

### **Background for Transition Visits**

- A team approach within the practice is recommended. Be sure that staff understands special situation of transition of care.
- The patient is not yet fully initiated into the “adult model” and may require assistance and support.
- Parents should be allowed to attend appointments *if* patient desires. It is recommended that the patient complete a visitor information form to inform new provider who, if anyone, can attend appointments. Consider asking the patient to sign a form allowing the healthcare team to communicate with the patient’s parents.
- Extra consideration in scheduling and confirming the appointment may be necessary.
- The patient may also need assistance with:
  - The “unknown” of new facility (directions, parking issues).
  - Insurance issues.
  - Expectations for what to bring to appointment
    - Insurance card
    - Paperwork from former pediatric endocrinologist
    - Forms for the new physician (online, mailed)
    - List of medications or prescription bottles
- The new healthcare team should greet the patient with the awareness that she is transferring care and provide support and assistance with the check-in process and paperwork.
  - Confirm contact information for the patient; ask about preferred name and how she prefers to be contacted (cell phone, text, email, depending on practice situation).
  - Consider developing “Welcome to the Practice” guide that would provide this information to your new patient.

### **The First Encounter: Allow Ample Time**

- Review HIPAA and determine if parents/others are permitted to receive/hear information about the transitioning young adult.
- Review contact information during office hours and for evenings/weekends in case questions arise.
- Review clinical summary with patient or if patient transitioning without a summary from prior physician, cover items on the clinical summary during history process.
- Pay special attention to concerns about body image, reproductive issues, learning disabilities, fears, coping, family stressors.
- Ask about any concerns or questions

- Ask about participation in Turner support network. Consider referral to local group if patient is not already participating.
- Review other conditions or issues associated with Turner Syndrome. Identify the primary care physician or the specialist who will have primary responsibility for handling each concern.
  - Fertility and family planning.
  - Hormone Replacement Therapy
  - Cardiovascular disease, hypertension.
  - Hypothyroidism
  - Celiac Disease
  - Depression, anxiety, and low-self esteem
  - Metabolic Syndrome, Diabetes risk.
  - Liver function.
  - Audiology evaluation.
  - Metabolic bone disease.
  - Exercise/Fitness/Weight control.
  - Learning Disabilities.
  - If there are multiple risk factors for aortic dissection, consider a wallet card or bracelet to alert medical personnel.

**Ongoing Monitoring<sup>1</sup>**

<b>Intervention</b>	<b>Frequency</b>
Cardiology Evaluation (MRI, EKG)	At baseline, prior to pregnancy planning, every 5-10 years as indicated.
Blood pressure	Annually
ENT and Audiology	Every 1-5 yr
Fasting glucose, A1C, lipids, cbc, BUN/creatinine, vitamin D	Annually
DEXA scan	At initial visit and then as indicated
Liver and thyroid screening	Annually
Celiac Disease Screen	As indicated
Psychosocial Evaluation	As indicated

- Discuss care plan for ongoing follow up:
  - Discuss/provide a Turner Syndrome Fact Sheet from the Turner Syndrome Society (<http://turnersyndrome.org/learn-about-ts/fact-sheet>)

<sup>1</sup> Bondy, CA. 2007. Care of Girls and women with Turner Syndrome: A Guideline of the Turner Syndrome Study Group. JCEM 92:10-25.

or from the Hormone Health Network

(<http://www.hormone.org/questions-and-answers/2011/turner-syndrome>) on recommended testing and follow-up. Review what is needed now and what the plan will be for ongoing/future visits.

- Discuss expectations of how an 'adult' clinic will work in the future (how the patient can get the most out of the visit).
- Discuss how to handle interim questions – Crisis and Non-urgent (When do you want the patient to call? With whom should they speak (nurse, MD)? What is the best way to communicate?)
- Let patient know if there is a specific urgent care/ER/hospital in which the physician works and assess if it is covered by the patient's insurance.
- Assess need for/willingness for any additional education.