

TSC Alliance

Terms of Use

Approved by Executive Committee: May 2, 2025

The following Terms of Use are entered into by and between You and the TSC Alliance (the “TSC Alliance”, “we”, or “us”).

The following terms and conditions, together with any documents they expressly incorporate by reference (collectively, the “Terms”), govern your access to and use of <https://www.tscalliance.org/> and all affiliated websites and subdomains (the “Site”) and our related services, (together with the Site, the “Services”), whether as a guest or a registered user.

Please read the Terms carefully before you start to use the Services. **By using the Services or by clicking to accept or agree to the Terms when this option is made available to you, you accept and agree to be bound and abide by these Terms and our Privacy Policy, incorporated herein by reference.** If you do not want to agree to these Term including the agreements incorporated by reference herein, you must not access or use the Services.

By using this Services, you represent and warrant that you are of legal age to form a binding contract with the TSC Alliance and meet all of the foregoing eligibility requirements. If you do not meet all of these requirements, you must not access or use the Services.

MODIFICATION OF TERMS

We reserve the right to change or modify these Terms at any time and in our sole discretion. If we make changes to these Terms, we will provide notice of such changes, such as by updating the “Last Updated” date at the beginning of these Terms. By continuing to use the Services at any point after such update, you confirm your acceptance of the revised Terms, and all of the terms incorporated therein by reference. You should review these Terms frequently to ensure that you understand the terms and conditions that apply when you access or use the Services. If you do not agree to the revised Terms, you may not access or use the Services.

USE OF THE SERVICES

- 1. Online Store.** The Services include an informational website available by the TSC Alliance to provide resources and support for patients, families, caregivers, healthcare providers, and researchers. The website may include links to surveys that you may complete to allow us to better understand certain diseases or health challenges and treatments. It also may provide information on various clinical research studies relevant to qualified individuals.
- 2. Eligible Users.** The Services are not intended for use by anyone under the age of 13.

PRIVACY POLICY

Please refer to our Privacy Policy for information about how we collect, use and share your personal information. By submitting your personal information through the Services, you expressly consent to the collection, use, and disclosure of personal information in accordance with the Privacy Policy.

COMMUNICATIONS

By using the Services you consent to receive electronic communications from us (e.g., via email, SMS text, or by posting notices to the Services). You agree that any notices, agreements, disclosures or other communications that we send to you electronically will satisfy any legal communication requirements, including, but not limited to, that such communications be in writing. You should maintain copies of electronic communications from us by printing a paper copy or saving an electronic copy. We have no obligation to store for your later use or access any such electronic communications that we make to you. We may also send you promotional communications via email and/or SMS text, including, but not limited to, newsletters, special offers, surveys, cart reminder messages, order confirmations, customer service, and marketing messages, and other news and information we think will be of interest to you. You may opt out of receiving these communications at any time by following the unsubscribe or opt out instructions provided therein.

DONATIONS

Payment processing services for the TSC Alliance, including the processing and storing of credit card data, are provided by third-party processors (each, a "Payment Processor") and are subject to the Payment Processor's terms and conditions ("Payment Processing Terms"). By agreeing to these terms and continuing to use the Services, you agree to be bound by the applicable Payment Processing Terms, as the same may be modified by a Payment Processor from time to time. As a condition of the TSC Alliance enabling payment processing services, you agree to provide the TSC Alliance accurate and complete information about you and your business, and you authorize the TSC Alliance to share with a Payment Processor this information and transaction information related to your use of the payment processing services provided by a Payment Processor.

LIMITED LICENSE

You are hereby granted a limited, revocable, nonexclusive, nontransferable, nonassignable, non-sublicensable, "as-is" license to access and use the Services and related content for your own personal, non-commercial use; provided, however, that such license is subject to the Terms and does not include any right to (i) sell, resell, or use commercially the Services, (ii) distribute, publicly perform, or publicly display any content, (iii) modify or otherwise make any derivative uses of the Services, or any portion thereof, (iv) use any data mining, robots, or similar data gathering or extraction methods, (v) download (other than page caching) any portion of the Services, except as expressly permitted by us, and (vi) use the Services other than for their intended purposes. This license is subject to your compliance with these Terms.

