



THE MAST CELL DISEASE SOCIETY, INC.

Ways to advocate for a child in the Emergency Room

1. Offer the copy of The Special Edition for Health Care Professionals and refer to the page on Pediatric Mast Cell Diseases.
2. Explain that mast cells in cutaneous lesions release mediators that result in systemic symptoms, sometimes severe, such as flushing, nausea, vomiting, diarrhea, headaches, itching, difficulty concentrating, dizziness, etc. (add your child's symptoms here.)
3. Explain clearly how your child manifests early signs of deterioration or anaphylaxis, especially if it is not a typical presentation:
 - Does your child develop hives or swelling around the face, mouth or eyes, or develop flushing or pallor?
 - Does your child get an itchy, red rash (other than hives)?
 - Does your child develop a cough, especially one that can be staccato in nature in younger children, or may mimic their asthma cough?
 - Does your child develop frequent sneezing and/or a runny nose?
 - Does your child exhibit shortness of breath?
 - Does your child complain of chest pain even in the absence of shortness of breath?
 - Does your child complain of a mouth or tongue that feels funny? (Note: this may happen well before any visible oral swelling can be recognized or appreciated on exam).
 - Does your child exhibit hoarseness or a change in voice?
 - Does your child clear his or her voice repetitively?
 - Does your child complain of trouble swallowing, or appear to be drooling excessively?
 - Does your child exhibit sudden abdominal pain?
 - Does your child develop nausea? vomiting? In some children, this may be the only initial symptom.
 - Does your child feel anxious, or tell you that something awful is happening?

You know your child best, so be sure to educate the ER about how to recognize early anaphylaxis in your child.

4. Make sure that all medications and IV additives are alcohol free.