TURNER SYNDROME SOCIETY OF THE UNITED STATES

STRATEGIC PLAN
2017-2019
# CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Our Organization</td>
<td>2</td>
</tr>
<tr>
<td>Our Community</td>
<td>3</td>
</tr>
<tr>
<td>Our Strategic Plan</td>
<td>4</td>
</tr>
<tr>
<td>Goal 1</td>
<td>4</td>
</tr>
<tr>
<td>Goal 2</td>
<td>5</td>
</tr>
<tr>
<td>Goal 3</td>
<td>6</td>
</tr>
<tr>
<td>Goal 4</td>
<td>8</td>
</tr>
<tr>
<td>Goal 5</td>
<td>8</td>
</tr>
<tr>
<td>Goal 6</td>
<td>10</td>
</tr>
<tr>
<td>Conclusion</td>
<td>12</td>
</tr>
<tr>
<td>Acknowledgement</td>
<td>12</td>
</tr>
</tbody>
</table>
In 1987, a small group of women living with Turner syndrome decided they needed a support system and founded the Turner’s Syndrome Society, later called the Turner Syndrome Society of the United States (TSSUS). They created TSSUS with the hope of connecting women, parents, and physicians linked to Turner syndrome (TS) to improve the understanding of the condition. Thirty years later, that hope remains central to the Society’s purpose.

Turner syndrome (TS) is a rare genetic condition that affects only girls and women. TS occurs when there is one complete X chromosome and the second X chromosome is missing entirely, or the X chromosome is present in a form that is incomplete or different in structure. Although considered a rare disease, TS is one of the most common genetic conditions, affecting 1 of every 2,000 - 4,000 live births. TS occurs in nearly 5% of all human conceptions. Unfortunately, death occurs in more than 90% of those fetuses. TS is a medical diagnosis and is categorized as a chronic rare disease. The TS community generally refers to TS as a genetic condition.

Every girl and woman with TS is unique, and no generalization will apply to everyone - no matter how accurate it is for the group. Typical signs of TS refer to features that are found more commonly in this population than in the general population. The most common traits and conditions related to TS include short stature (under 5 ft), delayed puberty because of ovarian failure, and heart defects. Additional health concerns may include, but are not limited to, hearing loss, social anxiety, learning disabilities, heart abnormalities, hypothyroidism, and high blood pressure.

All women and girls benefit from good medical care, informed emotional support, and careful screening for related conditions. TS is not directly treated by a doctor, but the individual health concerns that arise for each person with TS should be monitored and treated by the appropriate specialist. Some areas have coordinated TS clinics where patients see various specialists in the same day.

Medical developments include but are not limited to:

- Help of an obstetrician or reproductive endocrinologist who specializes in in-vitro fertilization for women with TS who are interested in starting a family.
- Growth hormone therapy (GHT) may be used as a treatment in cases of growth hormone deficiency or short stature.
- Estrogen hormone replacement therapy (ERT) used to induce puberty and maintain effective doses of estrogen through most of the adult years.
Our Organization

It is the hope of the TSSUS board and staff that someday every woman and girl with TS will have access to the best quality healthcare available, no matter her location or financial situation. The following three-year strategic plan is focused on making significant strides toward that goal, while at the same time, realizing it will take more time to fully achieve our vision.

Guiding Statements

Our Vision

That every woman or girl with Turner syndrome will have cutting edge health care ensuring the best quality of life.

Our Mission

TSSUS advances knowledge, facilitates research and provides support for all touched by Turner syndrome.

Guiding Values

Integrity  Respect  Collaboration  Empowerment
The Turner syndrome community includes of any person diagnosed with Turner syndrome, or those interested in supporting those with a Turner syndrome diagnosis. Everyone in the TS community is important in achieving our vision.

The primary TS community is women with TS, girls with TS, and their parents and family members. Empowering our primary community leads to the greater community becoming better educated and engaged in accomplishing our vision.

Our secondary community consists of all of those who help us in accomplishing our mission and vision. This community includes health care providers, researchers, counselors, our volunteers, and our donors.