INTELLECTUAL PROPERTY RIGHTS

You acknowledge and agree that the Services may contain content or features ("Service Content") that are protected by copyright, patent, trademark, trade secret or other proprietary rights and laws. The TSC Alliance name and logos are trademarks and service marks of the TSC Alliance (collectively the "TSC Trademarks"). Other TSC Alliance and its service provider content, names and logos used and displayed via the Service may be trademarks or service marks of their respective owners who may or may not endorse or be affiliated with or connected to the TSC Alliance. Nothing in these Terms or the Service should be construed as granting, by implication, estoppel, or otherwise, any license or right to use any of TSC Trademarks or other TSC Alliance and its service provider content, names and logos used and displayed via the Service, without our prior written permission in each instance. All goodwill generated from the use of TSC Trademarks or other TSC Alliance or its service provider content will inure to the exclusive benefit of the TSC Alliance or the applicable rights holder.

COPYRIGHT COMPLAINTS

We respect the intellectual property of others and ask that our users do the same. We respond to notices of alleged copyright infringement according to the process set out in the U.S. Digital Millennium Copyright Act. If you believe that your work has been copied or used on the Site in a way that constitutes copyright infringement, please send the following information to our Copyright Agent at dklein@tscalliance.org.

1. Your address, telephone number, and email address.
2. A description of the copyrighted work that you claim has been infringed.
3. A description of where the alleged infringing material is located on the Services.
4. A statement by you that you have a good faith belief that the disputed use is not authorized by you, the copyright owner, its agent, or the law.
5. An electronic or physical signature of the person authorized to act on behalf of the owner of the copyright interest.
6. A statement by you, made under penalty of perjury, that the above information is accurate and that you are the copyright owner or authorized to act on behalf of the copyright owner.
7. For clarity, only copyright infringement notices should go to our Copyright Agent. You acknowledge that if you fail to comply with the requirements of the section, your notice may not be valid.
8. The TSC Alliance may at its discretion, suspend or terminate the access of and take other action against users who infringe upon the intellectual property rights of others.

EDUCATIONAL DISCLAIMER

The Site is intended to provide basic information about tuberous sclerosis complex. It is not intended to, nor does it, constitute medical or other advice. Readers are warned not to take any action with regard to medical treatment or otherwise based on the information on Site without first consulting a physician. The TSC Alliance does not promote or recommend any treatment, therapy, institution or health care plan.

The information contained on the Site is intended for your general education and information only and not for use in pursuing any treatment or course of action. Ultimately, the course of action in treating a given patient must be individualized after a thorough discussion with the patient's physician(s).

EXTERNAL SITES

The Services may include hyperlinks to other websites or resources (collectively, the "External Sites"), which are provided solely as a convenience to our Site visitors. We have no control over any External Sites. You acknowledge and agree that we are not responsible for the availability of any External Sites, and that we do not endorse any advertising, products, or other materials on or made available from or through any External Sites. The TSC Alliance does not warrant against human and machine errors, omissions, delays, interruptions or losses, including loss of data nor does the TSC Alliance make warrantee that External Sites will be free of infection by viruses or other harmful mechanisms that manifest contaminating or destructive properties. Users of the Site are responsible for (1) implementing and maintaining adequate procedures and checkpoints to satisfy their particular requirements for accuracy of data input and output and (2) maintaining a means external to the Site for the reconstruction of any lost data. Furthermore, you acknowledge and agree that we are not liable for any loss or damage which may be incurred as a result of the availability or unavailability of the External Sites, or as a result of any reliance placed by you upon the completeness, accuracy or existence of any advertising, products or other materials on, or made available from, any External Sites.

PROHIBITED USES

You may not attempt or cause to attempt to gain unauthorized access to any portion or feature of the Services, or any other systems or networks connected to the Services, by hacking, password “cracking,” or any other illegitimate means. You may not breach or cause to breach the security or authentication measures on the Services, or any other systems or networks connected to the Services, or otherwise attempt to interfere with the proper functioning of the Services. You will not falsify your identity or impersonate another person, engage in conduct that limits the use and enjoyment of the Services, or any part thereof, by other users in any way, in each case as determined by us in our sole and absolute discretion.

