

# **DISEASE PREVENTION FOR OUR HOME**

The following protocol for our home is based on research taken from the internet as well as advice from other SMA parents. We have designed this protocol in the hopes that it keeps Shira healthy over the often difficult flu season which unfortunately puts a lot of our children in the hospital. We advise talking with your doctor about RSV and getting the vaccine for it as well as annual flu vaccines shots for the entire family.

## **IMPORTANT LINKS:**

### **CARE GUIDELINES FOR SMA CHILDREN WITH ACUTE RESPIRATORY ILLNESS**

[http://medicine.utah.edu/neurology/research/swoboda/sma/PDFs/SMA\\_Acute%20Respiratory%20Guidelines.pdf](http://medicine.utah.edu/neurology/research/swoboda/sma/PDFs/SMA_Acute%20Respiratory%20Guidelines.pdf)

## **RSV or Respiratory Syncytial Virus**

RSV is devastating for our children and unfortunately it can kill our children. When Shira was 6 months old she contracted RSV from her brother Sammy who was in day care at the time. Often RSV shows itself as a long drawn out really bad flu like illness with regular children often keeping them sick for long periods of time. It is important to separate sick regular children from SMA children to help stop the spread of illness. This is often a very difficult task if there is only one parent at home. If you can not keep children completely separated I advise at least keeping them as separate as possible.

### What is RSV

Please go to this link for a full description of RSV

<http://www.phac-aspc.gc.ca/publicat/ccdr-rmtc/03vol29/acs-dcc-7-8/acs7.html>

### How is RSV Spread?

#### **Epidemiologic features:**

RSV is spread from respiratory secretions through close contact with infected persons or contact with contaminated surfaces or objects. Infection can occur when infectious material contacts mucous membranes of the eyes, mouth, or nose, and possibly through the inhalation of droplets generated by a sneeze or cough. In temperate climates, RSV infections usually occur during annual community outbreaks, often lasting 4 to 6 months, during the late fall, winter, or early spring months. The timing and severity of outbreaks in a community vary from year to year. RSV spreads efficiently among children during the annual outbreaks, and most children will have serologic evidence of RSV infection by 2 years of age.

### What Is The Treatment For RSV?

#### **Prevention:**

Development of an RSV vaccine is a high research priority, but none is yet available. Current prevention options include good infection-control practices, RSV-IGIV, and an anti-RSV humanized murine monoclonal antibody. **RSV-IGIV or the anti-RSV**

**humanized murine monoclonal antibody can be given during the RSV outbreak season to prevent serious complications of infection in some infants and children at high risk for serious RSV disease (e.g., those with chronic lung disease and prematurely born infants with or without chronic lung disease).** Frequent

handwashing and not sharing items such as cups, glasses, and utensils with persons who have RSV illness should decrease the spread of virus to others. Excluding children with colds or other respiratory illnesses (without fever) who are well enough to attend child care or school settings will probably not decrease the transmission of RSV, since it is often spread in the early stages of illness. In a hospital setting, RSV transmission can and should be prevented by strict attention to contact precautions, such as handwashing and wearing gowns and gloves.

If your child is under 5 years old especially in the younger years and you have other children I would Advocate Strongly to get the antibody for your child!!! Shira was on the antibody for the first 21/2 years of life.

Here is a link to a video of Shira when she contracted RSV and ended up in the hospital. The doctors were not preventative in their approach and did not inoculate Shira or teach us about disease prevention. It is my hope that by you reading this you will take appropriate steps to lessen your child's exposure to the brutal virus.

Shira's video of her in the picu: <http://www.youtube.com/watch?v=DFhZr8VQguc>

## **WHAT CAN WE DO TO PREVENT COLDS AND FLUS IN OUR HOME?**

What we do in our home

### 1)KEEPING DIEESEASE OUT OF OUR HOME

The main thing we do is to try and stop disease from entering our home needlessly. Here are the steps we use with Shira.

- 1) Before suctioning we always use disinfectant on our hands
- 2) Suction Catheters must always be sterile if they touch the floor they are thrown out immediately.
- 3) We hand wash before touching Shira every time
- 4) Hand wash is kept at stations around our home

Entering our home:

A) No one enters our home if they are not feeling 100%!!

B) Healthy means no runny nose, no coughing, and no one sleeping with someone that is sick!!

C) The person entering our home must be symptom free for 24 hours  
D) Nobody enters our home that has been on a bus, in a mall, in school or any other crowded enclosed environment without changing their clothes first.

E) Everyone washes their hands with hand disinfectant immediately upon entering our home and then again with soap and water once they are in

F) No outdoor handbags, backpacks etc. are allowed upstairs in our home in the high traffic areas. We ask all help to bring bags used specifically for our home.

G) Everything we bring into our home we disinfect like Videos, DVD's, New Toys etc. or we live them in our basement for 48 hours first.

What About Our Other Children:

A) Upon entering our home from school Sammy washes his hands with disinfectant, takes off his clothes and puts them in the washing machine and then takes a shower.