Both communities are vital partners in attaining our vision. By empowering our primary community, the greater community becomes better educated about our needs, and in turn, more engaged in providing the health care women and girls with TS need. It is only through the work and support of these communities that our vision that every woman and girl with TS will have cutting edge health care to ensure the best quality of life can be achieved.
In November 2016, the Board of Directors of the Turner Syndrome Society of the United States met to finalize a three-year strategic plan. In preparation for this task, the Board reviewed surveys from more than 1,000 women with TS and parents or family members of those with TS to understand the issues that are in the forefront of their minds. Members of the Board also attended the Turner Research Network’s International Symposium to hear the discussion of more than 60 healthcare professionals and patient advocates that will result in the latest update of care guidelines for TS. The Board kept in mind the original intent of the Society yet respected that the TS community needs access to the highest quality healthcare and latest research available.

**GOAL 1**

**EMPOWER THE TS COMMUNITY WITH RESOURCES THAT INFORM HEALTH CARE DECISIONS**

TSSUS believes that those directly affected by TS, the women and girls with TS, and families are the best advocates for achieving better healthcare. By empowering our primary community, we believe they can make well-informed decisions about their healthcare. Four specific objectives have been identified to accomplish this goal:

1. **Provide a patient and family-friendly version of the 2017 TS Physician Care Guidelines.**

   TSSUS co-sponsored the Turner Resource Network (TRN) international symposium in July 2016, from which the latest TS Clinical Care Guidelines will be published. TSSUS will ensure that both the physician and patient versions of the TS Clinical Guidelines are regarded as the primary source for TS treatment decisions. The guidelines will be easily searchable, accessible immediately and continually publicized on the TSSUS website, newsletters, brochures, events, webinars, message boards and other sources of contact with the TS community.

2. **Provide a comprehensive collection of Turner syndrome information that will improve patient knowledge and can be used in collaboration with healthcare providers.**
This will include:

a. Providing Turner Topic Patient Guides on key TS issues for the next two years. Turner Topic Patient Guides are patient friendly, one-page summaries of a specific issue that may affect a person with TS that can be brought to a healthcare provider for further discussion between the patient and a professional.

b. Updating the TSSUS website with the latest resources and expanding information with relevant links and videos.

c. Using TS awareness and growth awareness months to share educational information about TS through a variety of media.

3. **Expand the educational reach of the TSSUS conference by providing conference resources to those who are unable to travel to our annual conference.**

Summaries or videos of future conference presentations will be made available online.

4. **Connect women and girls with TS, and their families with local providers, specialists and clinics that are familiar with TS healthcare by expanding the online provider directory.**

TSSUS will expand the directory by encouraging the TS community to share their local provider information so that others can benefit from their recommendations. In addition, TSSUS will continue to identify areas that have clinics offering coordinated care to women and girls with TS.

**ENSURE TS RESEARCH IS ROBUST AND CONTRIBUTES TO EVIDENCE BASED RECOMMENDATIONS FOR TS CARE**

"Evidence-based medicine is the integration of best research evidence with clinical expertise and patient values." *Sackett D et al.*

The TS Clinical Care Guidelines generated from the TRN’s 2016 International Symposium is a positive step toward achieving our vision, yet the document is recommendation based and not evidence based. One of the primary goals of TSSUS is to have evidence based clinical care guidelines. To that end, TSSUS is committed to achieving the following objectives:

1. **Supporting the Turner Syndrome Research Registry (TSRR) to ensure it serves as the highest quality source of TS data.**
The TSSUS launched the TSRR in 2016, supported by the Genetic Alliance and Patient Access PEER system, to allow patients and families a secure and private place to provide personal health information to support TS research. Participants of the registry manage their own information. Therefore, they may share information with multiple researchers now and for years into the future. TSSUS will continue to administer the registry and continue to enroll and expand its functionality so that it is a robust tool for researchers. The more personal health information that is available to the research community means that important research can continue. TSSUS will work to ensure researchers actively use the TSRR to inform or conduct research studies.

2. **Increase the quality of TS research by supporting the needs of TS researchers.**

TSSUS will continue to fulfill requests from researchers, for example, promoting research studies, reviewing surveys, writing letters of support for funding opportunities, and funding recruitment expenses held at the TSSUS conferences. As a steering committee member of the Turner Resource Network (TRN), TSSUS is dedicated to advancing TS research, including current, future, and international.

