

BITSS 2019 POLICIES AND PROCEDURES

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TUITION, DISCOUNTS, AND REFUNDS POLICY

Tuition

The tuition for participation in BITSS is \$1,325 and is due in full by April 1, 2019 (or, if an application is submitted after April 1, tuition will be due in full upon the application submission to secure a spot for the applicant in the program). Completion of all registration forms (including Application and Medical Forms) and payment in full is required to secure a participant's spot at BITSS.

Discounts and Financial Aid

- Families who complete and submit all registration forms and pay in full on or before December 31, 2018 are entitled to an early bird discount of \$75.
- Families who complete and submit all registration forms and pay in full from January 1 - January 31, 2019 are entitled to an early bird discount of \$50.
- A limited number of scholarships are available to aid Participants who are not able to pay the tuition in full due to financial circumstances. Participants may apply for scholarship assistance by completing the scholarship application form available here. Scholarship applications must be submitted as soon as possible following the Participant's submission of a Registration Form. Scholarships will be awarded based on financial need, availability of funds and at the complete discretion of the BITSS Board of Directors. BITSS will communicate scholarship award decisions on May 15, 2018, after consideration of all scholarship applications properly completed and submitted on or before May 10, 2018. If funds remain for additional scholarships after the initial awards, the BITSS Board of Directors will make and communicate additional scholarship awards by June 30, 2018. Scholarship funds will be available for tuition assistance only. Participants and their families will be responsible for any travel related expenses.

Refunds

- Families who wish to withdraw registration and notify BITSS in writing on or before March 1 may receive a full refund of the tuition amount paid.
- Families who wish to withdraw registration and notify BITSS in writing between March 2 and April 1 may receive a refund of amounts paid, up to 50% of the full tuition amount of \$1,325.
- Families who wish to withdraw registration and notify BITSS in writing between April 2 and May 1 may receive a refund of amounts paid, up to 25% of the full tuition amount of \$1,325.
- Refunds will not be provided after May 1.

PHOTOGRAPHY / VIDEOGRAPHY PERMISSION

During the summit, BITSS staff may take photographs and/or video of participants engaged in and enjoying the program. BITSS uses these photos and videos for purposes of sharing information with families during the week of the summit, and for promotional purposes.

MOBILE PHONE POLICY

BITSS's first priority is participant safety. For this reason, we encourage BITSS participants who have mobile phones to bring their phones along in case of emergency. Use of phones for other purposes will be limited. BITSS is focused on building community, engagement and togetherness. Smartphones should not be a distraction or escape. With these priorities in mind, the following policy applies to all BITSS participants.

The Boston International Turner Syndrome Summit is a week of independent living for the participants in a safe setting. We ask, for a week, that parents and guardians, on the one hand, and participants, on the other hand, disconnect from calls and texts with each other. BITSS staff will communicate during the course of the Summit to give families some insight into the activities and experience of the group. If parents or guardians wish to check in, they may reach out to the BITSS Director, who will respond as soon as reasonably possible. In the event of an emergency, our Directors are available by phone. Contact information will be provided to all registered families before opening day.

Participants are asked to engage actively with one another and BITSS Mentors and staff. Therefore, unapproved use of smartphones for phone calls or access to apps, social media, videos, internet or texting is off limits.

For safety reasons, participants who have brought a mobile phone will carry their phones when we leave the campus. There is no need to purchase a mobile phone or plan for BITSS. Participants will be grouped so that there is always at least one phone available within each group for purposes of emergencies. We will ensure that participants have programmed into their phones the numbers for the Directors and Mentors. In addition, participants will have emergency contact numbers in the lanyard that they will be asked to wear around their necks at all times (we will provide these). The "pull" of the mobile phone is strong. When the participants are in the dorms, phones may be collected by Mentors and returned for outings.

BITSS may confiscate, for later return, the phones of participants who use their phones in a manner that does not comply with the Mobile Phone Policy. We do not want to embarrass any of our participants by removing their phones, and we will do our best to handle this unpleasant task in a respectful and kind manner. Families, if you call, text, facetime, message or otherwise communicate with your child during BITSS week, you may jeopardize your child's continued access to their phone. Please help us help your children to retain our trust in them and to grow their independence and inner strengths by disengaging for the week. Your BITSS staff will be happy to provide you with updates on your child if you want to check in on them or if you have questions during the week.

If you have any concerns or needs that are specific to your situation, please get in touch with us well in advance.

