



**Midwest Special Needs Trust**  
**FY23 Annual Report**  
**July 1, 2022 - June 30, 2023**

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## Midwest Special Needs Trust Mission and Purpose

***To provide compassionate professional special needs trust administration services to enhance the lives and foster the ability of people with special needs.***

Midwest Special Needs Trust is an organization with a proud and distinct history. Established in 1989, the Missouri Family Trust (MFT), doing business as Midwest Special Needs Trust (MSNT), is a nonprofit 501(c)(3) corporation authorized by Missouri statute to administer special needs trusts for individuals with disabilities. MSNT is not a part of state government and does not receive state or federal appropriations. MSNT is governed by a nine-member Board of Trustees and its operations are conducted by staff under the direction of the Board of Trustees. Board members are appointed by Missouri's Governor with the advice and consent of the Senate. Six Board members are individuals who have a family member with a disability. Three Board members are individuals with expertise in business. Board members serve without compensation and are appointed to 3- year staggered terms. The composition of the Board is uniquely crafted to reflect our commitment towards a desired future, envisioned and articulated by the population we serve.

Individuals with disabilities and their families often live within strict financial parameters and normally would not otherwise have access to special needs trusts to protect their public benefits. MSNT accepts modestly sized trust sub-accounts and bases enrollment fees on a sliding scale for the purpose of providing an affordable pooled trust administration option.

MSNT also administers the Charitable Trust of the Missouri Family Trust, awarding grants to Missourians with disabilities who are living below the federal poverty level. The Charitable Trust program focuses on addressing unmet needs not covered by public benefits or other community resources. Grant funds are also available as approved by the Board of Trustees to assist with natural disasters and extreme emergencies. Awarding Charitable Grants makes a big impact on the community and is one of the many facets of our work that makes staff and the Board proud to represent MSNT.



## Midwest Special Needs Trust



## Executive Summary

This report highlights the achievements of Midwest Special Needs Trust (MSNT) during FY23 (July 1, 2022 – June 30, 2023) and outlines future opportunities and goals for sustainability and growth. Each year, MSNT pauses for reflection and establishes priorities for the coming year. The FY23 Annual Report is the compass used to set the overall direction for continuity of operations, resource management and performance measurement.

Some notable achievements, this past year included the following:

- MSNT’s Charitable Grant Program maintained the Candid Gold Seal of Transparency. Candid/GuideStar reviews the mission, legitimacy, impact, reputation, finances, programs and leadership structure of non-profit agencies.
- Awarded \$336,056 in Charitable Grants.
- Establishing trust sub-accounts with as little as \$500, net of the enrollment fee and keeping fees affordable and utilizing a sliding fee scale for enrollment fees:
  - MSNT discounted enrollment fees for 50% of Beneficiaries.
  - The average size of the 70 new sub-accounts in FY22 was \$ 18,543.
  - The average balance of active sub-accounts as of 6/30/23 was \$40,684.
  - MSNT has serviced 2,604 sub-accounts since 1989.
- MSNT processed 3,611 permissible distributions of over \$ 3.5 million for the benefit of Beneficiaries while protecting eligibility for important public benefits.
- MSNT continued to expand the True Link Prepaid Visa Card program to offer an alternative to paper checks for Beneficiaries, as appropriate.
- Additional staff earned the Cornell University Institute on Employment and Disability, Work Incentive Practitioner Certification.



## **MSNT Milestones**

- In 1989, Missouri Family Trust was created by Missouri state statute.
- In 1990, MFT was incorporated as a not-for-profit corporation.
- In 1991, MFT opened its first trust account.
- In 1993, federal statute was passed that defined and exempted first party special needs trusts as assets, protecting eligibility for public benefits.
- In 2006, MFT began doing business as Midwest Special Needs Trust, expanding its service area to include the states contiguous to Missouri.
- In 2011, MSNT state statutes were substantially updated.
- In 2012, MSNT moved to independent leased space, improving security, efficiency and effectiveness in daily operations.
- In 2013, MSNT trust accounts surpassed 1000 active trusts.
- In 2015, MSNT expanded its offices to accommodate staff growth.
- In 2015, an employee was hired to devote full time attention to the Charitable Trust program.
- In 2016, MSNT rebranded with a new logo, marketing materials and website.
- In 2017, MSNT successfully completed a Social Security Administration review and hired an additional Trust Specialist.
- In 2018, MSNT added the True Link Card program and presented to the Hong Kong government on special needs trusts and MSNT operations.