3. **Influence research on topics important to the TS community through establishment of a TS Research Grant Program.**

TSSUS will work to establish a TS research grant fund to support approved researchers who are using the Turner Syndrome Research Registry (TSRR). TSSUS will strive to establish a research program that will allow researchers to apply for funding for a project conducted through the Turner Syndrome Research Registry. The initial program will offer a grant to one researcher, as recommended by the Turner Resource Network Scientific Advisory Board. The Scientific Advisory Board has two patient advocate participants to ensure that the TS research that is considered is valuable to the TS community. In the future, the Research Grant Program will aim to offer more significant funds or offer grants to multiple researchers.

**ENSURE THE TS COMMUNITY HAS ACCESS TO ENRICHING CONNECTIONS, EVENTS AND OPPORTUNITIES**

Since its inception, TSSUS has remained focused on fostering relationships and creating programs to fulfill needs for the TS community. To strengthen our support, TSSUS intends to:

1. **Obtain funding to pilot the following new programs.**

TSSUS will expand programs and services for the TS community, including a health care consultant program and a new webinar series.
a. Establish a healthcare consultant program that can assist with navigating TS health care issues. TSSUS has set as a priority the need for our community to have access to the best quality healthcare and we recognize that not everyone in the TS community understands how to navigate TS care. The healthcare consultant would communicate directly with a member of the TS community and collaborate to create a care plan based on the individual’s needs/wants, finances and location. Initially this program would be rolled out to a limited number of our community members to determine the effectiveness and long-term viability of the program, with the goal of attaining additional funding to expand the program if warranted.

b. Develop a webinar and chat series with TS experts.
Educating the TS community is of utmost importance to TSSUS. Connecting TS experts and our community members online will further expand the knowledge of both our members and experts on issues affecting our community.

2. Host the TSSUS Annual Conference to provide the latest in TS advances and create personal connections.

TSSUS is committed to encouraging personal connections and providing educational sessions by leading TS specialists at our annual conference. It is a vital opportunity for the TS community to realize that they are not alone and offers the opportunity for all members of our community to connect in person and educate each other.

3. Serve as a lifeline and source of information to the TS community by providing daily, individualized support services.

TSSUS understands the importance of individual connections to our community and the emotional support often needed. The office will continue to connect people to TS providers, peer volunteers, and local resources in a respectful, patient and timely manner.

4. Continue to provide tools to local groups to aid in local connections.

TSSUS will continue to foster local connections by providing resource groups and local chapters with event funding, resources, connections to local healthcare providers, and insurance to facilitate local activities. TSSUS understands the importance of local support and personal connections and intends to continue to promote and fund local events for our TS community and its dedicated volunteers.

5. Expand TSSUS connection to the community through the initiation of local TS Days.

The office staff will coordinate the organization and preparation for these days, located in various cities across the country. A national representative (staff member or board member) will attend the event to connect local TS community members. These days will include both educational and social components.
**GOAL 4**

**BE THE PREMIER SOURCE OF TS INFORMATION**

TSSUS provides accurate and up-to-date information for anyone needing or wanting to know more about TS. To be the premier source of information, TSSUS knows it must make complex information simple, distinguish facts from opinions and communicate often. To ensure that TSSUS is the first place people turn, TSSUS will:

1. **Expand TS resources, including the web, social media, email, and local events.**

   It is paramount that the TS community has the resources it needs at its fingertips. TSSUS will strive to ensure all online properties are continually updated with new information and are easy to use for the TS community.

2. **TSSUS will stay up-to-date on medical developments by continuing to maintain active relationships with the Professional Advisory Board (PAB) and other experts in the field.**

   A strong working relationship between TSSUS, its PAB and TS experts ensure that the information TSSUS shares with the community is accurate and timely.

