



Dana-Farber
Cancer Institute



Boston
Children's

Dana-Farber/Boston Children's Cancer and Blood Disorders Center



Care After Stem Cell Transplant (SCT)

A Guide for Patients & Caregivers

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Care After Stem Cell Transplant (SCT)

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When to Call Your Care Team

Call if your child has a temperature of:

- **101.3 F (38.5 C) or higher or**
- **lower than 96.8 F (36.0 C) or**
- **100.4 F (38.0 C) or higher twice in 24 hours**

Note: If your child's temperature is **between 100.4 F (38.0 C) and 101.2 F (38.4 C)** wait 1 hour and check the temperature again. In 1 hour, or any time in the next 24 hours, if your child has a temperature of **100.4 F (38.0 C) or higher**, call right away. If at any time you think your child's temperature has increased (gone up), take the temperature again.

Also call if your child has:

Shaking or chills or looks sick	Diarrhea • Loose, liquid bowel movements 3 or more times a day	Constipation • No bowel movement in 2 days
Unusual bleeding • Nosebleed or bleeding gums that don't stop after 15 minutes of gentle pressure • Blood in urine or bowel movements	Change in appetite or fluid intake • For child <u>under</u> 1 year old: Nothing to eat or drink for 6 hours while awake • For child <u>over</u> 1 year old: Nothing to eat or drink for 8 hours while awake	Signs of a seizure • Confused, dazed, shaking, or looks awake but not responsive
Easy bruising or tiny red spots (red "freckles") on the skin	Headaches	Rash or change in skin color
Change in vision, hearing, or balance , or seems less alert	Vomiting multiple times in one day	New or unusual pain
Less urine output (pee) than usual or no urination for 6-8 hours while awake	Exposure to a person who has chicken pox, shingles, or any other contagious disease	A change that worries you, or if you think your child may need to be seen that day

Phone Numbers to Call

- Weekdays 8 a.m. to 5 p.m.: Jimmy Fund Clinic (617) 632-3270
- After 5 p.m. or anytime on weekends and holidays:
 - Solid tumor, neuro oncology, hematologic malignancy patients: Call (617) 632-3352 and ask for the pediatric oncology provider on call.
 - Stem cell transplant patients: Call (617) 632-3352 and ask for the pediatric stem cell transplant provider on call.
 - Bone marrow failure clinic patients: Call (617) 355-6363 and ask for the hematology provider on call.
- For life threatening emergencies call 911.

When to Call Your Care Team

In an Emergency

Call 911 right away if your child has:

- Trouble breathing.
- Blue or gray skin color.
- Unresponsiveness (not waking up or not responding to you).
- Signs of a seizure if you do not have a plan from your care team for responding to seizures.
- Excessive bleeding that seems life threatening.
- Other life threatening symptoms.

Less Urgent Medical Needs

Prescription Refills

Call the clinic at (617) 632-3270 at least 48 hours before your child will need a refill.

When you ask for a refill, you will need to give:

- Your child's name and date of birth.
- Name of the medication.
- Pharmacy phone number.

The information will then be sent to your care team.

Home Health or VNA Services

- If you have a question about a blood draw or medications that your child gets at home via home health care (VNA) services, call that healthcare company directly. If they are unable to help you, call the clinic at (617) 632-3270.
- Call the Jimmy Fund Clinic Case Manager at (617) 632-3258 if you have a question about home health care companies, supply companies, infusion companies, or health insurance issues.

Tests and Studies

- For questions about scheduled tests or results at Boston Children's Hospital, call (617) 355-6000.
- General information about tests and appointments is on the MyChildren's Patient Portal: <https://apps.childrenshospital.org/mychildrens/>

Division of Psychosocial Oncology and Palliative Care:

Call the Division of Pediatric Psychosocial services at (617) 632-5425 if you have a question about psychosocial services or need support.

Who to Call for Patient Care

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- For life threatening emergencies call 911.



Temperature and Fever

Fever is a sign of infection. It is a serious concern in patients whose bodies cannot fight infection well.