## **MSNT Milestones (continued)**

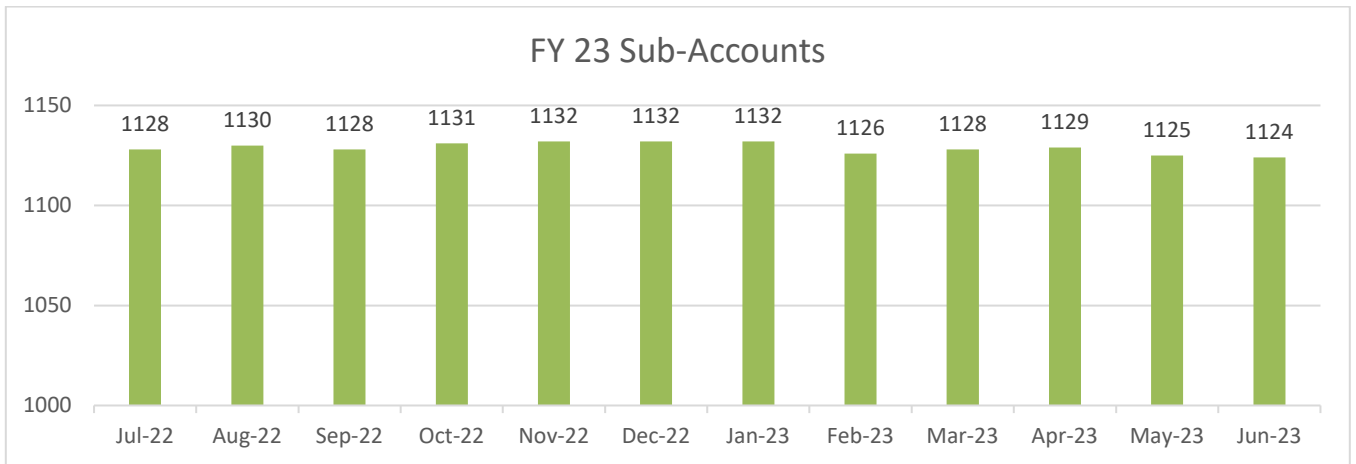
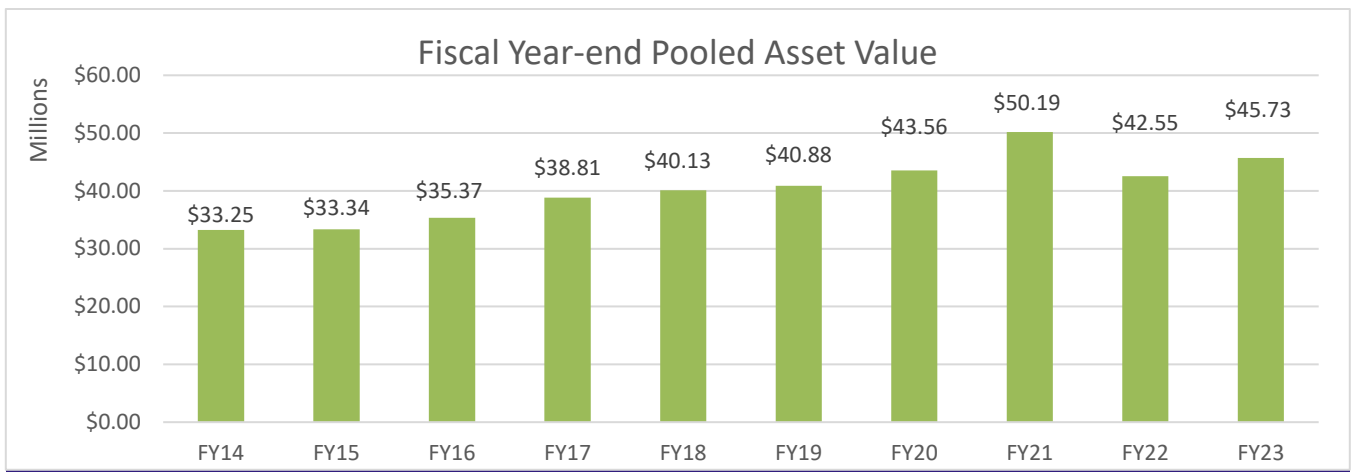
- In 2019, MSNT added another Trust Specialist and presented to the 5<sup>th</sup> World Congress on Adult Guardianship in Seoul, South Korea on special needs trusts and MSNT operations.
- In 2019, MSNT hired an Associate Director.
- In 2020, MSNT hired an Operations Specialist.
- In 2020, MSNT staff anticipated and overcame challenges to seamlessly transition to providing trust services remotely due to the COVID-19 global pandemic.
- In 2020, MSNT transitioned to True Link Financial Services.
- In 2020, MSNT awarded 6 COVID-19 Relief Grants totaling \$120,000.
- In 2021, MSNT hired a Trust Specialist I and Trust Specialist II for a total of 10 staff.
- In 2021, MSNT's Charitable Grant Program earned a 2021 Gold Seal of Transparency by Candid, formally known as GuideStar.
- In 2021, MSNT Board of Trustees increased individual charitable grant award maximum from \$1,500 to \$2,000.
- In 2021, MSNT Staff transition back to the office from remote work due to the COVID-19 global pandemic.
- In 2022, the Charitable Grant Program initiated True Link card use as another option to make grant award purchases.
- In 2022, MSNT moved from a quarterly to a monthly review of charitable general grant applications.
- In 2022, MSNT implemented a new Voice over IP phone system with modern administration and configuration tools, expanded features and dedicated lines for all staff.



