PROVIDER ASSESSMENT OF SKILL SET FOR YOUTH WITH TURNER SYNDROME
BY THE ENDOCRINE SOCIETY
ENDOCRINETRANSITIONS.ORG

KNOWLEDGE OF YOUR CONDITION
- Know what causes Turner syndrome (missing all or a piece of one of the X chromosomes).
- Understand the medical conditions that young women with Turner syndrome are at risk for:
  a) ovaries that don’t work properly—need to take hormones for breast development, menstrual periods, and strong bones—infertility
  b) thyroid problem
  c) diabetes
  d) celiac disease
  e) high blood pressure
  f) decreased bone strength
  g) potential heart problems and weakness of the large artery that leaves the heart (sudden chest pain or tightness in the chest could represent a serious problem; seek emergency care!)
  h) hearing problems
  i) learning difficulties
  j) psychosocial issues (maturity level/social anxiety)
- Understand options for becoming a mother.
  a) adoption
  b) donated egg
  c) risk of carrying a pregnancy

KNOWLEDGE OF YOUR MEDICAL CARE
- Know the name of your primary care physician and the contact information.
- Know the name of your gynecologist or endocrinologist and their contact information. Other subspecialists such as reproductive endocrinologists, cardiologists, and geneticists may be needed during certain stages of your life.
- Know the name of your other specialists and their contact information.
- Know how often you should be seen by your physicians.
- Know how frequently you should be monitored for your existing medical conditions.
- Know how frequently you should be monitored for the medical conditions for which you are at increased risk.
- Know the names of your medications and what they are for.
- Know how your medicines should be taken.
- Know what happens if they are not taken regularly.

KNOWLEDGE OF INSURANCE COVERAGE AND MANAGING YOUR PRESCRIPTIONS
- Do you have health insurance?
- Can you be covered on your parent’s insurance until you are 26?
- Can you get insurance through your college or work place?
- Know where you get your prescriptions filled and learn how to call for a renewal.

KNOWLEDGE OF WAYS TO STAY HEALTHY
- Try to maintain a healthy weight for your body and avoid obesity-related problems (regular exercise, learn about healthy eating).
- Have your blood pressure monitored, and if elevated, treated.
- Take your estrogen regularly (important for bone strength, heart health).
- If you are feeling sad or anxious don’t hesitate to contact your primary physician regarding mental health counseling.
- Exercise regularly (helps bone strength, heart health, weight, risk for diabetes, and mental health).

KNOWLEDGE OF SUPPORT/ADVOCACY GROUPS FOR INFORMATION
- Turner Syndrome Foundation turnersyndromefoundation.org
- Turner Syndrome Society turnersyndrome.org
- Magic Foundation magicfoundation.org
- Hormone Health Network hormone.org