A fever is a temperature of:

- 101.3 F (38.5 C) or higher, or
- 100.4 F (38.0 C) or higher twice in 24 hours

If you think your child does not look well or might have a fever:

- Take your child's temperature under their armpit, by mouth, forehead, or in their ear. **Never** take a rectal temperature.
- Take temperature the same way with the same thermometer, when possible.
- Do not give medicine to lower a fever until you ask your care team if it is ok.

If your child's temperature is:

- **Lower than 96.8 F (36.0 C)** →
- **101.3 F (38.5 C) or higher** →
- **Between 100.4 F (38.0 C) and 101.2 F (38.4 C),** wait 1 hour and take your child's temperature again.



When you check again in 1 hour,
or any time in the next 24 hours,
if your child's temperature is
100.4 F (38 C) or higher →

**Call your care
team right away.**



- **Weekdays 8 a.m. to 5 p.m. (617) 632-3270**
- **After 5 p.m. and on weekends and holidays:**
 - ◇ **call page operator (617) 632-3352.**
 - ◇ **ask for the pediatric oncology or stem cell transplant provider on call.**
- **For life threatening emergencies call 911.**

Call right away if your child has any signs of fever or infection.



Temperature Chart

°C	°F
35.8	96.6
36.0	96.8
36.2	97.2
36.4	97.6
36.5	97.7
36.6	97.9
36.7	98.0
36.8	98.2
37.0	98.6
Average Normal	
37.1	98.8
37.2	99.0
37.3	99.2
37.4	99.4
37.5	99.6
37.6	99.8
37.7	99.9
37.8	100.0
37.9	100.2
38.0	100.4
38.1	100.6
38.2	100.8
38.3	100.9
38.4	101.1

°C	°F
38.5	101.3
38.6	101.5
38.7	101.7
38.8	101.8
38.9	102.0
39.0	102.2
39.1	102.4
39.2	102.6
39.3	102.8
39.4	103.0
39.5	103.1
39.6	103.3
39.7	103.5
39.8	103.7
39.9	103.8
40.0	104.0
40.1	104.2
40.2	104.4
40.3	104.6
40.4	104.8
40.5	105.0



Discharge After Stem Cell Transplant

As you get ready for discharge from the hospital after stem cell transplant (SCT), it is very important to know the best ways to help your child stay healthy. It may take a while for their immune system to recover, and your child will need to take steps to avoid infection during this time. How long can vary for each patient:

- Autologous transplant (using your child's own stem cells): 60 days after transplant.
- Allogeneic transplant (using donor stem cells): up to 12 months after transplant.

Your care team will tell you when it is safe for your child to return to normal activities.

Before Discharge

Goals:

- ANC over 500 for at least 3 days.
- No infections or fever.
- Able to take in enough fluids and food.
- Clear follow-up plan.
- Able to take all needed medicine.
- Pick up all prescribed medicine from the pharmacy. The care team will explain what each is for and how and when to give them to your child.

Preventing Infection at Home

The best ways to prevent infection are to keep hands clean and avoid contact with anyone who is sick.

If your hands look dirty, you must clean them with soap and water.

- You must also wash hands after you:
 - Use the bathroom.
 - Touch pets or animals.
 - Come in from outside.
- You must also wash hands before AND after you:
 - Prepare or eat food.
 - Touch wounds.

It is important to limit the number of people your child is around.

- Limit visitors in your home. All visitors must be healthy, have not recently been with anyone who is sick, and should be up-to-date with vaccines.
- Your child should not go to other people's homes or indoor public places (school, stores, restaurants, places of worship).
- Your child can go to outdoor uncrowded places but should not be in crowded outdoor places (such as big sporting events or theme parks). They may go at times that are not busy.
- Your child should not be with people who are sick. If they must be with someone who is sick, limit the time together, wash hands often, and consider wearing a mask.

Discharge After SCT

Make sure your home is clean and has no dust, mildew, or mold.

- Limit clutter as it can trap dust and mites.
- Make sure air conditioners, central heating filters, and vents are working properly, clean, and free from dust.
- Do not use vaporizers, humidifiers or diffusers.

Your child should not have contact with dirt, soil, sand, or plants. This includes:

- Farms, digging sites, gardening, and lawn mowing.
- They should not touch any standing water (including plants and fresh flowers). If you have a Christmas tree, it should be a fake tree. You should not have a live Christmas tree inside your home.

