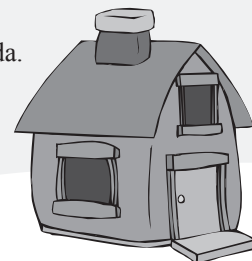
For more information, visit the PG4KDS website at stjude.org/pg4kds. You may also call the research nurses at 901-595-2482. If you are calling from outside the Memphis area, dial toll-free 1-866-2ST-JUDE (1-866-278-5833), then extension 2482.

Visit the Teen Art Show January 24

Child Life will host the annual St. Jude Teen Art Show Wednesday, January 24, from 2–4 p.m. in the Kay Kafe Rotunda.

We often spend much of our time away from our “actual” homes. This year through their artwork, our teen patients and siblings will convey their thoughts of “Home is Where the Heart is.”

Come support St. Jude teens and their art show. Light snacks will be served.



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. St. Jude is an Equal Opportunity Employer.

St. Jude complies with health care-related federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex.

ATTENTION: If you speak another language, assistance services, free of charge, are available to you. Call 1-866-278-5833 (TTY: 1-901-595-1040).

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-866-278-5833 (TTY: 1-901-595-1040).

تنبيه: إذا كنت تتحدث باللغة العربية فيمكنك الإستعانة بخدمات المساعدة اللغوية المتوفرة لك مجاناً. يرجى الاتصال بالرقم (الهاتف النصي): 1-866-278-5833 (1-901-595-1040).



St. Jude Children's Research Hospital

ALSAC • Danny Thomas, Founder

Finding cures. Saving children.

262 Danny Thomas Place
Memphis, TN 38105-3678