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## CLOSING THE GAP IN COST AND CARE

Finding resources and identifying funding vehicles make all the difference in a patient's financial well-being – and peace of mind.

[Fundraising Options: Where to Go for Help](#)

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It is an irony best classified as cruel: An injury to the spinal cord or brain not only turns a person's physical world upside down, it also brings the complexity and anxiety of financing treatment and accommodations for a catastrophic injury.

The sad truth is that most families are unprepared for the harsh financial consequences of such an injury. Insurance policies typically cover several weeks of rehabilitation care, but the average stay at Shepherd Center is nearly six weeks.

“Generally speaking, there is a mismatch between the costs of catastrophic care and the insurance coverage people have to cover those costs,” says Mitch Fillhaber, Shepherd’s vice president of managed care and marketing. “As a result, people are surprised to find out what catastrophic care costs.”

Further complicating the issue is the gap in coverage for related costs such as caregiving, ongoing therapy, adaptive technology, home modifications and transportation. So patients and families have to think creatively about how best to generate funds to help cover costs – and how to make sure every available dollar is spent in the smartest way possible.

Creative fundraising often begins at the local level – with patients and their families and friends organizing community support. Former Shepherd patients tell stories of receiving funds from golf tournaments, bike rides, carnivals and other fundraising events held in their honor. Contributions take the form of cash or equipment. Several nonprofit organizations and social networking sites exist to help people generate and accept donations ([see sidebar](#)).

Foundations and nonprofit organizations can also be a resource to help cover expenses. Former Shepherd patients Cindy Donald and Travis Roy have set up foundations that provide grants for equipment and therapy. Other foundations around the country do the same. The challenge is to conduct thorough research to identify a match between a foundation's focus and the patient's need.

Finally, government assistance can add support in the form of Supplemental Security Income (SSI) and Social Security Disability Income (SSDI), and through Medicaid and Medicare. People with disabilities who have very minimal income and resources may qualify for Medicaid and SSI, and those who have been gainfully employed and paid into the Social Security system may qualify for Medicare and SSDI.

In most cases of catastrophic care, patients must rely on some combination of public assistance and help from other sources, such as personal income, donations or grants. The added irony: One can cancel the other out. For example, if a patient's assets from any source – grants, donations, settlements, inheritance or other – exceed \$2,000, then Medicaid and SSI benefits can be lost.

This means that if a person is on Medicaid and SSI and receives an outright distribution of settlement money from a lawsuit or from a fundraiser or grant, he or she loses SSI and Medicaid government benefits. The same is not true for Medicare and SSDI, however. Those benefits are not “means tested,” meaning they are not constrained by income thresholds.

Thus, identifying techniques that maximize the value of every dollar is crucial. One way to protect means-tested government benefits is to set up a special needs trust (SNT), which provides financial support to individuals with disabilities while allowing them to remain eligible for public benefits. Funds placed into the trust aren't counted as an eligible resource and can be used to cover medical costs and other quality-of-life expenses.

“Patients who become eligible for Medicaid and were injured because of the fault of someone else, or those who have community support, should consider asset protection through a special needs trust,” says Liz Schoen, Shepherd Center's former general counsel. SNT funds can generally be used for everything except food and some shelter items. “That could include Shepherd's Beyond Therapy<sup>®</sup> program, recreational therapy, a modified vehicle, even a trip for the patient and a caregiver,” Schoen explains. “The trust supplements what government programs won't pay for.”

Special needs trusts generally fall into two categories depending on whether the trust is funded with assets of the trust beneficiary or someone else. First party SNTs are funded with assets that legally belong to the beneficiary. The trust is irrevocable, meaning it can't be revoked or terminated, and the beneficiary must be under the age of 65 and classified as “disabled” under the Social Security Administration definition. If funds remain in the SNT after the death of the beneficiary, they must first be used to reimburse Medicaid for all benefits paid out during the beneficiary's lifetime.

A third party SNT is funded by assets that don't belong to the beneficiary, such as those from a family member, friend or money raised through fundraisers. Also irrevocable, third party SNTs do not give Medicaid any claim to remaining trust assets upon the death of the beneficiary.

While SNTs help protect funds, they can be complex. “Many lawyers don't know how to set these up,” says Kristen Lewis, an attorney at Atlanta firm Smith, Gambrell & Russell who specializes in estate planning and SNTs. “It is imperative to find counsel who is experienced in this complex area and who knows the proper language to include in the trust document.” The trust document, she explains, details how the SNT assets can and cannot be used, and it must adhere to ever-changing Social Security Administration regulations.

A trustee, appointed in the trust document, is needed to administer and manage an SNT. “A trustee can be an individual, attorney or corporation, such as a bank,” explains Bill Frazier, senior vice president of SunTrust Bank, who oversees a national division handling SNTs. “When choosing a trustee, you need to make sure it's a good fit from an economic, investment and skill set standpoint. Trustees need to be knowledgeable in special needs trusts.”

Another option for those whose assets may be more modest is a pooled SNT trust. ([See the sidebar for a list of those types of trusts.](#))

Georgia's Department of Community Health (DCH) must approve each SNT application in the state, and the DCH turns to HMS Government Services, a private firm, to review applications. William Overman, who directs Georgia's trust unit for HMS, says once the trust is established, his office tracks the accounting, making sure all disbursements are within the law.

“We look at every single SNT application to make sure all the legal requirements are met when the trust is set up,” Overman says, “and then we review it each year.”

Because closing the gap between cost and care affects the quality of life for patients, Shepherd Center is working to become a greater resource in this area.

