

Emergency Preparedness Checklist for People with Thalassemia

- Your go bag should also include a manual or notebook for family members containing:
 - current medical information,
 - instructions on preparing and administering chelators and other medicines,
 - directions to the thalassemia treatment center or hospital,
 - important telephone numbers (doctor, etc.), and
 - diagnosis and treatment information.
- Consider wearing a medical alert bracelet with your hematologist's name and contact information, as well as other information that your hematologist recommends.
- Program your emergency contact information into your telephone under "ICE" (In Case of Emergency) so that emergency medical service responders can find the number.

This informational resource was developed by the Cooley's Anemia Foundation in collaboration with the Centers for Disease Control and Prevention. This publication was supported by Cooperative Agreement #3U27DD000331-05W1 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

Photos: Thatcher Hullerman Cook



Cooley's Anemia Foundation
www.thalassemia.org * (212) 279-8090



It's important that all families develop a plan of action to use in the event of an emergency situation, especially if your family includes a person with thalassemia.

Such a plan can help ensure you will have access to a transfusion or other thalassemia-related care even in an emergency situation.

Once you have developed your plan, make sure that you discuss it with your family and medical team and practice it with your family.



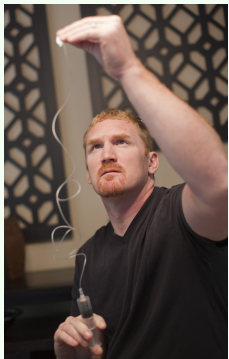
Cooley's Anemia Foundation
www.thalassemia.org * (212) 279-8090

Things to Think About

Here are some general questions to consider as you develop your family's plan:

- Do you have an emergency contact person who lives out of the area, in the event that you must evacuate out of your area? Do you, your family members and healthcare team members have that person's telephone number?
- Have you discussed emergency plans with your primary healthcare providers or your thalassemia treatment center?
- Do you know of an alternate hospital at which you can get a transfusion if your regular hospital is unable to treat you?

By thinking about these types of questions, you will be ready to prepare an emergency plan for you and your family.



General Tips for People with Thalassemia

The next page contains some tips that can help people with thalassemia manage their care during a state of emergency:

- Keep a medical "go-bag" or small suitcase of chelators, medications, and supplies packed at all times so that it is easy to grab and go. Keep as many chelating supplies on hand as your insurance will allow and be sure to change out supplies regularly so they can be used before they expire.
- Also include in your go-bag a letter from your hematologist with the following information:
 - the contact information for your hematologist or healthcare provider,
 - a basic description of thalassemia and its treatment,
 - information on how often you are transfused and information on antibody reactions and special instructions for type and cross,
 - what type of chelation therapy is prescribed and how often it is prescribed,
 - any information on complications (such as diabetes, cardiac dysfunction, etc.) as well as any treatments prescribed for these complications.

(continues on back page)