Pets

You may keep pets you already own, but your child should not touch reptiles (turtle, snake, lizard) or amphibians (frog, salamander).

- Your child should not clean up after their pet (such as a litter box, tank, or cage) or give them a bath.
- Pets who live outside (such as farm animals) should not come into the house.
- If you have other exotic pets (such as birds or ferrets), please talk with your care team.

Food

- Anyone making food for your child should wash their hands with warm, soapy water before and after preparing food.
- Kitchen areas and utensils used for food preparation should be kept clean.
- Dishes should be washed in hot, soapy water, either by hand or in the dishwasher.
- Your care team will give you details about foods your child should avoid.

Bathing and Swimming

- To take a bath with a CVC, cover the line and dressing with an occlusive dressing, such as Tegaderm® or Aquaguard®.
- Your child may not swim if they have an external Central Venous Catheter (CVC).
- Once the CVC has been removed and the wound has healed, your child may swim in a private pool, lake, or ocean. They should not swim in small ponds.
- Your child should wear water shoes, not be in the sun too much, and take a bath after they swim.

Vaccines

- Your child will get the flu and COVID-19 vaccines around 60 days after SCT (for autologous SCT) or 100 days after SCT (for allogeneic SCT).
- Around 6 months after SCT they will start to get their newborn and pediatric vaccines, even if they had them before SCT.
- It may take up to 2 years to get back up to date on vaccines.

Your child should not be around anyone who:

- Has not had chickenpox or the chickenpox vaccine, the seasonal flu vaccine, or the COVID-19 vaccine.
- Has a rash from a vaccine.
- Has received a live vaccine, particularly:
 - The oral polio vaccine within the past 6 weeks.
 - Nasal Flumist or Rotavirus vaccination within the past 7 days.

Travel

- Talk with your child's care team before making any travel plans.
- It is best not to travel on shared rides (trains, buses, taxis).
- Your child should only be in a car with household members (no mask needed).

Other

- When outdoors, use sunscreen (SPF 50 or higher) and wear a hat and protective clothing.
- Smoking, vaping, and tobacco or marijuana smoke should be avoided as they are risk factors for lung infections in people with poor immune function.
- Alcohol may interact with medications. Please talk about this with your care team if you have questions.

If you have questions about what your child should do or not do while recovering from a stem cell transplant, please ask your care team.

Who to Call for Patient Care

- Weekdays 8 a.m. to 5 p.m.: Jimmy Fund Clinic (617) 632-3270
- After 5 p.m. or anytime on weekends and holidays:
 - Solid tumor, neuro oncology, hematologic malignancy patients: Call (617) 632-3352 and ask for the pediatric oncology provider on call.
 - Stem cell transplant patients: Call (617) 632-3352 and ask for the pediatric stem cell transplant provider on call.
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- For life threatening emergencies call 911.



Visits to the Jimmy Fund Clinic After Discharge from Stem Cell Transplant (SCT)

The Jimmy Fund Clinic of Dana-Farber Cancer Institute (DFCI) is located on the 3rd floor of the Dana Building. SCT patients must wear a mask in the Dana Building. If you have questions or are going to be late, please call the clinic at (617) 632-3270.

If your child takes Cyclosporine (Neoral®, Sandimmune®, Gengraf®) or Tacrolimus (FK506/Prograf®):

- Do NOT take the morning dose of Cyclosporine or Tacrolimus before your clinic appointment. Bring the medicine with you.
- You will be scheduled to come to the clinic before 10 a.m.
- After their blood draw, have your child take your home supply of Cyclosporine or Tacrolimus.
 - The care team will call you if the next dose needs to be changed. If you do not get a call, continue to take the same dose.

At the Jimmy Fund Clinic (JFC)

- Check in at the front desk.
- Your child will be seen in a private room or exam room. They should not wait in the main waiting room.
 - A clinic assistant or nurse will be in your room within 15 minutes to do vital signs and/or lab tests. If they are not there in 15 minutes, use the nurse call button.
- When using the clinic restroom, wear a mask and wash your hands well with soap and water.
- The length of clinic appointments will vary.
- Patients may need to come to clinic 1 to 3 times a week for the first few weeks or months after discharge. Before leaving clinic, you will be told when the next appointment will be.