In addition, you agree not to and will not assist another to:

1. reverse engineer, disassemble, alter, decompile, duplicate, create derivative works from, make copies of, extract information from, distribute, license, lease, sell, resell, transfer, publicly display, publicly perform, transmit, stream, broadcast or otherwise exploit the Services, in whole or in part, except as expressly permitted by us;
2. upload, post or store any materials that directly or indirectly contain viruses, corrupted files or any other similar harmful mechanism;
3. link to, mirror, or frame any portion of the Services without our prior express written permission;
4. scrape, index, survey, or data mine any portion of the Services or unduly burden or hinder the operation of the Services; or
5. remove any notice of the proprietary rights of our licensors and us from any portion of the Services or printed version thereof.

TERMINATION

1. **You Terminate.** You may terminate these Terms at any time by discontinuing your access to and use of the Services. If you use the Services again, you will be deemed to have agreed to the Services.
2. **We Terminate.** You agree that we, in our sole discretion, and for any or no reason, may terminate these Terms without prior notice. You agree that any suspension or termination of your access to the Services may be without prior notice, and that we will not be liable to you or to any third party for any such suspension or termination.
3. **Other Remedies Available.** If we terminate these Terms or suspend or terminate your access to or use of the Services due to your breach of these Terms or any suspected fraudulent, abusive, or illegal activity (including, without limitation, if you engage in any of the Prohibited Uses), then termination of these Terms will be in addition to any other remedies we may have at law or in equity.
4. **Effect of Termination.** Upon any termination or expiration of these Terms, whether by you or us, you may no longer have access to information that you have posted on the Services, and you acknowledge that we will have no obligation to maintain any such information in our databases or to forward any such information to you or to any third party.

INTERNATIONAL ISSUES

We operate the Services from the United States of America. If you choose to access the Services from outside the United States of America, you are responsible for complying with applicable local laws.

DISCLAIMERS

THE SERVICES, CONTENT CONTAINED THEREIN, AND ITEMS LISTED THEREIN ARE PROVIDED ON AN "AS IS" AND "AS AVAILABLE" BASIS WITHOUT WARRANTIES OR CONDITIONS OF ANY KIND, EITHER EXPRESS OR IMPLIED. WE (AND OUR SUPPLIERS) MAKE NO WARRANTY THAT THE SERVICES: (A) WILL MEET YOUR REQUIREMENTS; (B) WILL BE AVAILABLE ON AN UNINTERRUPTED, TIMELY, SECURE, OR ERROR-FREE BASIS; OR (C) WILL BE ACCURATE, RELIABLE, COMPLETE, LEGAL, OR SAFE. WE DISCLAIM ALL OTHER WARRANTIES OR CONDITIONS, EXPRESS OR IMPLIED, INCLUDING, WITHOUT LIMITATION, IMPLIED WARRANTIES OR CONDITIONS OF MERCHANTABILITY, FITNESS FOR A PARTICULAR PURPOSE, TITLE, AND NON-INFRINGEMENT AS TO THE SERVICES OR ANY CONTENT CONTAINED THEREIN. WE DO NOT REPRESENT OR WARRANT THAT CONTENT ON THE SERVICES IS ACCURATE, COMPLETE, RELIABLE, CURRENT, OR ERROR-FREE. WE WILL NOT BE LIABLE FOR ANY LOSS OF ANY KIND FROM ANY ACTION TAKEN OR TAKEN IN RELIANCE ON MATERIAL OR INFORMATION, CONTAINED ON THE SERVICES. WHILE WE ATTEMPT TO MAKE YOUR ACCESS TO AND USE OF THE SERVICES AND CONTENT SAFE, WE CANNOT AND DO NOT REPRESENT OR WARRANT THAT THE SERVICES, CONTENT, OR ANY ITEMS LISTED ON OUR SERVICES OR OUR SERVERS ARE FREE OF VIRUSES OR OTHER HARMFUL COMPONENTS. WE CANNOT GUARANTEE THE SECURITY OF ANY DATA THAT YOU DISCLOSE ONLINE. YOU ACCEPT THE INHERENT SECURITY RISKS OF PROVIDING INFORMATION AND DEALING ONLINE OVER THE INTERNET AND WILL NOT HOLD US RESPONSIBLE FOR ANY BREACH OF SECURITY UNLESS IT IS DUE TO OUR GROSS NEGLIGENCE.

