

St. Jude Parents

DECEMBER 2015

New St. Jude strategic plan announced

St. Jude Children's Research Hospital President and Chief Executive Officer James R. Downing, MD, is a man with a plan: a \$7 billion, six-year strategy for conquering cancer and other childhood diseases.

"We're in a war against cancer with innocent children dying every day," he says. "As stewards of this extraordinary institution, we must continuously ask: 'Are we doing enough to win that war?'"

A year ago, with that challenge in mind, Downing enlisted the help of 180 people from across the institution who were organized into 15 working groups. Together, they created a bold plan for success on three fronts: in the clinic, in the laboratory and around the world.

During the past five decades,

St. Jude has made remarkable progress toward curing childhood cancer and other life-threatening diseases. Downing wants to build on that success, pushing cure rates ever higher, while developing tailored treatments to decrease side effects.

To do that, St. Jude plans to double the number of patients enrolled in St. Jude-led clinical trials. The hospital will also start a proton therapy program, create a national referral clinic for rare pediatric cancers, and launch a program aimed at harnessing the immune system to combat cancer.

The hospital's survivorship efforts will grow as well to increase the quality and length of life for current and future survivors.

"These are big efforts that no other single institution can do,"

Downing says.

One key initiative is the creation of a St. Jude-funded Clinical Research Consortium, a global group of institutions that will develop clinical trials for rare, aggressive diseases. About a dozen of the world's top institutions will be invited to work together on developing and running highly complex clinical trials.

In the coming years, St. Jude research in the areas of sickle cell disease, coagulation disorders and bone marrow failure syndromes will extend beyond symptom management to cures.

For all children and families who come to campus, Downing aims to create the gold standard for patient care.

"Our patients love St. Jude," he says. "But we want to enhance the patient and family experience to make it even better."

Downing says St. Jude has the obligation and the ability to help children around the world. Today, more than 80 percent of children with cancer live in low- and middle-income countries. More than half of those will die from their diseases. The St. Jude International Outreach Program is dedicated to changing that sobering statistic.

"Our goal is to ensure that pediatric cancer patients worldwide have access to care," Downing says.

The hospital's new strategic plan is extensive, and the potential exciting. But Downing says the aim is simple. It's a plan that hinges on the support of scientists, clinicians and staff. And of course, to be successful this vision for the future of St. Jude will rely heavily on the financial support of many generous donors.

"We're at a point in our hospital's history where it's clear we can do more. Because of our success, we have the opportunity and the responsibility to establish an agenda that will accelerate progress toward advancing cures for pediatric catastrophic diseases," he says.

"We must do what others cannot do."

What face mask can my child wear?

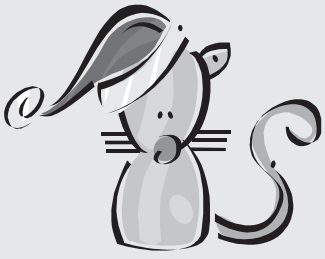


Are all face masks the same? The answer is no. Masks have many different levels of protection based on why they are being used. If your child has low blood counts (neutropenic), an N-95 mask should be worn, like the white "duck bill" mask that St. Jude provides. The N-95 is important to help protect your child from germs and mold particles.

Staff members have noticed that some parents have been ordering their own masks for color, comfort or style. We understand that your child wears the mask for a long time every day, and you may prefer a different mask. But keep in mind that as a team we want to make sure you are protecting your child's health as well as possible with the mask choice you make.

You can simply use the white "duck bill" masks provided at St. Jude. However, if you choose to order special masks, please make sure you order a mask with an N-95 level of protection. Also, please talk with your doctor or nurse about your choice.

To get the best protection, change the N-95 face mask when wet, soiled, or after one week of use. Handmade cloth masks do not provide any filtration protection from germs or mold. If you have questions ask your doctor or nurse first, so you will have the information you need to choose the best mask for your child.



Talking about Medicines

Knowing your child's medicines

By Shane Cross, PharmD, Pharmaceutical Services

During the course of treatment, the number of medicines your child takes can really add up. Because parents are so vital in the health care of their children, you need to know what medicines your child is taking. A list can be a helpful way to keep track of medicines. A list should include details such as the name of each medicine, the reason it is being used, the current dose and how often it is given. Be sure to update your list often.

Patients and parents who understand their medicines are more likely to use them correctly. By understanding these drugs, you can avoid harmful effects that might occur from taking too much or not enough.

If you do not understand something about a medicine, ask your child's doctor, nurse or pharmacist for help. Here are some other useful tools to help you with your child's medicines:

- Reading Patient Medication cards provided at St. Jude
- Using a pillbox
- Using a medicine calendar
- Using a watch, clock or cell phone alarm to remind you when doses are due

We understand that it can be hard to keep track of your child's medicines. The St. Jude staff is here to work with you. Together we can provide your child with the best possible care.

Christmas Eve Communion offered

Spiritual Care Services will offer Christmas Eve Communion to patients, families and staff in the hospital Chapel from 1:30 to 2:30 p.m. on Thursday, December 24. All are invited to attend.

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.

Medicine Room reminders

The Medicine Room is open 24 hours a day, 7 days a week, including holidays. Patients receive chemotherapy (cancer-fighting drugs), blood products, and other medicines and treatments in this area. The Medicine Room staff needs your help with the following guidelines.

- When your child is getting daily chemotherapy (chemo), the appointment in the Medicine Room should occur around the same time each day. Before you leave each day, please verify with your nurse when you should return for your child's next chemo dose.
- The first dose of GCSF or pegfilgrastim can be given no sooner than **24 hours after the end**

of your child's chemo. If your child's schedule gives an earlier appointment time, please ask the nurse or nurse scheduler to reschedule your child's appointment to the correct time.

- Whenever you come to the hospital, please bring all the medicines with you that you must give your child during the day. If you forget something your nurse can order it for you, but it will take a while to process through the pharmacy, which can delay your child's medicine doses.
- Please call before you come in with a sick child. This will speed up your child's registration, scheduling and ordering of any needed medicines, as well as make sure a room is set up and ready for your child.
- If you have not been called to the Medicine Room within 30 minutes of your scheduled appointment time, please let the patient representative know how long you have been waiting.

The staff hopes that these tips will decrease the time your child must wait to receive treatment in the Medicine Room. To learn more Medicine Room guidelines, see the handout "Do you know... Medicine Room."



St. Jude Children's Research Hospital

ALSAC • Danny Thomas, Founder

Finding cures. Saving children.

262 Danny Thomas Place
Memphis, TN 38105-3678