Toolkit 2:

For Families with a Child/Teen with vWD

1. What Families Should Know

- Children with vWD may:
  - Have frequent nosebleeds
  - Bruise easily (large bruises from small bumps)
  - Bleed longer from cuts or scrapes
  - Experience gum bleeding during brushing/dental work
- Teens may experience very heavy menstrual periods, which may be the first noticeable sign in girls.

2. Daily Management at Home

- Keep first aid supplies (gauze, bandages, ice packs) handy.
- Teach first aid for nosebleeds: sit upright, lean forward, pinch nostrils for 10–15 minutes.
- Use a child-friendly bleed log (with stickers or emojis) to help kids track episodes.
- Teach children how to ask for help when bleeding occurs.
- Communicate with the dentist and school staff about your child's condition.

3. Parent Tools

- Care Binder:
  - Emergency plan from your hematologist
  - Medication list and doses
  - Doctor and HTC contact information
  - Bleed logs and medical history
- Sample Letter for Schools: Explains vWD, symptoms, and what staff should do.
- Medication Checklist: Keep track of what is stored at home vs. school nurse's office.

4. Helping Teens Transition

- Encourage your teen to carry a medical ID or wallet card.
- Teach them how to explain vWD to coaches, teachers, or friends.
- Discuss safe sports and menstrual health options (such as hormonal therapy or tranexamic acid).
- Begin transition planning between ages 16–18 so they are ready for adult hematology care.

5. Emotional & Social Support

- Explain vWD in simple terms to siblings so they understand.
- Encourage open conversations about fears or frustrations.
- Connect with support groups, family camps, and peer networks.
- Remind your child that they can live a full, active life with good management.

6. Tools Included

- Child-Friendly Bleed Log
- Teen Transition Checklist
- Sample School Letter