LIMITATION OF LIABILITY

TO THE FULLEST EXTENT PERMITTED BY LAW, IN NO EVENT WILL WE BE LIABLE TO YOU OR ANY THIRD PARTY FOR ANY LOST PROFIT OR ANY INDIRECT, CONSEQUENTIAL, EXEMPLARY, INCIDENTAL, SPECIAL OR PUNITIVE DAMAGES ARISING FROM THESE TERMS, THE SERVICES, ANY ITEMS, OR FOR ANY DAMAGES RELATED TO LOSS OF REVENUE, LOSS OF PROFITS, LOSS OF BUSINESS OR ANTICIPATED SAVINGS, LOSS OF USE, LOSS OF GOODWILL, OR LOSS OF DATA, AND WHETHER CAUSED BY TORT (INCLUDING NEGLIGENCE), BREACH OF CONTRACT, OR OTHERWISE, EVEN IF FORESEEABLE AND EVEN IF WE HAVE BEEN ADVISED OF THE POSSIBILITY OF SUCH DAMAGES. ACCESS TO, AND USE OF, THE SERVICES IS UNDERTAKEN BY YOU AT YOUR OWN DISCRETION AND RISK, AND YOU WILL BE SOLELY RESPONSIBLE FOR ANY DAMAGE TO YOUR COMPUTER SYSTEM OR MOBILE DEVICE OR LOSS OF DATA RESULTING THEREFROM.

NOTWITHSTANDING ANYTHING TO THE CONTRARY CONTAINED HEREIN, IN NO EVENT SHALL OUR MAXIMUM AGGREGATE LIABILITY ARISING OUT OF OR IN ANY WAY RELATED TO THESE TERMS, YOUR ACCESS TO AND USE OF THE SERVICES, CONTENT (INCLUDING YOUR CONTENT), OR ANY ITEMS, PURCHASED, OR SOLD THROUGH THE SERVICES EXCEED THE GREATER OF (A) \$100 OR (B) THE AMOUNT PAID TO US BY YOU FOR THE SERVICES THAT IS THE SUBJECT OF THE CLAIM.

Some jurisdictions do not allow the exclusion or limitation of incidental or consequential damages, so the above limitation or exclusion may not apply to you.

INDEMNIFICATION

To the fullest extent permitted by applicable law, you agree to indemnify, defend, and hold harmless the TSC Alliance, its officers, directors, employees, and volunteers from and against all actual or alleged third-party claims, damages, awards, judgments, losses, liabilities, obligations, penalties,

interest, fees, expenses (including, without limitation, attorneys' fees and expenses) and costs (including, without limitation, court costs, costs of settlement, and costs of or associated with pursuing indemnification and insurance), of every kind and nature whatsoever arising out of or related to these Terms or your use of the Services, whether known or unknown, foreseen or unforeseen, matured or unmatured, or suspected or unsuspected, in law or equity, whether in tort, contract or otherwise (collectively, "Claims"), including, but not limited to, damages to property or personal injury, that are caused by, arise out of or are related to (a) your use or misuse of the Services; (b) any feedback you provide; (c) your violation of these Terms; (d) your violation of the rights of any third party, including another user; (e) any breach or non-performance of any covenant or agreement made by you; or (f) any off-chain benefits (including the furnishing, or any failure to furnish, or any acts or omissions of or attributable to you or any third party in respect of the same). You agree to promptly notify the TSC Alliance of any third-party Claims and cooperate with the TSC Alliance in defending such Claims. You further agree that the TSC Alliance shall have control of the defense or settlement of any third-party Claims. THIS INDEMNITY IS IN ADDITION TO, AND NOT IN LIEU OF, ANY OTHER INDEMNITIES SET FORTH IN A SEPARATE WRITTEN AGREEMENT BETWEEN YOU AND THE TSC ALLIANCE.

DISPUTE RESOLUTION

PLEASE READ THE FOLLOWING SECTION CAREFULLY BECAUSE IT REQUIRES YOU TO ARBITRATE CERTAIN DISPUTES AND CLAIMS WITH THE COMPANY AND LIMITS THE MANNER IN WHICH YOU CAN SEEK RELIEF FROM US.

