**A picture containing text, clipart

Description automatically generated**

**Applying for Disability Benefits related to Turner Syndrome**

**Can people with Turner syndrome qualify for disability benefits?**

Turner syndrome is not considered a disability so having TS alone doesn’t support the qualifications for being disabled. However, some people with TS are disabled as their health prevents them from:

* Attaining developmental milestones such as walking, talking, and learning as expected. <https://www.cdc.gov/ncbddd/actearly/milestones/index.html>
* Participating in age-appropriate activities and tasks
* Sustaining full-time employment in which the employee receives steady work and payment from the employer

For instance, significant hearing loss, severe lymphedema, overwhelming anxiety or depression may hinder your ability to go to work full-time consistently. Most people requiring disability benefits expect the process to be difficult and ask others to help them with the process. It’s rare for an application to be approved on the first submission but don’t give up.

**The Disability Programs**

The Social Security Administration (SSA) has two separate disability programs:

* Social Security Disability Insurance (SSDI) a program for disabled workers who have work history and have paid Social Security taxes. Learn more about SSDI here: <http://www.disability-benefits-help.org/ssdi/qualify-for-ssdi>
* Supplemental Security Income (SSI) does not have any work history requirements for disabled minors and adults. Learn more about SSI here: <http://www.disability-benefits-help.org/ssi/qualify-for-ssi>

Both of these programs require medical as well as financial/technical qualification.

**Medically Qualifying for Benefits**

In addition to meeting the financial/technical eligibility criteria for SSDI and/or SSI, the person for whom you are applying for benefits must also meet the SSA’s medical eligibility criteria in order to be found eligible.

The SSA uses a three-part review process for determining medical eligibility.

First they review medical records to determine if they exactly meet a listed condition in the Blue Book (<http://www.ssa.gov/disability/professionals/bluebook/>), which is a manual of disabling conditions and medical evidence necessary for proving disability.

When the medical records do not meet a listed condition, the SSA next reviews similar listings to see if they match in terms of severity level. If there is no “match”, such as in the case of Turner syndrome, then the SSA will review how well a person functions.

The SSA may consider applications filed for the following health sections (others may apply) for issues related to TS that cause significant impairment with daily life:

* endocrine system, growth disorders (children), low birth weight and failure to thrive (children), mental disorders, vision issues, hearing impairment, heart or other cardiovascular abnormalities, kidney, or bladder abnormalities,

If the health records of the individual do not meet the severity level of any listed condition, the SSA will:

* Review age-appropriate activities through a “childhood evaluation”, if you are applying for benefits for a minor OR
* Review “residual functional capacity”, if you are applying for benefits for an adult.

Both of these evaluations look at activities of daily living to determine if Turner syndrome presents a severe enough impairment to qualify medically for disability benefits even without meeting or matching a listed condition.

Regardless of how medical records are reviewed to determine eligibility, it is essential that the records of the person for whom you are applying for benefits are detailed and contain information on every aspect of the effects of Turner syndrome on the physical, mental, and emotional condition of the applicant.

**Applying for Benefits**

Adults apply at the local SSA office, or online (<http://www.ssa.gov/pgm/disability.htm>).

Parents should schedule an appointment with the local SSA office by calling 1-800-772-1213 to learn what information is required for the application process.

If you are unable to get your records together before the appointment, attend anyway, delaying the appointment will only delay the review of the application.

Collect and keep a copy of all necessary documentation prior to the appointment:

* Keep a daily health journal that lists all of your symptoms, appointments, results, and notes.
* Compile support information such as website pages, letters, research, etc. to prove how Turner syndrome or your condition effects your ability to function.
* Request or print medical records from doctors and mental health providers. Ask your doctors to support your filing by giving you a letter stating your inability to work.
* Collect financial documentation such as copies of tax returns
* For minors- school records, educational performance and evaluations that have been performed by school officials and educators
* Connect with people within your state who have been approved for disability, their information and support can better your chances of approval
* After being denied a second time, find a disability attorney with several years’ experience and speak to them immediately and provide them with all of the documentation you’ve provided.

Reference: Ram Meyyappan Social Security Disability Help and Jon Rodis, Disability Expert

**Contact TSSUS if you would like to speak to a disability expert at no cost**