## Overview of MSNT Historical Performance

Midwest Special Needs Trust continues to provide special needs trust administration services for people with disabilities and their families living in Missouri and the surrounding states (Arkansas, Illinois, Iowa, Kansas, Kentucky, Nebraska, Oklahoma and Tennessee).

In the last decade, the number of trust sub-accounts administered by MSNT has grown, and the value of trust assets has doubled. Trends are depicted in the following charts for both asset value and active sub-accounts.





## FY 2023 in Review

As of June 30, 2023, MSNT was administering 1124 active sub-accounts with an asset value of \$45.7 million collectively in pooled accounts. These numbers reflect growth from new deposits as well as investment earnings, which like the value of investments, can fluctuate depending on market performance and economic conditions. These numbers need to be considered in the context of two significant developments, one, in the federal Internal Revenue Code and, two, by the Missouri Department of Social Services in the MO HealthNet (Medicaid) program:

- The establishment of the ABLE accounts allowing another public benefit protective financial tool for up to \$15,000 a year.
- The passage of House Bill 1565 provided an increase of the Missouri Medicaid asset limit from \$1,000 to \$5,000, over a period of (5) years.
- Beginning in fiscal year 2022 and each successive fiscal year, a cost-of-living percentage will be measured and applied. Therefore, it is expected that the asset limit will continue to increase.

These federal and state policy changes are to be commended and provide some much-needed relief to the populations we serve. However, providing an alternative does impact the rate of expected growth in special needs trusts.

In FY23, MSNT continued its dedication to serve individuals and families of low to middle income who might otherwise be unable to fund a trust sub-account, keeping fees affordable and utilizing a sliding fee scale for enrollment fees. MSNT discounted enrollment fees for 50% of the 70 new sub-accounts for Beneficiaries. The average size of these new sub-accounts was \$ 18,543. The average of all active sub-accounts as of 6/30/23 was \$ 40,684. MSNT also opened 9 new inactive sub-accounts. This is another way MSNT helps families prepare for their future needs at very little cost.