These Terms, including all matters of construction, validity, and performance, and all disputes arising out of or connected with the Terms, the Site, and the Services (each a "Dispute," collectively, the "Disputes"), shall, in all respects, be governed by and construed in accordance with the laws of the State of Maryland without regard to any principles of conflict of laws, except that the arbitration clause herein shall be governed by the Federal Arbitration Act. Any Dispute shall be settled by mediation under the Commercial Mediation procedures of the American Arbitration Association (the "AAA"), except that if mediation of a Dispute is not successful within two (2) months of appointment of a mediator, such Dispute shall be settled by individual arbitration under the Commercial Arbitration Rules of the AAA. The place of mediation or arbitration shall be the AAA office nearest to Agency's principal place of business in Maryland. The language of the mediation or arbitration shall be English. The arbitrator shall be an expert attorney with experience in the field of intellectual property law. Notwithstanding this arbitration provision, any Dispute not resolved through arbitration that is less than \$10,000 USD and qualifies for treatment on a non-jury basis in a small claims court of in Maryland may be resolved in such small claims court on an individual basis at the election of either party. All Disputes shall be mediated, arbitrated, or litigated on an individual basis. You irrevocably waive any right it may otherwise have to proceed on a class or collective basis. Further, you irrevocably waive all right to trial by jury as well as any argument or claim of improper venue or forum non conveniens. The foregoing provisions shall not limit the right of the TSC Alliance to collect payments due or payable, or prevent either party from commencing any action or proceeding to compel arbitration, obtaining injunctive relief pending the appointment of an arbitrator, or obtaining execution of any award rendered in any such action or proceeding, or in any other manner provided venue for all such proceedings shall be in the state or federal courts within Maryland. The parties shall bear their own expenses, except that parties shall equally share the expenses of any mediator or arbitrator (except for the required non-refundable filing fees which shall be paid solely by the party asserting the Dispute). The prevailing party in any arbitration may seek from the arbitrator an award of the party's reasonable outside attorneys' fees and costs incurred. Judgment on any the award rendered by any arbitrator may be entered in any court having jurisdiction thereof.

GENERAL

- 1. Entire Agreement.** These Terms, any applicable supplemental terms, and our Privacy Policy constitute the entire legal agreement between you and us and will be deemed to be the final and integrated agreement between you and us, and govern your access to and use of the Services, and completely replace any prior or contemporaneous agreements between you and us related to your access to or use of the Services, whether oral or written.
- 2. Third-Party Beneficiaries.** Except as otherwise provided herein, these Terms are intended solely for the benefit of the TSC Alliance and you and are not intended to confer third-party beneficiary rights upon any other person or entity.
- 3. Independent Contractor.** Your relationship to the TSC Alliance is that of an independent contractor, and neither party is an agent or partner of the other. You represent and warrant that you are eligible to provide services as an independent contractor in the jurisdiction(s) in which you will access the Services and are solely responsible for your own tax and legal compliance.
- 4. Interpretation.** The language in these Terms will be interpreted as to its fair meaning, and not strictly for or against any party.
- 5. Severability.** Should any part of these Terms be held invalid, illegal, void or unenforceable, that portion will be deemed severed from these Terms and will not affect the validity or enforceability of the remaining provisions of these Terms.
- 6. No Waivers.** Our failure or delay to exercise or enforce any right or provision of these Terms will not constitute or be deemed a waiver of future exercise or enforcement of such right or provision. The waiver of any right or provision of these Terms will be effective only if in writing and signed for and on behalf of us by a duly authorized representative.
- 7. Governing Law.** All matters arising out of or relating to these Terms will be governed by and construed in accordance with the laws of the State of Maryland and the federal laws of the United States of America applicable therein without giving effect to any choice or conflict of law provision or rule.
- 8. Venue.** Subject to the above, any legal action or proceeding arising under these Terms will be brought exclusively in the State of Maryland, in Montgomery County, and we and you irrevocably consent to the personal jurisdiction and venue there.
- 9. Notices.** We may provide you with any notices (including, without limitation those regarding changes to these Terms) by email or postings on the Services. By providing us with your email address, you consent to our using the email address to send you any notices. Notices sent by email will be effective when we send the email, and notices we provide by posting will be effective upon posting. It is your responsibility to keep your email address current.
- 10. Assignment.** You may not assign any of your rights or obligations under these Terms, whether by operation of law or otherwise, without our prior written consent. We may assign our rights and obligations under these Terms in our sole discretion to an affiliate or in connection with an acquisition, sale or merger. These Terms shall be binding upon and inure to the benefit of the applicable parties and their successors and permitted assigns.

CONTACT US

dklein@tsalliance.org