B) Sammy does not kiss Shira on the face during school season

C) When Sammy is sick Shira and I move downstairs and live in our basement until Sammy is clear. I understand that many families do not have this option but I wanted to say if you can quarantine yourself off it is the best thing to do. Shira and I lived away from Maxine and Sammy for 4 weeks in 2007 and 7 weeks in 2006 but Shira did not get sick in those years. Shira had a mild cold in 2007 that was treatable at home and did not require hospitalization.

Around The House:

A) We clean out the bathtub before bathing Shira

B) We wash door handles and everything we touch with disinfectant

C) We don't leave dirty laundry on the floors it is kept in a secure place until washing or washed right away

Illness And Our Spouse

Maxine and I do not sleep together when we are sick or have any close contact. Because we are caregivers if we are to be around each other when one of us is sick we wear a mask and clean clothes. When we are sick we change our clothes several times through the day and always wear a mask around Shira and wash, wash, wash our hands a lot.

Below is more information about disease prevention:

## Prevention

These steps can help you stay healthy, even at the height of flu season:

- **Get an annual flu vaccination.** The best time to be vaccinated is October or November. This allows your body time to develop antibodies to the flu virus before peak flu season, which in the Northern Hemisphere is usually December through March. However, getting a flu shot later in the flu season may still protect you. It takes up to two weeks to build immunity following a flu shot.

Keep in mind that the flu vaccine doesn't offer complete protection, especially for older adults, but it can reduce the risk and severity of illness. According to the Centers for Disease Control and Prevention (CDC), when the match between flu vaccine and circulating strains of flu virus is close, a flu shot is between 70 and 90 percent effective in warding off illness in healthy people under age 65. It is less effective in older adults. Health experts recommend vaccinations for people over 50 because the flu shot may reduce the risk of flu-related complications, hospitalizations and deaths.

Healthy people ages 2 to 49 alternatively may receive the flu vaccine via a nasal spray called FluMist. It protects against the same strains of influenza that the flu shot does. Like the flu shot, FluMist is given every year. Because FluMist contains live, but weakened, flu viruses, it shouldn't be given to pregnant women, people with weakened immune systems and those with chronic illnesses. A study published in 2006 found that FluMist was only between 30 and 57 percent effective in preventing the flu in adults. However, another study in 2006 found that giving nasal spray vaccine to school-age children helped to reduce the spread of flu in the community. And in 2007, researchers compared the effectiveness of FluMist with the flu shot in children ages 6 months to 5 years. The children treated with FluMist experienced about half as many cases of flu as did those treated with the shot. However, FluMist increases the risk of wheezing in this age group — especially in those who already have asthma or recurrent wheezing and in all children under age 2. In 2007, the Food and Drug Administration (FDA) therefore approved FluMist for children older than 2 years who don't have asthma

or recurrent wheezing. Consult with your doctor about which form of vaccination may be best for you or your child.

You can get the flu vaccine from your doctor, at public health centers and many pharmacies. In some areas, flu vaccines are also available at senior or community centers and at supermarkets.

- **Wash your hands.** Thorough and frequent hand washing is the best way to prevent many common infections. Scrub your hands vigorously for at least 15 seconds, rinse well and turn off the faucet with a paper towel. Or use an alcohol-based hand gel containing at least 60 percent alcohol.
- **Eat right, sleep tight.** A poor diet and poor sleep both lower your immunity and make you more vulnerable to infections. A balanced diet that emphasizes fresh fruits and vegetables, whole grains, and small amounts of lean protein works best for most people. On the other hand, the amount of sleep needed for a healthy immune system varies from person to person. In general, adults seem to do best on seven to eight hours of sleep a night. Older children and teens need more rest — between nine and 10 hours every night.
- **Exercise regularly.** Regular cardiovascular exercise — walking, biking, aerobics — boosts your immune system. Exercise won't prevent infection, but if you do come down with the flu, you may have less severe symptoms and recover more quickly than do people who aren't as fit.
- **Avoid crowds during flu season.** Flu spreads easily wherever people congregate — in child care centers, schools, office buildings, auditoriums and public transportation. By avoiding crowds whenever possible during peak flu season, you reduce your chances of infection.

Important Links:

Centers For Disease Control and Prevention <http://www.cdc.gov>

Mayo Clinic <http://www.mayoclinic.com>

Dr. Swoboda Web Site:

<http://medicine.utah.edu/neurology/research/swoboda/sma/index.htm>

Dr. John Bach Web Sites:

<http://www.theuniversityhospital.com/ventilation/html/selectedstudies/studypulmonary.htm>

<http://www.doctorbach.com>

# Dr. Mary Schroth

Associate Professor

University of Wisconsin at Madison

\Hospital-

Clinical Science Centre

Office Suite K4/942

Office Phone: (608) 263-8555

Email: [mschroth@wisc.edu](mailto:mschroth@wisc.edu)