**GOAL 5**

**ACHIEVE $1,000,000 IN REVENUE IN 5 YEARS**

In order to attain our vision that *every woman and girl with TS will have cutting edge healthcare ensuring the best quality of life, TSSUS needs to increase funding.* This goal extends beyond our three-year plan. To achieve this goal, TSSUS will:

1. **Establish a fundraising and development staff position.**

   A staff person dedicated to searching for new sources of funding and ensuring that TSSUS communicates our goals and programs effectively is important.
2. **Develop and implement a strategic development plan to fund new programs and the new development position.**

   New programs, such as the healthcare consultant, monthly webinar and research grants require funding. A clear development plan that will lead to acquiring funds to support these programs and position are necessary for the long-term support of the programs and position.

3. **Host Chasing Butterfly Walks and increase revenue by 10% each year.**

   Chasing Butterfly Walks foster local relationships, generate awareness of TS, educate and raise funds. The walks reach donors beyond our existing stakeholders.

4. **Increase Annual Campaign contributions by 10% each year.**

   TSSUS will launch an annual campaign early in the 4th quarter and continue to market it through year-end. The campaign will continue to be a critical component to increasing TSSUS revenue.

5. **Maintain level grant funding and foundation support; and continually seek new funding sources.**

   It is imperative that TSSUS maintains connections with current organizations providing grant funding and regularly demonstrates results of this funding. In addition to retaining existing funding, new funding avenues will be continually explored to allow TSSUS to expand its programs and services.

6. **Increase overall grants and revenue by 30% to $850,000 by the end of 2019.**

   An overall increase in revenue will lay a strong foundation to reaching $1 million in 5 years.

**GOAL 6**

**CONTINUE TO BE THE LEADER FOR ADVOCACY AND ADVANCEMENT OF TS INITIATIVES**

TSSUS has been the leader in advocating for the TS community for the last 30 years. Relationships among women and girls with TS, families, healthcare providers, researchers, and other TS organizations have been built and expanded in the interest of creating awareness, educating, and acquiring the best quality care for women and girls with TS. TSSUS has continually been at the forefront of this movement. TSSUS recognizes that there is much work to be accomplished and that there are many organizations
within the TS community with whom to collaborate to ensure attainment of our vision. TSSUS will continue to be the leading advocate for the TS community by:

1. **Ensuring TSSUS has strategic relationships with TS stakeholders and influencers.**

   TSSUS will establish or keep connections with other TS organizations, health professionals, government entities, TS clinic directors, TS specialists, pharmaceutical companies, the National Institutes of Health (NIH), universities, hospitals, and researchers.

2. **Actively participating in the Turner Resource Network (TRN) Steering Committee and supporting TRN approved projects.**

   The TRN brings together many facets of the TS community and as an active member of the steering committee, TSSUS bridges the gap between researchers, healthcare professionals and advocates. The voice of women and girls with TS continues to need to be heard and understood and TSSUS intends to be that voice.

3. **Providing leadership and support for the 2018 Professional Symposium.**

   TSSUS is committed to bringing together the leading healthcare professionals, researchers and advocates to advance TS health care. TSSUS offers financial support and program management to ensure that the symposium generates quality information for the TS community. TSSUS will continue its ongoing collaboration with other TS organizations to support the next symposium.

4. **Identifying areas for advocacy and participate in initiatives to further goals of TSSUS.**

   TSSUS will continue to represent and encourage the TS community to participate in legislative advocacy in areas such as rare diseases, prenatal screenings, and related initiatives. Additionally, surveys initiated by TSSUS will allow us to understand the views and needs of the TS community to advocate more effectively.

5. **Maintaining an active Professional Advisory Board (PAB) and maintaining relationships with experts in TS field.**

   A strong working relationship between TSSUS and its PAB and TS experts ensures that the information TSSUS shares with the community, is accurate and timely. These relationships ensure connections to existing and new entities in the TS community as well as new research and developments that are of interest to our community.
CONCLUSION

As TSSUS reaches its 30th year of operation, the society and its members remain committed to the success and growth of TSSUS. This 3-year strategy will guide TSSUS activities that will advance our mission. TSSUS welcomes feedback and input on these goals and will continue to solicit input on TSSUS programs and services.

ACKNOWLEDGEMENTS

The Turner Syndrome Society of the United States would like to thank past and present:

- Community partners and sponsors,
- Volunteers and local leadership,
- Board members,
- Professional Advisory Board members,
- Staff and consultants