



Creating a Calm Clinic Visit

Welcome to the Bleeding Disorder Family!

Finding out your child has a bleeding disorder can be overwhelming. This resource is designed to help guide you through a comprehensive clinic visit. Comprehensive care examines the whole person, including both physical and mental health. This resource, combined with our Comprehensive Clinic Visit Checklist, will help ease the anxiety of the first clinic visit.

Who's Who at the Clinic

Keep in mind you may not need to see every provider:

POSITION	WHAT THEY WILL DO FOR YOU
Hematologist	The hematologist will be making most of the care decisions. You will meet with your hematologist at least once a year. They can answer questions about treatment options, medication choices, infusions, clinical trials, answer genetics questions, refer you to specialists, and oversee your child's care.
Nurse Coordinator	The nurse coordinator will assist in coordinating all of your child's care. He or she will order lab work, assist with your prescriptions, complete referrals if needed and be your main point of contact. He or she will also go over home infusion or self-infusion. It is their role to make sure all of your questions are answered and all of your medical information is up to date.
Research Nurse/ Clinical Research Assistant	He or she will review all of the possible clinical trials and programs available to your child's specific bleeding disorder.
Social Worker	The social worker at the clinic is there to help assist, advocate, ease fears, to connect you to local chapters, help you navigate patient assistance programs and provide general support. The social worker can assist with school and insurance issues, give parenting tips, and help with life adjustments.
Physical Therapist	Frequently bleeding takes place in muscles and joints. When needed, the physical therapist will examine your child's joints and muscles for any evidence of damage. He or she is a great resource regarding participation in sports and other physical activities

The roles of these team members overlap, but if you feel like you have not had all of your questions answered, ask someone and they will direct you to the team member that can help.

What to Expect While at an Annual Clinic Visit:

All Comprehensive Clinics are different. Depending on your clinic, you may experience only some or all of these things. A comprehensive clinic visit can be anywhere from 2-4 hours depending on who you need to see.

SERVICE

Registration

Be prepared with:

- Insurance card
- Photo identification
- Visit co-pay if one is required

Vital Signs

- Height
- Weight
- Pulse
- Temperature
- Blood Pressure

Nurse Coordinator

Plan to discuss:

- Identify and answer questions and concerns
- Review logs and assess the number of bleeds since your last visit
- Discuss how infusions are going and try to problem solve any issues
- Update immunizations
- Update family history
- Review current product
- Discuss any new products that may be available
- Review any product issues

Hematologist

Plan to discuss:

- Identify and answer questions or concerns
- Physical exam
- Review of bleeding history
- Treatment plan adjustments
- Treatment plan for the year
- Order any appropriate lab work or radiologic studies such as x-rays or MRI's
- Discuss research opportunities and clinical studies

Social Worker

Plan to discuss:

- Identify and answer questions or concerns
- Emotional well-being, parenting issues
- Provide resources and information
- Connect to local chapters and/or experienced families
- Something about insurance support?
- Available insurance support programs
- Insurance issues
- Patient assistance programs if applicable.

Research Nurse

Plan to discuss:

- Identify and review any clinical trials available
- Obtain consent for clinical trial
- Assist in filling out any questionnaires or forms related to research

Physical Therapist

Plan to discuss:

- Examine and measure joints
- Discuss any bleeds that have occurred
- Discuss any rehabilitation issues
- Activities and sports participation

Lab Work

- Should include a variety of tests. Common clinic lab work can include:
 - Complete Blood Count (CBC)
 - Chemistry Panel
 - Factor Activity
 - Inhibitor

Comprehensive clinic visits can be long. Creating a "To-Go" Bag can help prepare you for a clinic visit:

- ✓ Snacks
- ✓ Drinks
- ✓ Cell phone chargers
- ✓ Kids items: books, small toys, comfort item
- ✓ Infant items: Diapers and wipes, formula, bottles, change of clothing
- ✓ Cash for a vending machine