What to Bring to the JFC:






- For your first visit to clinic, bring all the bottles of medications and your list of discharge medications. The care team will go over with you the doses and when to take them.
 - Review all medications from home with your care team before taking them during clinic.
 - For all medications, remember to call your pharmacy for a refill before the medication runs out even if you have a scheduled clinic appointment. Refills may take 48 hours to be filled.
- You may bring toys or books from home, and there are also activities in clinic to help pass the time.
- You may bring lunch and snacks from home, or you may order lunch from the cafeteria.

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Food Plan After Stem Cell Transplant (SCT)

This food plan is for your child to use while in the hospital and at home after having a stem cell transplant (SCT). It is meant to help your child's body as the immune system heals. Follow this food plan until your child's care team tells you to stop.

Food Groups	Foods Allowed	Foods NOT Allowed
Meat, Poultry, Eggs, and Seafood 	<ul style="list-style-type: none"> Meats, poultry, and seafood cooked to safe internal temperatures Hot dogs, lunch and deli meats heated until steaming hot before eating (temperature should be 165°F/73.8°C) Pasteurized eggs and egg products 	<ul style="list-style-type: none"> Raw or undercooked meat, poultry, or seafood Smoked meats (like salmon/lox) Unpasteurized meat spreads or pates Foods with raw eggs (including homemade Caesar dressing, homemade mayonnaise, homemade egg nog, and cookie dough)
Milk and Milk Products 	<ul style="list-style-type: none"> Pasteurized milk and milk products Hard cheeses Processed/pasteurized cheeses (like cheddar, mozzarella, cream cheese) 	<ul style="list-style-type: none"> Unpasteurized milk and milk products Unpasteurized or soft cheeses made from (raw) milk such as queso fresco, blue-veined, feta, brie, and camembert
Fruits and Vegetables 	<ul style="list-style-type: none"> Washed fresh vegetables including lettuce/salads Cooked sprouts Washed fruits with thin skins Thick-skinned fruits (like oranges, melon, kiwi) 	<ul style="list-style-type: none"> Unwashed fresh vegetables including lettuce/salads Raw alfalfa and bean sprouts Unwashed fresh fruits
Juices, Drinks, and Water 	<ul style="list-style-type: none"> Bottled water (recommended while in hospital) City water including tap water (upon discharge) Well water boiled for at least 2 minutes 	<ul style="list-style-type: none"> Unpasteurized cider or juices Ice from communal ice machines
Other 	<ul style="list-style-type: none"> Restaurant food (including fast food and food from take-out, drive-through, and delivery) Commercially packaged honey 	<ul style="list-style-type: none"> Pre-prepared salads Unpasteurized honey

Always follow these steps for food safety:

- **Clean:** Wash hands and surfaces often.
- **Separate:** Separate raw meat from other foods.
- **Cook:** Cook to the right temperature.
- **Chill:** Refrigerate foods right away.
- Never buy food displayed in unclean conditions.
- Avoid buffet style foods including salad bars.



- Buy produce that is not bruised or damaged.
- Only use canned food from cans with no dents, cracks, or bulging lids (clean lids once home).
- Do not leave cooked food out of the refrigerator or oven for more than 60 minutes.
- Throw away leftover cooked foods after 2 days.
- When ordering restaurant food, don't hesitate to ask questions about how the food is prepared.

For more information, visit www.fda.gov/food/buy-store-serve-safe-food/safe-food-handling.

Follow this plan for 60 days (autologous transplants) or at least 6 months (allogeneic transplants) or until the care team tells you to change the diet.

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- For life threatening emergencies call 911.



Mouth Care

It is important to keep your child's mouth and teeth clean to prevent infection and mouth sores.

Brush after each meal and before bed using a soft toothbrush with fluoride toothpaste. Most children under 6 years old should have their mouth care done or supervised by an adult caregiver.

- Soft electric toothbrushes can be used.
- How much toothpaste to use:
 - Age 3 and under: A small smear.
 - Ages 3-6: A pea size drop.
 - Over age 6: About 1 inch.
- Rinse the mouth with water often to keep it moist.
- Do not use mouthwash that contains alcohol as it can dry the mouth.

