

## Special Needs Trust Rules 2024

Special Needs Trust--The Spina Bifida Association of Maryland (SBAM) has a special program to help families establish a fund to support a person with spina bifida upon the death of the parents. This is done through a Special Needs Trust.

There are three **Broad Requirements** for SBAM members to participate in this program.

1. The family must create a legal entity called a Special Needs Trust and obtain the approval of the Internal Revenue Service. The Internal Revenue Service will assign an identifying number that is unique to your Trust.
2. One time each year, the family can apply to have SBAM make a deposit into the Trust. If you do this, you are not eligible to use the Brace Fund that year to help pay your medical expenses. That means you have to pay your medical bills out of your pocket that year. If a family uses the Special Needs Trust program, that family is permitted to return to regular Brace Fund participation the following year. However, the money SBAM deposited into the Trust must remain there until the death of the parents.
3. The money SBAM deposits into the Trust cannot be spent during the lifetime of the parents. Parents must sign a statement agreeing to this restriction. Upon the death of the parents, the money must be used to help support the person with spina bifida. The Trust contains the name of an Administrator who is responsible for disbursing the funds properly. There is one special situation where you can receive an exception to **Broad Requirement 3**. If an unusual situation produces a large, unexpected medical expense for the person with spina bifida, the money deposited into the Trust by SBAM can be used. This requires unanimous approval of the Council.

If you need financial assistance with your current medical bills, you should not participate in this program. This program is designed to help after the parents are deceased. It is not designed for today's medical bills. Instead, the Brace Fund is designed for today's medical bills. In other words, if a family participates in this program, the family must be prepared to pay medical bills out of its own pocket.

In addition to those three **Broad Requirements**, the family must meet two **Rules of Eligibility**.

1. The family must be active members of SBAM. This is an integrity feature. That means we want to know the family well. The family must have attended 3 of the 5 General Membership Meetings held the previous year.
2. The family must apply in person at the General Membership Meeting held in May of the current year. Again, this is an integrity feature. We want to know the family well and we want to see the family often.

**Example:** In order to receive a payment into their Special Needs Trust in 2024, the family must have attended 2 of the 5 General Membership Meetings held in 2024. In addition, the family must apply by November 1, 2024.

In special situations, we can allow an exception to the **Rules of Eligibility**.

1. We expect few or no exceptions to **Rule of Eligibility 1**. An exception can be given only with the unanimous approval of the Council.
2. **Rule of Eligibility 2** can be waived if the Brace Fund Committee decides that an unusual situation prevented the family from attending the General Membership Meeting in May of the current year. We expect such situations to be rare.

**Special Notice:** SBAM might conduct an audit to ensure that the family has complied with the **Broad Requirements**. Specifically, you might be asked to prove you have stored the funds properly and that the funds have not been spent before the death of the parents.