MSNT is proud to have staff complete the following:

- Cornell University Institute on Employment and Disability, Work Incentive Practitioner Certification
- Cannon Trust School Essentials in Trust and Estate Planning Certificate

MSNT was pleased to conduct presentations or introductions for:

- Missouri Association of County Developmental Disability Services Annual Conference
- Kirksville Community Engagement Conference
- Woodhaven
- St. Louis Arc
- University of Missouri-Columbia Elder Law Course
- Department of Education Transition Training Institute
- Missouri Oral Health Policy Conference
- Special Olympics Staff

MSNT was pleased to exhibit for:

- Real Voices, Real Choices
- Missouri Association of County Developmental Disability Services Annual Conference
- MO NAELA Winter Symposium
- Kirksville Community Engagement Conference
- Missouri Assistive Technology Conference – Power Up 2023
- Missouri Association of Public Administrators Annual Convention
- Special Education Day
- Missouri Oral Health Policy Conference
- Special Olympics State Outdoor Games
- Missouri Disability Empowerment Foundation Parent and Professionals Special Education Law Workshop

MSNT staff attended the following conferences:

- Stetson National Conference on Special Needs Planning and Special Needs Trusts
- Association of Trust Organizations
- 7<sup>th</sup> Annual Charting the Life Course Showcase 2023





## FY 2023 MSNT Accomplishments

- **Continued to support proper trust administration to protect important public benefits for trust sub-account Beneficiaries**
  
- **Staff certification/training**
  - Cornell University Institute on Employment and Disability, Work Incentive Practitioner Certification
  - Cannon Trust School Essentials in Trust and Estate Planning Certificate
  
- **Large Distributions**
  - Authorized 16 large requests for funds totaling \$33,5154 to establish and further fund ABLA Accounts and purchase prepaid burial polices and vehicles.
  - Authorized 16 distributions for irrevocable prepaid burial policies totaling \$70,196.00
  
- **Outreach**
  - Met with representatives from several financial trust organizations to provide information about MSNT's affordable trust services and charitable commitment.
  - Mailed approximately 300 introductory letters to public administrators, personal injury and elder law attorneys.
  
- **Charitable Trust**
  - Maintained Candid/GuideStar's Gold Seal of Transparency.
  - Awarded \$336,056 in Charitable Grants.



## Special Needs Trusts - Making a Difference for People with Disabilities

MSNT Trust Specialists work diligently each day to open trust sub-accounts and process requests for funds for important supplemental needs not covered by public benefits. During FY23, MSNT made 3,611 allowable distributions for over \$3.5 million for the benefit of MSNT Beneficiaries. 22 Beneficiaries made up more than 36% of the disbursements from sub-accounts, totaling more than \$444,300 in approved request for funds; ranging from vehicles, ABLÉ Accounts, supplemental medical needs, and household items. Of these 22, 10 are Sole Trustee Beneficiaries. MSNT recognizes the importance of trust sub-account in the lives of Beneficiaries, and we share the following brief stories from FY23 as examples demonstrating how a trust sub-account can enhance the quality of life for a Beneficiary.<sup>1</sup>

- During FY23, MSNT authorized 16 distributions for irrevocable prepaid burial policies totaling \$70,196. MSNT encourages all beneficiaries to purchase an irrevocable prepaid burial policy as no payments may be authorized from a First Party trust sub-account after death, per Social Security Program Operations Manual System (POMS). When beneficiaries do not have an irrevocable prepaid burial policy at the time of their death, it can frustrate family members who do not know the trust cannot pay for the funeral costs. It can also be a financial burden. Trust Specialists talk to Beneficiaries, Co-Trustees and Responsible Parties as part of their everyday conversations and reviews. This is a decrease from FY22; MSNT authorized 18 distributions totaling \$76,284.21 for irrevocable prepaid burial policies.
- During FY23, MSNT authorized 18 distributions totaling \$200,951.42 to the ABLÉ Account Program(s). Distributions from a special needs trust to an ABLÉ Account are allowable in accordance with the Center for Medicaid and Medicare Services (CMS) and Social Security Program Operations Manual System (POMS). By having both a special needs trust sub-account at MSNT and an ABLÉ Account, the Beneficiary can be supported in multiple ways while preserving public benefits. MSNT is happy to support any Beneficiary, Co-Trustee or Responsible Party who chooses to open an ABLÉ Account with trust sub-account funds. This is a decrease from FY22; MSNT authorized 22 distributions totaling \$249,833.23 for ABLÉ Accounts.
- The Sole Trustee Program continued to be a success in FY23. Now completed on a Fiscal Year basis, Trust Services was able to contact 85% of Sole Trustee Beneficiaries; an increase of 20% from FY22. Trust Specialists spend a considerable amount of time with Sole Trustee Beneficiaries. Currently, MSNT serves as Sole Trustee for a husband and wife. When their