“Right now, the legal team at Shepherd can help patients with powers of attorney and advance directives,” Schoen says, “but the hospital wants to do more to help protect our patients. In the future, Shepherd Center hopes to bring in experts such as Kristen Lewis, Bill Frazier and Bill Overman, who can explain special needs trusts and direct patients and their families to people who can help.”

## Fundraising Options: Where to Go for Help

It can be daunting when facing all the expenses needed to care for individuals living with brain and/or spinal cord injuries. But there is help. Patients can supplement their treatment funds through grants, fundraisers and contributions from generous individuals. Here is a list of resources.

### FOUNDATIONS

Christopher and Dana Reeve Foundation

[www.christopherreeve.org](http://www.christopherreeve.org)

This foundation does not give grants to individuals, but serves as a great resource for people with paralysis. Click on the "Paralysis Resource Center," and there is information on every aspect of being paralyzed, as well as a way to find resources in your area.

Dreams of Recovery Foundation

[www.dreamsofrecovery.org](http://www.dreamsofrecovery.org)

When former Shepherd Center patient Cindy Donald discovered that most insurance programs wouldn't cover the cost of Shepherd's revolutionary Beyond Therapy® program, she decided to take some of the money that had been donated to her to pay for a friend's therapy. Out of that gesture, the Dreams of Recovery Foundation was born. The foundation now gives grants of up to \$15,000 to pay for therapy programs not covered by insurance, equipment for the improvement of everyday life and grants to institutions for research.

Travis Roy Foundation

[www.travisroyfoundation.org](http://www.travisroyfoundation.org)

A year after former Shepherd Center patient Travis Roy was paralyzed from the neck down while playing in a collegiate hockey game, he started a foundation to help others with spinal cord injuries improve their quality of life through adaptive equipment. The Foundation raises about \$500,000 a year and makes 70 to 100 grants annually, ranging from \$1,000 to \$7,000 to provide adaptive equipment, such as voice-activated software, ramps and stair platforms.

Brain and Spinal Cord Injury Trust Fund Commission

[www.bsitf.state.ga.us](http://www.bsitf.state.ga.us) 404-651-5112 or 888-233-5760

Created by a Georgia constitutional amendment, the Trust Fund for Brain and Spinal Injury is designed to provide for things that are not covered by private insurance, Medicaid or Medicare, and funds are provided only once all other means of payment have been exhausted or refused. Outstanding medical bills, medical insurance premiums and medication costs are not eligible for a grant, but things like physical, cognitive and behavioral therapy, adaptive equipment, tutoring, caregiving, vehicle modifications and home modifications are eligible. Application guidelines are available on the website.

To get a broader list of foundations that give grants to people with disabilities, visit the listing on the Foundation Center's website at [foundationcenter.org/getstarted/topical/disabilities.html](http://foundationcenter.org/getstarted/topical/disabilities.html).

### FUNDRAISING OUTLETS

HelpHOPELive

[www.helphopelive.org](http://www.helphopelive.org) or 800-642-8399

Formerly NTAf, works with families and volunteers throughout the United States to start successful fundraising campaigns for people who are facing a transplant or have sustained catastrophic injuries. Funds raised are tax-deductible and are sent to and held by HelpHOPELive in regional restricted funds. Disbursements are then made to the individual to pay for uninsured medically related expenses, such as specially equipped vans and durable medical equipment, home modifications, home health care services, physical therapy and insurance premiums and co-payments.

MedGift

[www.medgift.com](http://www.medgift.com)

Medgift is a combination social networking site and gift registry for patients and people who care about them. Patients can set up a personalized home page, share updates and provide a gift registry of needs. Contributors can pay for hospital expenses and other needs and wishes. Patients can also ask for non-monetary gifts, such as babysitting, prayers, transportation and visits.

Fundly

[www.fundly.com](http://www.fundly.com)

Fundly is an online fundraising management website for political campaigns, nonprofits and individual fundraisers. Like MedGift, individuals can set up a customized fundraising page and promote the campaign through Facebook, Twitter and email. Fees are based on a percentage of the donations.

### OTHER RESOURCES

Home Modifications

The Council for Disability Rights lists fundraising sources for home modifications at

[www.disabilityrights.org/mod3.htm](http://www.disabilityrights.org/mod3.htm). There is also a downloadable PDF of home modification resources available on the Reeve Foundation website. Also, see a previously published Spinal Column magazine article at: [www.shepherdcentermagazine.org/spring-2012/accessible-living/](http://www.shepherdcentermagazine.org/spring-2012/accessible-living/).

Transportation

[www.nmeda.org](http://www.nmeda.org) or 800-833-0427

National Mobility Equipment Dealers Association (NMEDA) is a nonprofit trade association of mobility equipment manufacturers, dealers, driver rehabilitation specialists and other professionals dedicated to improving the lives of people with disabilities and assisting with driving independence using wheelchair-accessible vehicles.

Community Trusts

When considering a special needs trust to protect government eligibility, it might be beneficial or necessary to put funds into community or pooled trusts, rather than an individual trust. In many cases, these trusts can provide comprehensive special needs trust services, including service as a trustee, co-trustee or trust administrator. Here are a few that provide those services:

- Georgia Community Trust: [www.georgiacommunitytrust.com](http://www.georgiacommunitytrust.com)
- Family Network on Disabilities: [www.fndfl.org](http://www.fndfl.org)
- Secured Futures: [securedfutures-snt.org](http://securedfutures-snt.org)
- The National Foundation for Special Needs Integrity: [www.specialneedsintegrity.org](http://www.specialneedsintegrity.org)