

# Turner Syndrome Levels of Care *Pediatric Designation Criteria*



# Turner Syndrome Levels of Care

Designation Criteria	Level 1 TS Provider Requirements	Level 2 TS Coordinated Care Clinic Requirements	Level 3 TS Coordinated Care Center Requirements	Level 4 TS Regional Resource Center Requirements
→ Minimum Staff Requirement To Build Expertise	Single Discipline – Endocrinology or Genetics	Single Discipline – Endocrinology or Genetics	Single Discipline – Endocrinology or Genetics	Single Discipline – Endocrinology or Genetics
→ Required Specialties	<i>Strongly suggested: Develop Referral Sources to Specialty Providers</i>	Coordinated Care with Cardiology, Endocrinology, ENT, and Neuropsychology – at minimum	Coordinated Care with Cardiology, Endocrinology, ENT, and Neuropsychology – at minimum	Coordinated Care with Cardiology, Endocrinology, ENT, and Neuropsychology – at minimum
→ Abide By And Share Current 2017 TS Care Guidelines	Follow TS Care Guidelines	Follow TS Care Guidelines	Follow TS Care Guidelines	Follow TS Care Guidelines
→ Share Information On Advocacy Organizations	• Advocacy Connection – share local/national information	• Advocacy Connection – share local/national information	• Advocacy Connection – share local/national information	• Advocacy Connection – share local/national information
→ Community Visibility		Webpage / Link (Scheduling, etc.)	Webpage / Link (Scheduling, etc.)	Webpage / Link (Scheduling, etc.)
→ Refer To TSGA KidNECT Document		KidNECT – Networking, Education, Comprehensive Coordinated Care, Transition	KidNECT – Networking, Education, Comprehensive Coordinated Care, Transition	KidNECT – Networking, Education, Comprehensive Coordinated Care, Transition
→ Coordinated Scheduling		Offer Same Day Visits with Multiple Specialists	Offer Same Day Visits with Multiple Specialists	Offer Same Day Visits with Multiple specialists
→ Research - Data Collection			REDCap for TS	REDCap for TS
→ Transition To Adult Care			Transition Program with Coordinated Adult Providers	Transition Program with Coordinated Adult Providers
→ Input From Advocates			PFAC – Patient/Family Advisory Council	PFAC – Patient/Family Advisory Council
→ Extended Coordinated Care			Must coordinate access to all Speciality Providers - see list	Must coordinate access to all Speciality Providers - see list
→ Regional Leadership Role				Multi Institutional Research TS Fellowship/ Mentoring Program Regional Resource/Support for Clinic, Centers, and Providers



# KidNECT Care Model™

## Networking

- For patients and families to share information and find support

## Education

- Sharing of resources, ensuring that patients and families are knowledgeable, promoting self-advocacy
- Includes information for newly-diagnosed

## Comprehensive Coordinated Care

- Health care that is supported by an interdisciplinary team of specialists that are looking at the patient as a whole person

## Transition

- Supporting the transitions through life, from pediatric to adult care and fostering the highest level independence whenever possible
- Ensuring that a community of support, beginning with medical providers, is available





# Implementing KidNECT Care Model™

## Examples:

### Networking

- For patients and families to share information and find support  
*Examples: working with an family advocate to connect families, establishing space at clinic where girls and families can connect, sharing support group contact information, sharing online support options*

### Education

- Sharing of resources, ensuring that patients and families are knowledgeable, promoting self-advocacy  
*Examples: sharing contact information for advocacy organizations, encouraging use of evidence-based reliable resources, encouraging patients and families to ask questions, ensuring that families know what to expect now and in the future with TS*
- Includes information for newly-diagnosed  
*Examples: distributing the TSGA Resource Kit, directing families to advocacy organizations websites, connecting families to others in their community*

### Comprehensive Coordinated Care

- Health care that is supported by an interdisciplinary team of specialists that are looking at the patient as a whole person  
*Example: TS specialists are working together to ensure that all patient needs are identified and met or, in the absence of an interdisciplinary team, coordinated care is offered through referrals*

### Transition

- Supporting the transitions through life, from pediatric to adult care and fostering the highest level independence whenever possible  
*Examples: helping patients and families prepare for transition beginning in the mid teen years, using TS Transition tools with patients, referring patients to expert adult providers, connecting with adult providers to ensure continuance of care*
- Ensuring that a community of support, beginning with medical providers, is available  
*Examples: acknowledging that girls, women, and families living with TS deserve excellent medical care but also often have needs that extend into the community, developing relationships with community resources to fully support patients during transition, working to ensure that excellent care is available for adults*

# Specialty Providers for Turner Syndrome Care

## TS Specialty Providers Recommended for Interdisciplinary Care or Referral

- Cardiologist
- Dentist/Orthodontist
- Endocrinologist
- ENT
- GI Specialist
- Gynecology/Reproductive Endocrinologist
- Nephrologist/Urologist
- Neuropsychologist/Anxiety Specialist
- Nutritionist
- Optometrist/Ophthalmologist
- Physical Therapy
- Podiatrist
- Psychologist Occupational Therapy
- Rehab (PT, OT, SLP)
- School/Education Advocate
- Speech-Language Therapy

## Additional Services

- Driving/Life Skills Support
- Financial Skills Support
- Vocational Support



Online Tool Kit





web [TSGAlliance.org](http://TSGAlliance.org)

email [TSGA@TSGAlliance.org](mailto:TSGA@TSGAlliance.org)