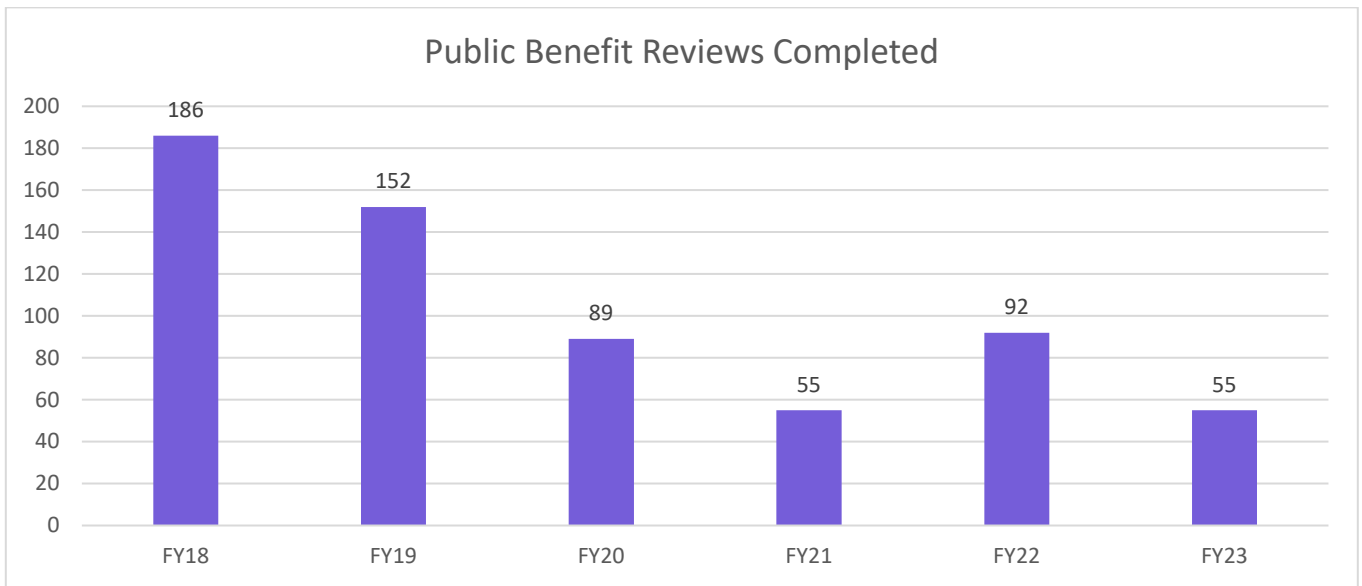
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<sup>1</sup> *The names and other details were changed to protect the confidentiality of Beneficiaries.*

trust sub-accounts opened, both in the First Party Pool, they struggled with submitting appropriate request for funds, understanding MSNT's roles and responsibilities and were routinely asking for additional funds for miscellaneous items and for large amounts of money. MSNT Trust Specialists worked with the couple to set an appropriate budget. As the Trust Specialists continued to work with them, they supported the couple's move to an apartment from a skilled nursing facility and guided them in making appropriate decisions regarding use of trust sub-account funds. The couple is doing well on their own and submit for their allotted monthly amount to be issued on their True Link Cards, following the requirements to submit receipts after all purchases. Without the assistance and patience of the Trust Specialists, this couple may not have been able to live independently and afford their supplemental needs