PARTICIPANT CODE OF CONDUCT

Participants are expected to behave appropriately and promote a safe, fun and healthy environment through productive participation. Disciplinary action may be imposed whenever a participant commits or attempts to commit any act of misconduct while participating in BITSS. Acts of misconduct may include, but are not necessarily limited to:

- Possession, use, or distribution of an illegal or controlled substance, or look-alike drug.
- Unauthorized and/or illegal possession, use, or distribution of any alcoholic beverage.
- Theft of property or services.
- Intentional or willful and wanton destruction of property.
- Assault and/or battery.
- Possession of a weapon.
- Conduct that constitutes harassment or abuse that threatens the mental well-being, health or safety of any individual.

Consequences include, but are not limited to, time away from the program, notifying parents, and/or removal from the program for the safety and well-being of other participants. No reimbursements or refunds will be available in the event that a participant is removed from the program as a consequence for violating the Code of Conduct. Disciplinary action may also be imposed whenever a participant commits any acts of misconduct during an off-site event or activity.

HEALTH AND WELLNESS POLICY AND PROCEDURE

BITSS encourages all participants to learn the nuts and bolts of taking personal responsibility for health and wellness, and we will work with participants to understand the importance of good nutrition, exercise, cleanliness, and hygienic behaviors. Our full time nursing staff will care for participants who become ill with symptoms that can be readily managed onsite and will consult as needed with BITSS's Medical Advisor, a physician who serves on BITSS's Board of Directors. Our nursing staff will contact parents or guardians and will provide updates as to the participant's progress. For more serious illnesses, or in the case of emergency, participants will be transported to Massachusetts General Hospital or other nearby medical facility. Parents or guardians will be solely responsible for all costs related to medical care needs.

All medications, prescription and non-prescription, must be delivered to the BITSS nurse on staff at registration. All such medications must be in their original bottles and, in the case of prescription medications, with their original prescription label with the participant's name on it. We will not accept or administer medications that arrive in any other manner. Please do not send participant's medication in daily pill organizers.

Each registering participant / family will receive by separate email a Medical History and Consent form to complete. Please complete and return this form promptly. Once the Medical History and Consent form has been submitted, it is the responsibility of each participant and her family to provide BITSS with any updates or changes to the information provided on the form.

At BITSS, some of our time together is spent thinking and talking about Turner syndrome. We provide information through a Q&A with medical professionals, and we provide the participants with ample opportunities to share experiences with one another in a supportive environment. This means that any topic that relates to Turner syndrome will likely come up at some point during the week, including (but not limited to): fertility challenges and alternative approaches to forming a family for those who hope to parent one day; cardiac issues; and learning differences. It is helpful to us and to our participants if families ensure that there are no big surprises for their daughters during BITSS. If you haven't already discussed with your daughter how having Turner syndrome impacts her physically, emotionally, academically and/or otherwise, please take the time to have these conversations with her before she joins us at BITSS. You may also find that your daughter comes home with some new information about Turner syndrome for you to consider and discuss together. Your BITSS Board and staff includes adult women with TS, medical professionals, and parents and other family members of individuals with TS. We are here to support you if we can in these conversations before or after BITSS week - please don't hesitate to reach out to us if we can offer any guidance or support.

TRAVEL POLICY

BITSS is happy to assist families by meeting arriving participants at Logan Airport or South Station bus and train terminal and transporting them to BITSS. Similarly, BITSS is happy to arrange to transport participants to Logan or South Station for travel home at the end of the week. If you believe that such assistance may be helpful / necessary, please let us know your travel arrangements as soon as possible. If you do need support with pickups, please ensure that:

- the participant's scheduled arrival time in Boston is on July 28, 2018 between the hours of 9am and 2pm, and
- the participant's scheduled departure time from Boston is on August 4, 2018 between the hours of 9am and 2pm.

If your travel arrangements necessitate pickups or drop offs outside of those windows, you must contact us at info@bitssummit.org to discuss arrangements before finalizing your travel plans.

RELEASE OF LIABILITY

This is a legally binding Consent Form and Release of Liability made voluntarily on behalf of the Participant, the Parent or Guardian, and on behalf of their heirs, executors, administrators, legal representatives, and assigns.

The undersigned hereby acknowledges that participation in the Boston International Turner Syndrome Summit (“BITSS”), including participation in recreational events on- and off-site and transportation to offsite events, involves inherent risk of physical injury and assumes all such risks. The undersigned hereby agrees that for the sole consideration of BITSS allowing the participant to participate in the above named activity for which or in connection with which BITSS has made available any equipment, facilities, grounds or personnel for such programs or activities, the undersigned does hereby release and forever discharge BITSS and its Directors, employees and agents, of any and all claims, demands, rights and causes of action of whatever kind or nature, arising from and by reason of any and all known and unknown, foreseen and unforeseen bodily and personal injuries, damage to property, and the consequence thereof, resulting from participation in or in any way connected with the above named activity.