Dental Visits

Patients should see a dentist regularly. Good dental care is important during treatment. Speak to your care team before seeing the dentist.

Mouth Sores

Some chemotherapy medicines and radiation can cause sores known as *mucositis* in the digestive system (mouth, throat, stomach, and intestines).

Things That May Help

- Drink cold or room temperature fluids through a straw.
- Avoid hot, spicy, and acidic foods.
- Eat foods that are soft (such as blended or puréed).
- Cut food into small pieces.

Call your care team if your child:

- Has pain or difficulty eating or drinking.
- Develops spots or sores in their mouth.

Who to Call for Patient Care

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- After 5 p.m. or anytime on weekends and holidays:
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Chickenpox (Varicella) & Shingles (Zoster)

Chickenpox (also known as *varicella*) is caused by the varicella-zoster virus. It is spread through the air and is very contagious (spreads easily from one person to another). While rare, people with weakened immune systems can also get chicken pox from the vaccine. If you or someone else who lives with your child recently got the chickenpox vaccine, or plan to get vaccine, please talk to your child's care team.

- Chickenpox usually starts with a fever and feeling very tired (similar to flu symptoms).
- Next an itchy rash with clear, fluid-filled bumps will usually appear.
- The fluid-filled bumps will open, and the spots will become dry and crusted as they heal.
- New spots can develop over several days, and the rash lasts about 7 days.
- **Chickenpox can be more serious for children who have a weakened immune system.**

Shingles (also known as *herpes zoster*) is an infection that is caused by the varicella-zoster virus. After a person has recovered from the chickenpox, the virus stays in the body with no symptoms. If the immune system is suppressed (weakened), the virus may become active again. People with weakened immune systems can also get shingles after the chickenpox vaccine. If you or another adult who lives with your child recently got the shingles vaccine, or plan to get this vaccine, please talk to your child's care team.

Shingles can be painful and cause a deep burning feeling. This usually starts with:

- Pain in one area of the body.
- A patch of red blisters that form a line on the skin.

Exposure

Call your child's care team right away if your child has been around someone with chickenpox or shingles, even if your child previously received the vaccine.

- Your child may need medication to protect against or treat the virus.
- Medication must be given as soon as possible after exposure.

Treatment

If your child has symptoms of chickenpox or shingles, call your healthcare team right away.

- Your child may need medication to help control the virus.
- Admission to the hospital may be needed for treatment.
- To protect other patients from chickenpox or shingles, the healthcare team will ask you to follow specific precautions while in clinic or in the hospital.

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- After 5 p.m. or anytime on weekends and holidays:
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- For life threatening emergencies call 911.

Please share this handout with any healthcare provider your child sees outside of the Jimmy Fund Clinic. It explains the vaccines that your child needs after a stem cell transplant.

Vaccination Schedule for Patients After Stem Cell Transplant

Vaccination or Toxoid (May use any formulation of combined vaccines)	Time Post Stem Cell Transplant Prior to receiving non-live vaccinations (except influenza and COVID), patients should be at least 6 months from transplant, off exogenous immune suppression, and off IVIG for at least 2 months.							
Inactivated Influenza ¹	Yearly seasonal, October through March. Eligible patients are >100 days post allogeneic HSCT and on <0.5mg/kg/day of systemic corticosteroids; >60 days post autologous SCT							
COVID-19 ²	ONLY patients that meet current CDC age-based eligibility criteria Eligible patients are >100 days post allogeneic HSCT and >60 days post autologous SCT.							
	6 months	8 months	10 months	12 months	18 Months	24 months	26 - 36 months	Notes
Diphtheria, Tetanus, Acellular Pertussis (all ages)	DTaP	DTaP	DTaP					TDap Booster at age 11-12 years, then TD every 10 years thereafter
H. Influenzae Type B	HiB	HiB	HiB					
Hepatitis B	Hep B	Hep B	Hep B					
Pneumococcal-Conjugate (PCV20)	PCV20	PCV20	PCV20		PCV20			
Inactivated Polio Virus	IPV	IPV	IPV					
Hepatitis A				Hep A	Hep A			
Meningococcal Quadrivalent ³ (age >11 or <11 if asplenic)				Men ACW				Booster recommended at age 16-18 years
Meningococcal B ⁴ (ages 16 – 23)				Men B				Ages 16-18 preferred
Human Papillomavirus ⁵ (ages 9-26 years)				HPV	HPV	HPV		
MMR (live attenuated) ⁶	No Live Vaccines are given until at least 2 years post-HSCT and then only when other clinical criteria are met***					MMR	MMR^	Second dose can be given one month later for age >13 years
Varicella (live attenuated) ⁶						VZV	VZV^	
Palivizumab ⁷	Administered q28 days from November to April, ONLY in patients that meet clinical and age criteria							
Nirsevimab ⁸	Administered as a single dose, given one month prior to start of RSV season. ONLY in patients that meet clinical and age criteria							