- MSNT administers a sub-account, in the Third Party Irrevocable Pool, for a young woman named Erin. Erin has significant muscular side effects from her autoimmune disease. To help combat her side effects, MSNT authorizes disbursements for a personal trainer. Erin's personal trainer, Cody, has provided her with the strength and mobility to help ease her side effects, helping ensure she can remain living on her own.
- MSNT Beneficiary, Melanie, has had her trust sub-account since 2007, funded with a personal injury settlement. Melanie recently called in explaining she needed a new wheelchair, as hers was damaged when she had a minor accident outside of her home. While she was not hurt, her wheelchair was no longer usable. Melanie's co-trustee submitted a request for funds for a similar wheelchair to be purchased from a big box store; which was authorized. However, after additional discussions with Melanie, it was determined she would benefit from an electric wheelchair, one that not only was more comfortable, but also suited her needs. Trust Specialists worked with Melanie, her Co-Trustee, and her son to find a provider in her area. A request for funds was submitted, reviewed, and approved as appropriate for a much more appropriate wheelchair.
- When trust sub-accounts are initially funded and opened, the Beneficiary usually has many urgent or immediate needs—like household supplies, a vehicle, or clothing. After completing a new Beneficiary phone call, the Trust Specialists appropriately assist all parties involved with submitting requests for funds, understanding special needs trust administration, and answering questions about allowable expenses. This fiscal year, MSNT Trust Specialists spent countless hours working with several new Beneficiaries, including a home visit, hundreds of requests for funds, and daily communication (both phone and email).
- The primary purpose of a special needs trust and subsequent trust sub-account is to protect the public benefits of the Beneficiary. Missouri Department of Social Services, Family Services Division requires all MO HealthNet (Medicaid) cases to undergo an annual

renewal of eligibility (also known as annual reviews, reinvestigations, redeterminations). Regularly, Beneficiaries, Co-Trustees, and Responsible Parties request MSNT Trust Services to perform a Public Benefit Review to help obtain necessary documentation for MOHealthNet’s annual renewal. These reviews include sending a standardized letter to the requesting agency, like Medicaid or the Social Security Administration, a copy of the trust agreement and any amendments, and a year of quarterly sub-account statements. The graph below shows the number of Public Benefit Reviews since 2018. Medicaid paused all reinvestigations during the COVID 19 pandemic, resulting in a significant decline in Public Benefit Reviews completed by Trust Specialists. In April 2023, Medicaid announced that reinvestigations would resume. An increase for FY24 is expected.



