

St. Jude Parents



APRIL 2019

Helping families navigate the affiliates

Patients who will be seen at St. Jude Affiliate Clinics have a new ally in Memphis – the affiliate patient navigator.

What is the Affiliate Program?

The Affiliate Program extends St. Jude research treatment plans to children beyond the hospital walls. St. Jude partners with health care institutions in eight cities, including: Baton Rouge and Shreveport, Louisiana; Tulsa, Oklahoma; Springfield, Missouri; Peoria, Illinois; Huntsville, Alabama; Johnson City, Tennessee; and Charlotte, North Carolina.

These affiliate clinics allow patients from those areas to receive care closer to home. The affiliates help expand the number of children receiving St. Jude services and ease financial and other burdens on these patient families. Affiliates also help increase the number of children on St. Jude protocols (treatment plans) to help find cures faster and save more children.

St. Jude benefits are extended to

patients receiving care at the affiliate clinics. When the affiliate provider orders treatment-related care, it may be covered at no cost to the patient family. As always, there might be exceptions. If your child is seen at an affiliate clinic, discuss all options with the affiliate team to make sure you get the greatest cost benefit.

What is the affiliate patient navigator?

The new affiliate patient navigator is a person who helps educate families about their local affiliate clinic and hospital. This staff member also helps patient families prepare to return home. Families can meet with the affiliate patient navigator before returning home either for a brief visit or for a longer visit before care is transferred to the affiliate clinic.

Each affiliate clinic has its own processes based on its hospital's policies and procedures. Those processes may seem different than what patient families have learned during their time at St. Jude. The affiliate patient

navigator can tell families what to expect and who to contact for needed resources at their affiliate site. The navigator helps alleviate fears and fosters a smooth and safe transition of care for patients and their families.

Meeting the navigator

The affiliate patient navigator receives the names of new St. Jude patients who live in areas close to affiliate clinics. The navigator talks to each patient's clinical team to find out if that patient might return home during the treatment plan. If yes, the navigator will reach out to the family by phone or text to schedule a meeting.

If you want to find out more about the St. Jude Affiliate Program or the affiliate patient navigator, call 901-595-8802 or email

AffiliateHelp@stjude.org.

Using social media wisely

Patients and families coping with serious illness face many challenges. Support from friends within the St. Jude family and friends and family at home can be an important part of the treatment process.

The St. Jude staff knows that one common way to maintain these relationships, both inside and outside St. Jude, is through social media. This is most true when you are a long distance from your friends and family. A few examples of social media sites are Facebook, Twitter, Instagram and CaringBridge. While these resources might be helpful for you, it is important to be aware of the risks and the ways you can help keep you and your child safe.

To learn ways to protect you, your child and others, read "Do You Know... Using Social Media" at www.stjude.org/using-social-media or ask a staff member to print a copy for you.

You can also find helpful information at OnGuardOnline.gov, a website run by the Federal Trade Commission.

St. Jude Teen Formal 2019: A Night Under the Big Top

The St. Jude Child Life staff is excited to host the 2019 Teen Formal Thursday, May 16, from 5:30–8:30 p.m. in the Domino's Event Center on the St. Jude campus. This year's theme is "A Night Under the Big Top." The event will include world-class music entertainment from a nationally known DJ, amazing food, photos, limo ride and prizes, as well as a take-home gift for each guest.

The teen formal is open to patients and one guest each. All patients and guests attending must be between the ages of 15 and 19 by May 16, 2019, and enrolled in school. Formal invitations have been mailed to active and eligible St. Jude patients. The invitation includes information about how to register

online and about signing consent forms for the formal. As participants register, information about tux fest, dress fest, and salon service appointments will be available. Patients and guests must register before the formal by Friday, April 19.

To learn more about the teen formal, talk to your child life specialist or email questions to:

teenformal@stjude.org.





Talking about Medicines

Measuring liquid medicines taken by mouth

By Shane Cross, PharmD, Pharmaceutical Service

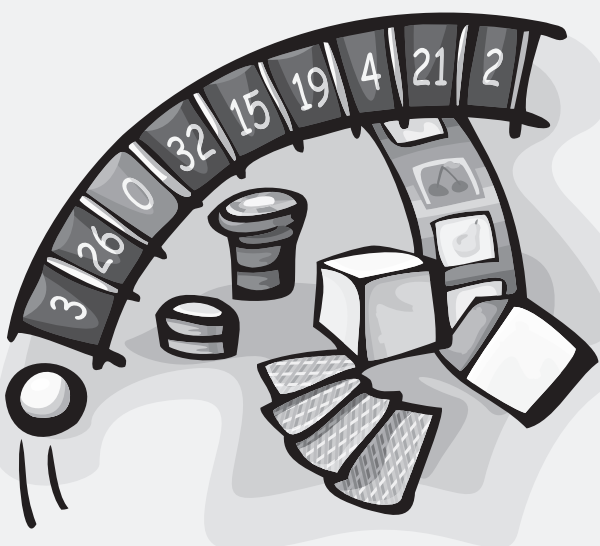
For medicines to be safe and effective, the patient needs to get the correct dose each time. When working with liquid medicines taken by mouth, it is important to measure each dose correctly.

Several devices can be used to measure liquid medicines. Some of these include oral (by mouth) dosing syringes, oral droppers and plastic medicine cups.

Unfortunately, many people still rely on household spoons—teaspoons and tablespoons—for giving medicine. These spoons are not accurate. One type of teaspoon can hold twice as much as another. Using kitchen spoons when giving medicine can be dangerous for your child.

You can help keep your child from getting too much medicine or not enough. Whenever you give your child a liquid medicine, be sure to use a labeled dosing device, not a household spoon. This will help ensure that you give the exact amount prescribed.

Ask your doctor, nurse or pharmacist for help if you have questions about how to measure your child's liquid medicines.



Casino Royale night planned for young-adult patients

The St. Jude Child Life staff will host a Casino Royale night for young adult patients Monday, April, 22, from 5:30–7:30 p.m. There will be food, music, prizes and casino games in the Domino's Event Center.

This event is open to patients and one guest each who are 19 years or older by the event date. Invitations have been mailed to active and eligible St. Jude patients. The mailings include details about how to register online and about signing consent forms. All those who wish to attend must register by April 15.

To learn more about this young-adult event, talk to your child life specialist or email questions to AYAEvent@stjude.org.

St. Jude Parents is published on the first of each month by Patient Education 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 Samantha Ransone, RN, PhD, at 901-595-3334 (ParentsNewsletter@stjude.org) or Lois Young (loislane.young@comcast.net). 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.

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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 الاستعانة بخدمات المساعدة اللغوية المتوفرة لك مجاناً. يرجى الاتصال بالرقم 1-866-278-5833 (الهاتف النصي: 1-901-595-1040).



St. Jude Children's Research Hospital

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