Vaccination Schedule for Patients Post Hematopoietic Stem Cell Transplant (HSCT)

RSVPreF3 ⁹ (RSV vaccine, adjuvanted)	Administered as a single dose, given one month prior to the start of RSV season. ONLY in patients that meet clinical and age criteria
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†Patients with evidence of or at risk for poor immune reconstitution should be considered for immune-milestone based revaccination. Established immune milestones triggering revaccination include 1) CD4>200 Tcells/uL 2) T cell function (PHA) 3) IgG>400mg/dL off IVIG and with normal IgM and IgA.

Patients with hypogammaglobulinemia or B cell aplasia dependent on IVIG or hizentra, are typically not re-vaccinated. However, it is possible that protective T cell immunity could still be achieved and can be considered on a case-by-case basis. Unfortunately, outside of influenza and COVID vaccination there is as yet no safety or efficacy data to support routine vaccination in these populations.

¹Inactivated Influenza vaccine: for patients 6 months of age and older. SCT patients not previously immunized against influenza should receive two doses administered ≥4 weeks apart.

²COVID-19: for patients 6 months of age and older. Moderately to severely immunocompromised patients should receive 3 doses of the updated COVID-19 vaccine, with dose interval based on brand:

Pfizer-BioNTech: for patients ≥ 6 months of age, 3 doses. 2nd dose given 3 weeks after 1st dose. 3rd dose given at least 8 weeks after 2nd dose for children aged 6 months to 4 years and at least 4 weeks after 2nd dose for all other ages.

Moderna: for patients ≥ 6 months of age, 3 doses. 2nd dose given 4 weeks after 1st dose. 3rd dose given at least 4 weeks after 2nd dose.

³Meningococcal quadrivalent: for patients > 11 years of age, per standard CDC immunization guidelines, but can be given to younger patients who are functionally or anatomically asplenic. **Can give Menveo or MenQuadfi based on availability**

⁴Men B: now recommended for adolescents and young adults, with age 16-18 preferred, but can be given to patients > age 2 who are considered high risk. **Can give Trumenba or Bexsero based on availability**

⁵HPV: Ages 11 through 12 years old should get a 2-shot series separated by 6 to 12 months. The series can begin at 9 years old. A 3-shot series is recommended for those with weakened immune systems and those who start the series after their 15th birthday.

⁶Administration of MMR and VZV 24-month doses must be given as individual vaccines to simulate primary vaccination, but second dose (^26-36 months) can be given as MMRV (ProQuad). Patients should have evidence of response to non-live vaccinations (typically pneumococcal titers) be 2 years from transplant, off exogenous immune suppression for at least 1 year and off IVIG for at least 5 months.

⁷ Criteria for Palivizumab administration: 1) < 2 years of age and within 1 year of allogeneic transplant or less than 6 months off immune suppression following allo-HSCT 2) < 2 years of age and within 3 months of autologous transplant 3) <2 years of age with pulmonary GVHD, regardless of time post-transplant. **PRIOR AUTHORIZATION required for outpatient dosing, can give first dose in inpatient setting just prior to discharge.**

⁸Criteria for Nirsevimab administration: 1) All infants aged <8 months 2) Infants and children aged 8-<20 months who meet criteria for high risk for severe RSV disease.

⁹Criteria for RSVPreF3 administration: Adults aged ≥ 18 years who have undergone hematopoietic cell transplantation and/or cellular therapy procedures. To be given on or after day +100 post SCT. **Can give Arexvy or Abrysvo based on availability.**