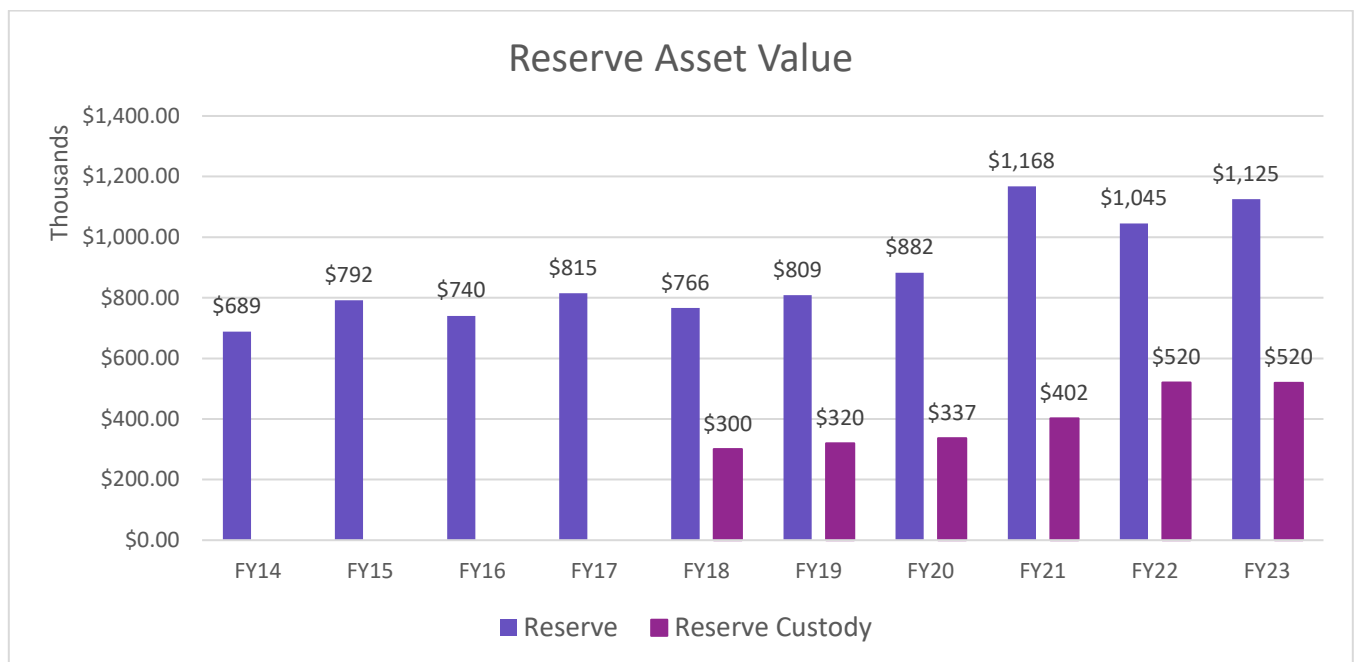


## MSNT Operational Budget & Reserves

Each year the MSNT Executive Director is responsible for developing a budget for Board review and approval. The projected budget estimates income and expenditures for the upcoming fiscal year based on previous budgets, actual expenditures for the previous year, and data analysis related to growth projections. At each quarterly meeting, the Executive Director prepares for the MSNT Board financial reports that present quarterly income and expenses in summary form, compared to the previous year and budget.

MSNT operated well within budget in FY23. MSNT remains solvent.

The MSNT Board established a reserve account in 2008 to serve as an organizational safety net and promote sustainability for MSNT. In 2018, the Board established an additional reserve account with shorter term investments. These accounts continue to grow through the careful stewardship of the Board. Reserves provide an essential safety net to provide cash flow if the economy shrinks or there is a market correction that negatively impacts investment accounts.



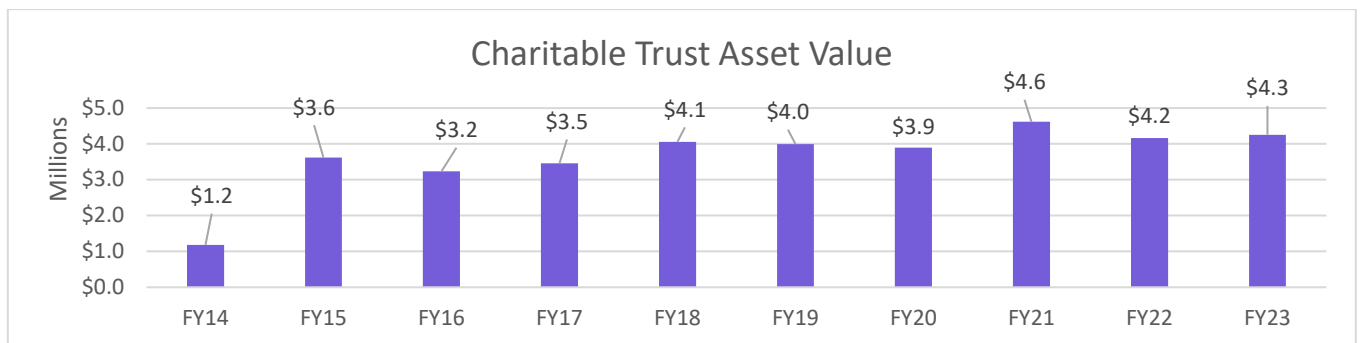


## Charitable Trust – The Year in Review

The Charitable Trust provides grants to Missourians with disabilities who are unable to afford supplemental needs not covered by Medicaid or other public benefits. The Charitable Trust has two primary sources of funding.

- The Charitable Trust of the Missouri Family Trust receives 25% of the sub-account balance at termination of the trust as permitted by state and federal statute.
- As a 501(c)(3) organization, MSNT is eligible to accept donations that are added to the Charitable Trust and are tax deductible by the donor.

The Board of Trustees continues to develop strategies to promote sustainability of the program by promoting growth of the Charitable Trust fund through investments and solicitation of donations to the Charitable Trust.



Year	Available for Distribution	# of Grants Awarded	Amount Awarded <sup>i</sup>
<b>FY 23</b>	\$340,377	249	\$336,056
<b>FY 22</b>	\$300,855	259	\$307,529
<b>FY 21</b>	\$244,924	257	\$243,547
<b>FY 20</b>	\$243,620	345	\$326,950
<b>FY 19</b>	\$487,399	505	\$453,163
<b>FY 18</b>	\$325,588	353	\$290,033
<b>FY 17</b>	\$129,564	223	\$176,825
<b>FY 16</b>	\$316,143	340	\$275,349
<b>FY 15</b>	\$220,947	196	\$139,108
<b>FY 14</b>	\$137,859	163	\$117,432

<sup>i</sup>Amount available for distribution is from annual report; number of grants and amount awarded reflects all current FY urgent care awards and general awards from last quarter of previous FY plus the first three quarters of the current fiscal year.

