

# St. Jude Parents

OCTOBER 2018

## Together

### A credible source of information and hope

**S**t. Jude recently launched *Together* ([together.stjude.org](http://together.stjude.org)), a new, web-based resource for families and patients facing pediatric cancer. When a child is diagnosed with cancer, parents often have more questions than answers. In many cases, they turn to the internet and find a flood of information and opinions. Some is accurate and helpful. Some isn't. There is a need for one complete, credible source of information and hope.

The St. Jude staff designed *Together* as a "home base to face

cancer." It offers trustworthy information and a community of support for anyone with childhood cancer. The content covers the entire cancer journey. Families can use the website as a resource from diagnosis through treatment and into life after cancer.

*Together* includes:

- Expert, medical information
- Articles and videos about diagnosis, treatment, next steps and life after cancer
- Stories from childhood cancer patients, survivors and families
- Practical ideas from specialists,

parents, patients and survivors. To extend the vision of our founder Danny Thomas, St. Jude offers *Together* to families regardless of where they receive treatment. St. Jude staff and faculty helped guide topics and reviewed each article. All people touched by childhood cancer deserve a community where they can learn, connect and support one another.

Feel free to visit and explore the site. Share your own story or ideas for new topics. Email them to [together@stjude.org](mailto:together@stjude.org).

### What, when and how much you can record at St. Jude

St. Jude staff members know there are many events during treatment that you may wish to photograph, videotape, stream or audiotape. To protect the health, safety and privacy of you, your child, the staff and all St. Jude patients, please follow these guidelines for when you can and cannot make photos and recordings:

- You may not photograph or record any medical care being given to the patient because it may interfere with the safety and health of you, your child or the staff. Also, staff have the right to refuse to be in any photo or recording, and

they are not allowed to take part in recorded interviews about a patient's care or treatment. You should always ask first.

- Important events occur during treatment that you may want to celebrate and share. The following events may be photographed and recorded:

- First and last day of chemotherapy (after chemo has been given)
- Birthdays
- Special patient events (such as Halloween or graduation days)
- St. Jude staff and volunteers may not, at your request, use any

device to record medical care being given to a patient. However, if you or your child has a medical or communication need to have recorded information, the staff can help you record that information or get it in a form that is easy to use. This ensures that patients and caregivers with impaired communication skills have an equal chance to take part in St. Jude services.

- You may take photos and make recordings of yourself or your children while at St. Jude. However, you must always respect the privacy of other patients, their family members, St. Jude staff and volunteers. Do not take photos or recordings of anyone without permission.
- St. Jude staff may ask you or your family members to delete your photos or recordings or take other actions if they believe the recordings would affect patient care or someone's privacy. Please follow these requests.

If you have a question about these rules, ask a St. Jude staff member or email your question to the Patient and Family Experience Office at [patientandfamilyexperienceoffice@stjude.org](mailto:patientandfamilyexperienceoffice@stjude.org).

If you would like other memory making ideas, talk to a child life specialist or call Child Life at 901-595-3020.

### Tdap vaccine offered to caregivers

In recent years, the number of infants with whooping cough (pertussis) have increased, because protection from the disease has been fading in adults.

St. Jude offers the Tdap (tetanus diphtheria pertussis) vaccine free to patient parents and other adult caregivers. Vaccination is ongoing for our patient care employees.

Tdap vaccine protects against all three diseases—tetanus (lockjaw), diphtheria, and pertussis (whooping cough). Both diphtheria and pertussis are spread through person-to-person contact. Diphtheria is rare in the United States as a result of widespread vaccination against the disease.

The US Centers for Disease Control and Prevention (CDC) recommend that adults 19 years or older who did not receive Tdap as a preteen or teen should receive a single dose of Tdap. Pregnant women should receive a dose of Tdap during each pregnancy, preferably at 27 through 36 weeks. This helps increase the amount of disease protection passed to the baby.

This free Tdap vaccine service will be offered for parents and other adult caregivers Monday–Friday from 1–4 p.m. in the Patient Care Center Assessment and Triage area of the Outpatient Clinic.

If you have questions about the Tdap vaccine, talk to your doctor or your child's primary clinic.



## Talking about Medicines

### Special delivery: Pharmacy follow-up calls for oral chemo delivered to homes

By Shane Cross, PharmD, Pharmaceutical Service

Many St. Jude patients receive oral chemotherapy (chemo) as part of their treatment. Oral chemo is any cancer-fighting medicine taken by mouth. When the St. Jude Pharmacy gives you oral chemo drugs at the hospital, a pharmacist gives you a Patient Medication sheet and medicine counseling. The pharmacist can help answer questions you might have about the drug.

If your child's doctor allows it, St. Jude can deliver some courses of oral chemo by FedEx to your home. An adult must be at home to sign for this type of medicine delivery.

It is important for you to be well informed about the proper use of your child's medicines. The St. Jude Pharmacy works hard to ensure the safe and correct use of oral chemo. This includes making sure the medicine is delivered to the correct person and that you clearly understand how to use it.

If you receive a new chemo drug or a change in the dose of oral chemo at home, a St. Jude pharmacist will call you after the FedEx package has been sent. The pharmacist will ask if you received the right medicine and will briefly review the correct use of the drug. The pharmacist also can answer your questions about the oral chemo or other drugs that your child is taking.

If the pharmacist cannot reach you to discuss your child's oral chemo, please call the St. Jude Pharmacy. The staff wants to make sure you received the medicine and will briefly review the guidelines for giving the drug to your child. Every oral chemo order sent by FedEx will include a note card that tells you how to contact the St. Jude Pharmacy.

If you have questions about this process or about any of your child's medicines, call the Pharmacy at 901-595-4166. If you are outside the Memphis area, dial the Pharmacy's toll-free number, 1-866-820-2442.

## Get ready patients and families: Halloween plans are in the works

Halloween is almost here at St. Jude and employees are gearing up for one of the best celebrations ever. The Halloween committee has been planning for months and has added some new treats for 2018. Outpatients and families can look forward to a new route, special trick-

or-treat bags and entertainment from some roving tricksters while navigating the booths.

Inpatients and their families will still be able to take part in reverse trick-or-treating, where the candy comes to you. Stay tuned for more details as Halloween approaches.

*St. Jude Parents* is published on the first of each month by Patient Education and Information 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 Wright, RN, MSN, at 901-595-5453 ([ParentsNewsletter@stjude.org](mailto:ParentsNewsletter@stjude.org)) or Lois Young ([loislane.young@comcast.net](mailto: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](http://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 الاستفادة 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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*Finding cures. Saving children.*

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