In FY23, there were 249 grants totaling \$336,056 awarded to Missourians with disabilities living in poverty – 167 Urgent requests totaling \$228,768, and 82 General requests totaling \$107,288.

Charitable staff work conscientiously to award grants throughout the state. We share the following brief stories from FY23 as examples<sup>2</sup> of how the Charitable Trust has made a difference:

- Denise became disabled after a stroke at the age of 49. In addition to a brain injury and subsequent vision issues from the stroke, she also had Cancer that was treated with radiation therapy. The radiation treatment was lifesaving but led to acute bone loss in her upper jaw and other oral complications. Her medical expenses contributed to her losing her housing. When she reached out to MSNT’s grant program for help to pay for bone graft surgery, she was living at a mission. She received a grant to cover the \$1,825 cost of her bone graft and will soon be fitted for dentures - the next step in restoring her oral health. She is looking forward to a nourishing diet that she can chew, as well as better health, and a beautiful smile.
- Lisa’s above-the-knee amputation at age 38 has been a challenge to her independence for over two decades. As she ages, shopping is becoming increasingly difficult for her, and her reliance on store-provided scooters makes her errands difficult. She often arrives at her very busy, local grocery store or her pharmacy to find that all scooters are in use or inoperable. There were a few times when Lisa would wait in the entrance area for a scooter, but none would become available. A \$720 grant paid for a mobility scooter which will help increase Lisa’s independence and allow her to complete her shopping errands at her convenience.
- In 2020, Mia was born prematurely at 28 weeks. She experiences several areas of development delay including with her gross motor development. Although Mia was already receiving many therapies, including physical therapy, her care team and mother believed classes at a children’s gym would provide extra “therapy” through fun, group activities designed to improve motor skills. Because the expense of the classes was out of reach for Mia’s mother, she asked MSNT to consider a \$1,000 grant to cover the cost of year-round classes. For the second year in a row, MSNT has paid for the additional therapy to ensure Mia can access this important care in a fun setting.

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<sup>2</sup> *The names and other details were changed to protect the confidentiality of beneficiaries.*



## ***FY 24 Goals***

Although MSNT goals include growth in the number of sub-accounts administered with continued emphasis on quality service, FY24 goals also reflect key efforts to better serve Beneficiaries.

Through the thoughtful and strategic efforts of a prudent Board, MSNT is poised for continued growth. Toward that end, the following goals have been established for the coming year:

- Finalize new Master Trusts with Joinder Agreements
- Responsively update and revise Board Policies
- Increase the number of sub-accounts
- Increase the amounts deposited into sub-accounts
- Promote Inactive Trusts as an estate planning tool
- Recruit Additional Board Members
- Complete a Strategic Planning Process
- Increase Charitable donations
- Create educational Trust Services videos
- Launch online portal to manage Charitable Grant applications





## ***Acknowledgements and Appreciation***

The success of Midwest Special Needs Trust is the direct result of the vision and persistence of dedicated families who saw a better future for their loved ones with disabilities through the use of Special Needs Trusts. Their commitment to MSNT and their volunteer service as MSNT board members, education and outreach leaders in their communities, have built a solid foundation for MSNT, for which we are most appreciative.

We are humbled by the trust and confidence the Beneficiaries and their families have placed in us and we will continually strive to earn their confidence and trust.

We are also filled with gratitude for the many attorneys, human service professionals and Public Administrators who recognize the value of our services and refer clients to MSNT. Statewide, MSNT administers 467 trust sub-accounts for 51 different Public Administrators. We appreciate their trust and confidence.

We also want to acknowledge the hard work of the staff and the leadership of Midwest Special Needs Trust.

Let this acknowledgment serve as a tribute to the past and a reminder of our ongoing commitment to be diligent in utilizing our expertise to ensure each special needs trust meets its intended need.